

“We go hunting together”

**Cultural and community inclusion as a moderator of
social inequality experienced by
Aboriginal and Torres Strait Islander people with disability**

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A thesis submitted in fulfillment of the requirements for the degree of
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Abstract

Background: As a group intersecting two marginalised populations, Australian Aboriginal and Torres Strait Islander people with disability experience greater social inequality and isolation compared to other groups, including Aboriginal and Torres Strait Islander people without disability, and people with disability. There is a limited amount of research into Aboriginal and Torres Strait Islander disability, and that which exists has inadequately captured the personal experiences of social exclusion and inequality. This is a gap both in research and in Australian social policy, and masks an urgent need to respond to a critical social justice issue that affects some of Australia's most vulnerable people.

Aims: The aims of this study are to first understand the depth and nature of the social inequality that Aboriginal and Torres Strait Islander people with disability experience as a population group intersecting two marginalised populations; and then the impact of an Indigenous culture of inclusion as an affirming force upon their health and wellbeing. This was achieved through an emancipatory and participatory research methodology that promoted the personal testimony of Aboriginal and Torres Strait Islander people with disability in research.

Methods: This study uses a mixed methods approach involving quantitative and qualitative data analysis. The qualitative research involved the statistical analysis disaggregated data from various Australian Bureau of Statistics datasets to benchmark the prevalence and profile of disability amongst the Aboriginal and Torres Strait Islander population, and then compared social health and wellbeing outcomes of Aboriginal and Torres Strait Islander people with disability to other groups. The qualitative research included personal testimony obtained through interviews with 47 Aboriginal and Torres Strait Islander people with disability as well as testimony collected from an Elders forum that was sourced through an Indigenous, community-directed participatory methodology. This methodology was developed specifically for research involving a marginalised participant group.

Results: Aboriginal and Torres Strait Islander people with disability experience an intersectional social inequality and discrimination that is greater than other population groups, including Aboriginal and Torres Strait Islander people without disability, and

the population of people with disability. The finding of intersectional inequality and discrimination experienced by Aboriginal and Torres Strait Islander people with disability is acute and pervasive across all aspects of their lives. They are also exposed to higher levels of multi-faceted traumas at both the personal level and within their communities. Parity in the participation by Aboriginal and Torres Strait Islander people with disability in cultural and community activities is the sole categorical exception to the inequality, discrimination and trauma that they otherwise experience in their lives.

Interpretation: The sustained exposure to intersectional inequality is constant and acute in the lives of Aboriginal and Torres Strait Islander people with disability, and is detrimental to social health and wellbeing. Australian Indigenous and disability policy and service systems have been unresponsive to the intersectional nature of inequality, which means that the marginalisation and vulnerability experienced by Aboriginal and Torres Strait Islander people with disability has remained deeply entrenched. An Indigenous culture that fosters the social inclusion of people with disability acts as a moderating force to the inequality, discrimination and trauma that they experience in other aspects of their lives.

Conclusion: The implications of this research are wide reaching. The finding of intersectional inequality and its detrimental consequences upon the social health and wellbeing urges a redesign of Australian Indigenous and disability policy to be more responsive to intersectional inequality. As an affirmative strategy, parity in the cultural and community participation by Aboriginal and Torres Strait Islander people with disability is the foundation for an Indigenous cultural model of inclusion as an approach to future research, policy and service systems. This study provides a proof of concept for a community-directed emancipatory and participatory methodology that can be extended beyond Aboriginal and Torres Strait Islander community that was involved in this research and applied in social inclusion research that involves other vulnerable groups.

Certificate of original authorship

I, Scott Christopher Avery, declare that this thesis, is submitted in fulfilment of the requirements for the award of Doctor of Philosophy in the Faculty of Health at the University of Technology, Sydney.

This thesis is wholly my own work unless otherwise reference or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

This thesis includes Indigenous Cultural and Intellectual Property belonging to the Australian Aboriginal and Torres Strait Islander disability community, their Elders, and the First Peoples Disability Network (Australia) as their community-controlled representative organisation. Where I have used Indigenous Cultural and Intellectual Property, I have followed the relevant protocols and consulted with the Aboriginal and Torres Strait Islander disability community about its inclusion in my thesis, and the Indigenous Cultural and Intellectual Property rights are retained by the Aboriginal and Torres Strait Islander disability community.

This research is supported by the Australian Government Research Training Program.

Signature:

Production Note:

Signature removed prior to publication.

Date: 30 April 2019

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Amongst Aboriginal and Torres Strait Islander people, the term ‘Elder’ is assigned to people as a sign of respect for those venerated in their community for holding a quiet, humble authority on cultural wisdom, much in the way that the title ‘Professor’ conveys respect and esteemed knowledge in academic circles. If there was a person who exudes a knowledge that is both humanly wise and scholarly, it would be Professor Joanne Travaglia, who I have been blessed to have as my primary supervisor throughout this thesis. Professor Travaglia has been there from the start when this project was just fragments of an idea, and she has guided me through the academic discipline to produce something that now reads, looks and smells like a very heavy book.

Another person who has been in this from the very start is my good friend and ‘brother’ Damian Griffis. He was the first person that I went to with the idea of doing research that came from the First Peoples disability community, and has been the constant voice that first encouraged me to make it happen and to keep on going. Along with my friends and colleagues at the First Peoples Disability Network, he has been a sounding board for the First Peoples disability community. There will be more on the First Peoples Disability Network in the following paragraphs.

I have been fortunate to have an excellent (and patient) PhD supervisory team and support structures along the way, starting at the University of New South Wales and continuing at the University of Technology Sydney. It was an esteemed Aboriginal

academic Professor Lisa Jackson Pulver who first planted the seed of doing a research degree in my mind. “You should do a PhD”, she once told me, with an air of authority that made it somewhat inevitable that it would happen. As Associate Supervisor, Lisa helped me establish this as a project with a distinctly Aboriginal flavour. Dr Deborah Debono joined the team as Associate Supervisor, helping me through the hard yards of completing the thesis. My gratitude goes to Chris Rossiter for proofing the final draft of this thesis and picking up the typographical errors that I am famous for. I have also been blessed by the presence of Dr Megan Williams, who I regard as my spiritual supervisor and who has had the uncanny knack of sending me encouragement and support right at the moments I have most needed it.

This thesis is a study in community research that is shared with the First Peoples disability community. It could not have happened without the trust, stories and wisdom that has been freely shared by the participants and Elders of our community. To my friends and colleagues at the First Peoples Disability Network – Damian Griffis, Aunty June Riemer, Lisa Hindman, Uncle Paul Calcott, Aunty Gayle Rankine, Aunty Kay Sadler, Aunty Maureen Logan, Lai Ha Wu, Jake Briggs, Michelle Bates, Mel Marne, Sara Irvine, Ben Riemer and our growing band of travelers – you have individually and collectively inspired and supported me, from acting as a sounding board for ideas, running interference when I needed thinking space, and making sure I was ‘keeping it real’.

My thanks go to my friends at the Lowitja Institute, particularly Romlie Mokak, for being there at the start with moral and financial support. Knowing that you have had my back covered has given me confidence to speak frankly on the more uncomfortable accepts of social inequality that have been raised through this research.

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In addition to the daily doses of inspiration coming from my friends and colleagues at the First Peoples disability community, my thesis was propelled along by a series of ‘dares’. Many of these dares came by chance encounters and over coffee

conversations. The first, as previously mentioned, came from Professor Lisa Jackson Pulver. Later at a workshop held by the National Indigenous Research and Knowledges Network, esteemed Aboriginal academic Professor Eileen Moreton Robinson issued a challenge to make our Indigenous culture intelligible to others. From that challenge, the emphasis on 'Culture is Inclusion' was spawned. When I was experimenting with an idea of 'apprehended discrimination', which is a concept that I developed and is central my explanation of social isolation, Professor Leanne Dowse dared me to go back into the testimony and find the evidence that led to its conceptual development. Having then presented the concept of 'apprehended discrimination' to Human Rights researchers at the Australian Human Rights Commission, Nick Deveraux from the Commission dared me to come up with its opposite. From this came a consideration of 'apprehended inclusion', which appears in the discussion chapter of this thesis as a promise of hope for the future. That these and other concepts appear in this thesis in the form that they do are the rewards for paying attention to clever people who have been engaged with me so enthusiastically on what this research has been about.

Whilst I have had many members in my cheer squad, the loudest chants have come from within inside my home. In many ways, my PhD has been a fifth family member that has needed nurturing and care over many years. In doing this study, I've had the privilege of a supportive family in Alison, Zoe and Tegan to give me the space and freedom to pursue my research, all of who have made the sacrifices alongside me. Whilst it has always been tricky to pick a favourite girl, my beautiful wife Alison was always there at the door when I can back from my road trips, whether it was a day of ups or a day of downs, and you share in whatever becomes of this as much as I do.

Marrambu to everyone who has supported and guided me.

Original published works by the researcher contributing to this thesis

This thesis contains three original published works from the research that was undertaken during my candidature. These published works are:

1. Avery S. (2016a) *Intersectional Dimensions on the Right to Health for Indigenous Peoples – A Disability Perspective*. Prepared for the United Nations Expert Mechanism on the Rights of Indigenous Peoples (EMRIP) study on ‘The Right to Health for Indigenous Peoples’. First Peoples Disability Network (Australia). March 2016.
2. Avery S. (2016b) ‘The life trajectory for an Aboriginal or Torres Strait person with disability’. In: *Aboriginal and Torres Strait Islander Perspectives on the Recurrent and Indefinite Detention of People with Cognitive and Psychiatric Impairment*. Avery S., and Keyser P. (eds) First Peoples Disability Network (Australia), April 2016. Chapter 2, pp. 6-9.
3. Avery, S. (2018) *Culture is Inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability*. First Peoples Disability Network (Australia). Sydney.

The first publication (Avery, 2016a) was prepared as a submission into a United Nations study on the rights of Indigenous People. This contributed an intersectional approach to analysing health inequalities experienced by from a perspective of people with disability. This paper is attached as Appendix E to this thesis.

The second publication (Avery, 2016b) is a chapter in a series of papers and was prepared as a research primer by a consortium of Indigenous, disability and legal researchers in a submission into an Australian Senate Inquiry into the indefinite detention of people with disability. This research primer was later published by First Peoples Disability Network (Australia) in a book format as a community resource. This publication further developed the intersectional approach to the research and

applied it across the life trajectory of an Aboriginal and Torres Strait Islander person with disability. This chapter is attached as Appendix F to this thesis.

The third publication, *Culture is Inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability* (Avery, 2018), is a condensed summary of the community directed model of co-production in Chapter 4, the research methods in Chapter 5, and the research findings from Chapters 6 to 9. It was published in July 2018 for use as a resource guide by the First Peoples disability community, policy makers, educators, and service providers to Aboriginal and Torres Strait Islander people with disability. *Culture is Inclusion* (Avery 2018), as its abbreviated title is referred to throughout the thesis, introduced a number of concepts and terms that are referenced within this thesis, and is the cornerstone publication to date from this research. This book is attached as Appendix G to this thesis.

For ease of reading, a citation to the researcher's prior published works are referenced on their first appearance in this thesis, after which these terms are demoted by single inverted commas.

Statement of Research Impact - Conference, Community and Policy engagements by the researcher

Keynote addresses

The following is a Schedule of keynote addresses that I have been invited to give:

Date	Title of Paper	Conference	Location
31 October 2018	Culture is Inclusion	National NDIS Community Mental Health Conference	Melbourne, Australia
17 November 2018	Inclusive education for Aboriginal and Torres Strait Islander children with disability	Equity Matters Disability Symposium - NSW Teachers Federation	Sydney, Australia
21 November 2018	Culture is Inclusion: Re-imagining accessibility and inclusion through the power of storytelling	OzeWAI (Australian Web Adaptability Initiative) Conference	Sydney, Australia
17-21 September 2019	Culture is Inclusion: Truth telling, healing and the self determination of First Peoples with disability	Kāpō Māori Aotearoa Biennial Conference	Napier, New Zealand.
6-8 November 2019	Culture is Inclusion	Australasian Society for Intellectual Disability Conference (Invitation accepted)	Adelaide, Australia

Conference presentations

The following Schedule is a list of Conferences that I have presented at over the duration of the research:

Date	Title of Paper	Conference	Location
8 May 2015	Living Our Ways - A Critical Approach to the Intersection of Indigeneity and Disability	13th Nordic Network for Disability Research (NNDR) Conference	Bergen, Norway
15 September 2015	‘Living My Way’ – The untold story of disability in childhood development	Secretariat of National Aboriginal & Islander Child Care (SNAICC) National Conference	Perth, Australia

Date	Title of Paper	Conference	Location
26 April 2016	Living Our Ways: A Community-driven research program to understand the Intersection	32nd Pacific Rim Disability and Diversity Conference	Hawaii, USA
6 May 2016	Empowerment: The First Peoples Disability Network	National Aboriginal and Torres Strait Islander Suicide Prevention Conference	Alice Springs, Australia
10 November 2016	Living our ways: A community-driven research program to understand the intersection of rights for Indigenous people with disability	Lowitja Institute: International Indigenous Health and Wellbeing Conference	Melbourne, Australia
17 November 2016	Elevating voices of Indigenous People with disability	Nga Pae O Te Maramatanga International Indigenous Knowledges Conference	Auckland, New Zealand
21 March 2017	Experiences of Aboriginal and Torres Strait Islander people with disability: the numbers the stories (co-presented with the Australian Bureau of Statistics)	Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) National Indigenous Research Conference	Canberra, Australia
10 October 2017	Culture is inclusion: A community-driven approach for the social inclusion of Indigenous people living with disability	33rd Pacific Rim Disability and Diversity Conference	Hawaii, USA
14 November 2017	The numbers and the narrative: a community-based model of research co-production to understand the needs of Aboriginal and Torres Strait Islander people with disability	National Health and Medical Research Council - Lowitja Institute Knowledge Translation Symposium	Brisbane, Australia

Conference presentations (abstracts accepted)

This Schedule is a list of upcoming Conferences where my abstract has been accepted:

Date	Title of Paper	Conference	Location
8-10 May 2019	Culture is Inclusion: A narrative study of inclusion and disability in Australian Indigenous communities	15th Nordic Network for Disability Research (NNDR) Conference	Copenhagen, Denmark
18-20 June 2019	Community leadership in inclusion and disability research (Moderator - Interactive workshop)	Lowitja Institute International Indigenous Health Conference	Darwin, Australia
21-27 July 2019	Intersecting injustices: Altering the matriculation pathway to prison for Australia's Indigenous people with disability	XXXVIth International Congress on Law and Mental Health	Rome, Italy

Expert witness testimony at Australian Government Inquiries

This Schedule is a list of formal Inquiries convened by Australian Governments, both Commonwealth, State and Territory, where I have been requested to appear as a witness and speak on aspects of my research:

Date	Title of Presentation	Committee	Location
12 August 2014	Action to Prevent Foetal Alcohol Spectrum Disorder	Legislative Assembly of the Northern Territory	Darwin, Northern Territory
5 February 2015	Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia	Senate Community Affairs References Committee	Sydney, NSW
27 March 2015	Advocacy services in the National Disability Insurance Scheme	Joint Standing Committee on the	Canberra, ACT

Date	Title of Presentation	Committee	Location
		National Disability Insurance Scheme	
19 June 2015	Closed session - Private briefing to Committee	Joint Standing Committee on the National Disability Insurance Scheme	Canberra, ACT
20 November 2015	Current levels of access and attainment for students with disability in the school system, and the impact on students and families associated with inadequate levels of support	Senate Standing Committee on Education and Employment	Melbourne, Victoria
24 February 2016	Interface principles between the NDIS and forensic disability	Joint Standing Committee on the National Disability Insurance Scheme	Canberra, ACT
29 April 2016	Indefinite detention of people with cognitive and psychiatric impairment in Australia	Senate Community Affairs References Committee	Via teleconference
13 October 2016	Expert witness testimony	Royal Commission into the Detention and Protection of Children in the Northern Territory	Darwin, Northern Territory
17 May 2017	The provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition	Joint Standing Committee on the National Disability Insurance Scheme	Penrith, NSW

Representations at the United Nations

This Schedule is a list of United Nations human rights forums that I have attended as a representative of the First People Disability Network to present aspects of my research:

Date	Title of Paper	Forum	Location
6-11 November 2014	Civil sector delegate	UN Convention Against Torture - Sessional hearing for Australia	Geneva, Switzerland
14-16 June 2016	Civil sector delegate	9th Conference of State Parties on the Convention on the Rights of Persons with Disabilities (COSP 9)	New York, USA
16-June 2016	Recurrent and indefinite detention of people with cognitive impairment (side-event)	9th Conference of State Parties on the Convention on the Rights of Persons with Disabilities (COSP 9)	New York, USA
7-8 July 2016	Participant	Expert Meeting on Indigenous Disability - Joint Special Rapporteurs on the Rights of Indigenous Peoples and Right of Persons with Disability	Geneva, Switzerland
13-July 2016	Recurrent and indefinite detention of Aboriginal and Torres Strait Islander people with cognitive impairment (Side event)	Expert Mechanism on the Rights of Indigenous Peoples	Geneva, Switzerland

Research engagements

This Schedule is a list of engagements with Universities and research institutions where I have received a personal invitation to present on the research, with a minimum of 20 people in attendance:

Date	Presentation Title	University
24 October 2016	Honouring Songlines (co-presented with Associate Professor Karen Soldatic)	University of Western Sydney
5 April 2017	Young people with complex support needs - Knowledge exchange for research policy and practice	University of New South Wales, Sydney
4 September 2017	Intersecting Injustices - Aboriginal and Torres Strait Islander Justice Forum	Centre for Aboriginal Economic Policy and Research, Australian National University, Canberra
8 September 2017	Health Evaluation Framework Forum	Melbourne School of Population and Global Health, University of Melbourne
25 September 2017	Community led partnership forum - Panel	Social Policy Research Centre Conference, University of New South Wales, Sydney
4 October 2017	Disability Research Workshop	Lowitja Institute of Aboriginal and Torres Strait Islander Health Research, Melbourne
20 October 2017	Closing the Gap Breakfast Seminar	Australian Physiotherapists Association, Sydney
26 July 2018	<i>Culture is Inclusion</i> (Sydney Book Launch)	Australian Human Rights Commission, Sydney
4 December 2018	<i>Culture is Inclusion</i> (Melbourne Book Launch)	Iverson Health Innovation Research Centre, Swinburne University, Melbourne
6 December 2018	Research Co-production with people with disability workshop	Disability Innovation Institute, University of New South Wales, Sydney
21 February 2019	Sustainable Health Care Forum	Social Policy Research Centre, University of New South Wales, Sydney

Community engagements

This Schedule is a list of engagements with community-based organisations where I have received a personal invitation to speak on the research, with a minimum of 20 people in attendance:

Date	Audience	Location
31 May 2016	Legal Aid NSW Criminal Law Conference	Sydney, Australia
6 September 2016	Australian Community Workers Association (ACWA) Leaders forum	Parramatta, Australia
15 September 2016	Hypotheticals Panel - NSW Council of Intellectual Disability Conference	Sydney, Australia
13-14 March 2017	Global Network of Indigenous People with Disabilities meeting	Wellington, New Zealand
16 March 2017	NDIS Healing the Spirit Gathering	Grafton, NSW, Australia
24 May 2017	Living My Way Conference	Wagga Wagga, NSW, Australia
7 June 2017	Aboriginal Blind Persons Gathering - FPDN in partnership with Blind Citizens Australia	Sydney, Australia
7 November 2017	Disability Service Organisations South Australia - Peer Groups and Services Development day	Adelaide, Australia
26 July 2018	Culture is Inclusion (Book Launch)	Sydney, Australia
16 August 2018	Building the Aboriginal Disability Sector Conference	Tamworth, Australia
18 September 2018	Australian Human Rights Commission (AHRC) - Research workshop	Sydney, Australia
26 September 2018	Aboriginal and Torres Strait Islander Healing Foundation - Knowledge Circle	Canberra, Australia
16 October 2018	Lowitja Institute Roundtable on Aboriginal and Torres Strait Islander Mental Health	Canberra, Australia
12 November 2018	Indonesian Disabled Peoples Organisations Workshop (Hosted by People With Disability (Australia))	Sydney, Australia
16 November 2018	Building the Aboriginal Disability Sector Conference	Adelaide, Australia
4 December 2018	<i>Culture is Inclusion</i> (Melbourne Book Launch)	Melbourne, Australia
19 December 2018	Inaburra Preschool Staff Briefing	Menai, Australia

Date	Audience	Location
19 January 2019	UTS Big Thinking Forum Resilience and Recovery: Getting By and Getting Better (Panel participant), Sydney Festival	Sydney, Australia
14 February 2019	Victorian Council of Social Services - Disability Advocacy Resource Unit	Melbourne, Australia

Policy engagements

This Schedule is a list of engagements that have been organised and/or involved Government Agencies, both Commonwealth, and State and Territory, where I have received a personal invitation to contribute on my research, with a minimum of 20 people in attendance:

Date	Presentation	Audience	Location
13 July 2015	Aboriginal and Torres Strait Islander Engagement Plan	National Disability Insurance Agency	Sydney, Australia
11 August 2015	Invited Briefing to Vietnamese Government Delegation	Australian Human Rights Commission, and Department of Foreign Affairs and Trade (Cth)	AHRC, Sydney, Australia
20 January 2016	National Aboriginal and Torres Strait Islander Disability Action Plan development meeting	Department of Social Services (Cth)	Sydney, Australia
9 September 2016	NSW Police Engagement Framework - Disability Focus Group	NSW Police (NSW)	Parramatta, NSW
5 December 2016	International Day of People with Disabilities address	Department of Juvenile Justice (NSW)	Sydney, Australia
2 May 2017	Redfern Statement Disability Roundtable	Aboriginal community sector; Department of Prime Minister and Cabinet, and Department of Social Services (Cth)	Sydney, Australia

Date	Presentation	Audience	Location
8 August 2017	Aboriginal Disability Program Reference Group	Department of Primary Industries (NSW)	Sydney, Australia
10 August 2017	Indigenous Advisory Committee Roundtable on the NDIS (Prime Minister and cabinet)	Indigenous Advisory Council, Department of Prime Minister and Cabinet (Cth)	Sydney, Australia
17 August 2017	Government Ministerial Forum	Commonwealth Government Ministerial Forum (Cth)	Canberra, Australia
22 August 2017	Research Webinar	Australian Bureau of Statistics	Canberra, Australia
9 February 2018	Disability Justice Workshop	Department of Social Services (Cth)	Melbourne, Australia
1 May 2018	Building Accessible and Inclusive Communities for Aboriginal and Torres Strait Islander People with Disabilities Workshop	Department of Social Services (Cth)	Sydney, Australia
14 May 2018	Closing the Gap Refresh - Concept Design workshop	Department of Prime Minister and Cabinet (Cth)	Sydney, Australia
14 June 2018	Closing the Gap Refresh - technical Design workshop	Department of Prime Minister and Cabinet (Cth)	Canberra, Australia
23 August 2018	Culture is Inclusion presentation - Indigenous Roundtable	Australian Bureau of Statistics	Canberra, Australia
15 November 2018	Culture is Inclusion presentation - ABS Staff	Australian Bureau of Statistics	Adelaide, Australia

Research grants and awards arising from this research

Awards

1. Lowitja Institute of Aboriginal and Torres Strait Islander Health - Research Support Scholarship. Awarded November 2014.
2. Finalist, National Disability Awards in the category of 'Inclusion'. Awarded December 2018.

Competitive Research Grants

1. Lead Investigator, 'Living our ways: A proposal to develop a First Peoples disability research agenda'. Awarded under the National Disability Research Development Agenda, December 2015.
Amount: \$500,000 over 2 years.
(Academic Advisory Panel: Professor Joanne Travaglia, Dr Megan Williams, Professor Melissa Haswell, Professor Leanne Dowse, Dr Ruth McCausland, and Mr Damian Griffis).
2. Project Lead (Community), 'Wellbeing through cultural participation: An affirmative strategy for the inclusion of Aboriginal and Torres Strait Islander people with disability'. Awarded by the Lowitja Institute of Aboriginal and Torres Strait Islander Health.
Amount: \$300,000 over 1 year.
(Project Lead (Academic): Professor Leanne Dowse).

Commissioned research

1. Lead researcher, 'Attitudes of Aboriginal and Torres Strait Islander people to foster caring'. Commissioned by the Department of Family and Community Services, NSW.
Amount \$40,000 over 1 year.

Indigenous cultural considerations in preparing the thesis

In researching from within an Aboriginal and Torres Strait Islander community and culture, there are a number of cultural considerations that have influenced how I have written and produced my thesis. Many of the cultural norms are informal, not documented, and have influenced me by being embedded within a community organisation that actively practices and promotes Aboriginal and Torres Strait Islander cultural values. These aspects are introduced within this preface in order to help explain the cultural influences behind decisions that I have made. Some readers from an institutional research background, or who are not Indigenous, may not be accustomed to this.

About the title: “We go hunting together”

The phrase “*We go hunting together*”, used in title of this thesis, is drawn directly from the testimony of one of the research participants. These words came from a respected Elder from one of the Aboriginal communities in central Australia. I was introduced to her and other Elders from her community through this research. I have since developed a deep respect for the cultural authority and leadership that she and our Elders have in our communities.

In choosing a title for this thesis, I wanted to establish a direct connection with the people who shared their stories with me. “*We go hunting together*” captures the Indigenous culture of inclusion that is the focal point of this study. It is a state of mind that exists at a personal level, within our communities, and with the First Peoples disability community at large.

“*We go hunting together*” also represents the knowledge that comes from our Elders within the First Peoples Disability community, so using this phrase in the title is my way of embodying the legacy of their wisdom in this research. Our respected Aunt has since passed, but she can continue to teach us through her words. Her family has granted their blessing for me to use her words in this way.

Writing in as third person and in passive voice

The First Peoples disability community as reflected in the organisational values of the First Peoples Disability Network has a self-effacing culture that avoids putting one's self forward ahead of the community as a collective. They further avoid using language that may be personally confrontational, instead preferring use of passive or indirect language. I have accommodated these cultural norms within the body of the thesis by referring to myself as 'the researcher' in third person, as opposed to first person references. I have also defaulted to a passive writing style.

Community permissions obtained for use of photos

Depending on the circumstance and site, taking photos whilst in Aboriginal and Torres Strait Islander communities may not be cultural appropriate. When I have taken photos to illustrate an issue referred to in this thesis, I have asked for express permission to take the photo from the community members, and I have recorded this permission in a footnote in the section where the photo is used.

Glossary of key terms and phrases used in this thesis

A. Original terms and concepts devised by the researcher

In order to overcome limitations in the existing research vocabulary, I have created a number of terms and concepts to describe aspects of this study. Some of these terms and concepts were initially introduced in my previous original publications listed earlier in this preface, and have been expanded upon within this thesis. Other terms have been introduced for the first time in this thesis.

A glossary of the original terms and concepts devised by me in this research are listed below:

‘Apprehended discrimination’

This term was introduced initially in *Culture is Inclusion* (Avery, 2018, p. 102-106) to describe the pathway through which Aboriginal and Torres Strait Islander people with disability progress through, from an intuitive fear of discrimination to a rational expectation that they will experience discrimination, then self-exclusion as a way to avoid discrimination.

‘Cultural Model of Inclusion’

This concept was initially introduced in *Culture Is Inclusion* (Avery, 2018. P. 190-191) and expanded upon in this thesis to describe a model of social inclusion of people with disability that is derived from Indigenous cultural values, and is differentiated from deficit-based models of disability.

‘Intersectional discrimination’

‘Intersectional discrimination’ is derived from the theory of ‘intersectionality’ (Crenshaw 1991) that describes the unique layering of discrimination when a person belongs to a group that traverses two or more marginalised populations. Conceptually, ‘intersectional discrimination’ can apply when there are intersections across a range of attributes including race, disability, gender, sexuality, age and education. This intersectional focus for this study is the First

Peoples with disability community as a group that intersects the Aboriginal and Torres Strait Islander population and the population of people with disability.

The term ‘intersectional discrimination’ was introduced initially in *Culture is Inclusion* (Avery, 2018, p. 35 and pp. 98-101) to explain the interaction of racism and ableism as a unique form of discrimination that is experienced by Aboriginal and Torres Strait Islander people with disability.

‘Intersectional inequality’

‘Intersectional inequality’ is also derived from the theory of ‘intersectionality’ (Crenshaw 1991). This research has diligently adhered to ‘inequality’ as a concept that is measurable. Whilst noting the inter-relationship with an underlying social ‘inequity’, ‘inequality’ is placed at the forefront of this research to generate the empirical evidence of social outcomes that are experienced by Aboriginal and Torres Strait Islander people with disability compared to other groups. Generating the evidence of unequal social outcomes experienced by Aboriginal and Torres Strait Islander people with disability is a precursor to morally and ethically formed arguments that highlight the underlying social inequity and injustices.

The term ‘intersectional inequality’ was initially introduced in *Culture is Inclusion* (Avery, 2018, pp. 107-150) to describe the systemic inequality that Aboriginal and Torres Strait Islander people with disability experience as a group intersecting two marginalised populations compared to other population groups.

‘Matriculation pathway into prison’

This phrase illustrates the accumulated impact of ‘intersectional inequality’ and ‘intersectional discrimination’ has across the life trajectory of an Aboriginal and Torres Strait Islander person with disability that results in their increased likelihood of ending up in prison, rather than into education, employment or other areas of personal fulfilment. This thesis continues to expand upon earlier versions of this concept that have been included in the researchers’ prior publications (Avery, 2016, p. 9; Avery 2018 , pp. 37-44) to incorporate additional empirical data and analysis form this study.

‘Paradox of low hanging fruit’:

This concept was constructed and introduced in this thesis to describe how market forces drive access to social programs towards an equilibrium access point. By not reaching people with relatively high access barriers, market-based approaches to social programs paradoxically increase the social inequality within the populations that the social program is intended to benefit.

‘Rock up recruitment’

This term was introduced initially in *Culture is Inclusion* (Avery, 2018, p. 60) to describe a flexible and non-threatening approach to purposive and convenience sampling that was used in the recruitment of participants. The term is derived from a colloquial description of the researcher’s practice to ‘rock up’ to Aboriginal communities who were selected as sites for the research and work seamlessly within their established communication networks.

‘Trauma clusters’

This term is used in this thesis to describe the congregation of trauma within tight-knit Aboriginal and Torres Strait Islander communities when large proportions of the community are affected by trauma and chronic exposure to discrimination. It relates to the notion that trauma is contagious (Avery, 2018, p. 175) that was conceived by the researcher after a personal experience of ‘catching trauma’ whilst visiting a community and interviewing a succession of people who were affected by acute traumatisation.

B. Commonly used terms as applied in this thesis

The section provides a guide to how some commonly used key terms are defined for the purpose of this thesis.

‘Aboriginal and Torres Strait Islander’, ‘Indigenous’ and ‘First Peoples’

‘Aboriginal and Torres Strait Islander people’ and ‘First Peoples’ are used interchangeably in the document, and reflects varying preferences based on the context. The First Peoples Disability Network (Australia), the community-based disability organisation which hosted this research, prefers the terminology of ‘First Peoples’ when referring to its community. In contrast, the Australian Bureau of Statistics incorporates the identifier ‘Aboriginal and Torres Strait Islander’ in the description of the National Aboriginal and Torres Strait Islander Social Survey (NATSISS), which is a primary dataset used for statistical analysis. Ultimately, they are different identifying terms used to refer to the same population group.

Where possible, the term ‘Indigenous’ is avoided as a reference to Australian Aboriginal and Torres Strait Insider people. This is to conform to the cultural protocols and preferences of the First Peoples Disability Network who have hosted me during my research. As such, the term ‘Indigenous’ is used when directly referencing another publication or Australian Government policy that includes that term, or when making references outside the Australian setting to draw comparisons to Indigenous peoples internationally.

‘Community’

In the broadest sense, a ‘community’ is a group of people with shared beliefs, values and experiences. The shared experiences of Aboriginal and Torres Strait Islander people mean that the term ‘community’ has a special connotation for them. It is not only a term that describes physical connection of a group of people, but also a spiritual sense of belonging. In Aboriginal and Torres Strait Islander affairs, there are a variety of contexts in which ‘community’ can be

used. Two prevalent examples of contrasting contexts in the use of ‘community’ are:

- **Spatial references** to ‘community’: In this context, ‘community’ is used to locate a person’s sense of belonging which is place-based or geographical. For example, people may identify as belonging to an Aboriginal nation, and/or a town or locality.
- **Non-spatial references** to ‘community’: In this context ‘community’ is used independent of geographical markers and used to locate a person’s sense of belonging based on their shared experiences with other people. In this sense, Aboriginal and Torres Strait Islander people with disability may be viewed as a ‘community’ based on shared experiences of disability, that transcends geographically based markers.

Notably, an individual may have multiple affiliations with different communities. For example, an Aboriginal or Torres Strait Islander person with disability may identify as a member of the disability community as well as a member of an Aboriginal nation. For the purposes of this thesis:

- ‘Community’ is used to refer to the First Peoples disability community. This is to convey the focus of the project, which is to narrate the shared experiences of Aboriginal and Torres Strait Islander people with disability.
- To avoid confusion within this thesis, place-based names are referred to as ‘research sites’.

‘Deadly Deaf Mob’

The ‘Deadly Deaf Mob’ is the name used by a network of Deaf and hearing impaired Aboriginal people who connect principally via social networking. This term contains two Aboriginal colloquialisms: ‘Deadly’ which is used as a term of affection by Aboriginal people to express admiration for another person or experience; and ‘mob’ which is a shorthand way by which Aboriginal people

can identify each other and where they are from. One of the participant cohorts in this study are Deaf Aboriginal people, and the term “Deadly Deaf Mob” is used as a reference for this cohort out of respect to their preferred means of self-identification.

‘First Peoples disability community’ and ‘First Peoples Disability Network’

On a final point of clarification, ‘First Peoples disability community’ is used to refer to the group of Aboriginal or Torres Strait Islander people with a shared experience of disability, whereas the ‘First Peoples Disability Network’ is used to specifically refer to the community-based organisation established by the First Peoples disability community.

Dedication

This thesis is respectfully dedicated the greatest teacher without a title that I have known.

Now a speckle in the night's sky, I like to think you would be a bit proud of this work...even if you might not admit it.

Prologue – An Indigenous Culture of Inclusion

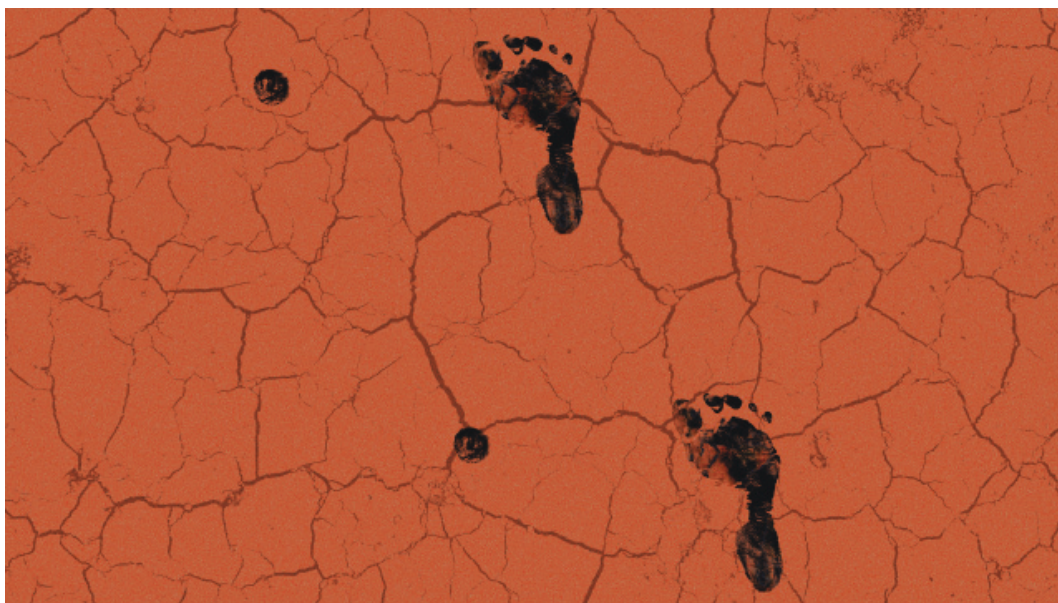
“To understand ‘disability’ in Aboriginal and Torres Strait Islander communities today, you need to cast your mind back 20,000 years to ancient times.

The archaeological site at Lake Mungo, part of the Willandra Lakes Heritage site in south west New South Wales, contains the oldest footprints found in Australia, giving insight into the Aboriginal society in ancient times. Amongst the collection of footprints is a single track-line of one right footprint deeply impressed into the clay, but no corresponding left footprint was discovered. Trackers from the Pintubi people of Central Australia, traditional custodians of the land, were sought for their advice on what this meant. Looking at the track, they told the archaeological research team, “yes, this is definitely a one-legged man” (Markey, 2016). Using sophisticated scientific modelling techniques, further analysis by the archaeological team indicated that the one-legged man was possibly moving as part of a hunting pack and moving at pace, upwards of an incredible twenty kilometres an hour (Webb, 2007). Using traditional knowledge, the Pintubi people, skilled in reading the nuances in the track-lines, suggested that the one-legged man simply threw away his walking stick and hopped at speed to keep pace with the hunting pack.

The story of the one-legged Mungo man actively participating in a hunting group is symbolic of the diversity and inclusion in First Peoples cultures. It is derived from a belief system and worldview of humanity in which biological, physical and intellectual differences are accepted as part of the fabric of society.....[This is] the first stop in the narrative journey of Aboriginal and Torres Strait Islander people with disability.

These footprints survived for a reason. They survived to tell us a story.”

Prologue from *Culture is Inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability* (Avery, 2018, at p.2; p.iv).



Source image: *Culture is Inclusion: A Narrative of Aboriginal and Torres Strait Islander people with disability* (Avery 2018, p. 3). Concept design: Scott Avery. Graphic Design: Tracy James Creative. Publisher: First Peoples Disability Network (Australia). Used with express permission.

“We go hunting together”

**Cultural and community inclusion as a moderator of
social inequality experienced by
Aboriginal and Torres Strait Islander people with disability**

1. Introduction

1.1 Introduction

This thesis is a study on the experiences of Australia's Aboriginal and Torres Strait Islander people with disability as told through their personal testimony and statistical data. It explores the social inequality that they experience as a group of people at the intersection of two marginalised population groups; the first being Aboriginal and Torres Strait Islander people, and the second being people with disability. It also investigates the Indigenous cultural dimensions that foster the inclusion of people with disability in cultural and community events within Aboriginal and Torres Strait Islander communities.

The specific issues affecting Aboriginal and Torres Strait Islander people with disability as a unique group have been afforded little attention in research and social policy. In the absence of prior research on disability and Aboriginal and Torres Strait Islander communities, this research was designed as a grounded, exploratory study on the nature and prevalence of disability and inclusion in Aboriginal and Torres Strait Islander communities.

The research utilises a mixed methods approach (Leech and Onwuegbuzie; 2008; Creswell and Plano Clark, 2011; Bowers et al, 2013; Shorten and Smith, 2017) in constructing a narrative of disability and inclusion in Aboriginal and Torres Strait Islander communities, utilising quantitative and qualitative data. The quantitative component of the research sources statistical data from various datasets held by the Australian Bureau of Statistical (ABS). There are two applications of the statistical data. Statistical data is used to derive an estimate of the prevalence and profile for the Aboriginal and Torres Strait Islander population from the best available data. Estimating the prevalence of disability amongst the Aboriginal and Torres Strait Islander population is particularly significant in defining the scope of the research problem, and this has not been attempted in previous research or government reporting. Statistical data are also used to determine the scale of social inequality that Aboriginal and Torres Strait Islander people with disability experience as a population

sub-group that intersects two marginalised populations. This is done through a comparative analysis of social, health and wellbeing outcomes across population sub-groups including: Aboriginal and Torres Strait Islander people with severe or profound disability; Aboriginal and Torres Strait Islander people with some disability; Aboriginal and Torres Strait Islander people without disability; people with disability who are not Aboriginal and/or Torres Strait Islander; and the general Australian population.

The qualitative component of the research utilises data sourced from the personal testimony of Aboriginal and Torres Strait Islander people with disability. Testimonial data was obtained principally through face to face interviews with 47 people who self-identified as being an Aboriginal or Torres Strait Islander person living with disability, with additional testimonial data obtained at a forum of Aboriginal and Torres Strait Islander Elders. The interviews were designed to facilitate the participation of Aboriginal and Torres Strait Islander people in the research by building upon the question “what is your story?”

There are two applications of the qualitative data. The first application is to contextualise the population-wide quantitative data on social inequality experienced by Aboriginal and Torres Strait Islander people with disability with verbatim testimony about the human impact of social inequality. This data is organised thematically and presented concurrently with the quantitative data on social inequality. The second application of the qualitative data is to conjoin it with the researcher’s field notes to construct a series of ‘yarning pieces’. These are individual case vignettes that draw upon a distinctively Indigenous concept of ‘yarning’ as story-telling to convey the inter-relationship of thematic issues that can come together in the life of an individual person.

The research involves an acutely marginalised group that traverses two marginalised population groups: Aboriginal and Torres Strait Islander people and people with disability. The intersection of these two marginalised populations posed ethical issues for the research which on one hand required a respect for the cultural dimensions of undertaking research in Aboriginal and Torres Strait Islander communities, whilst concurrently being responsive to the entrenched social isolation and vulnerability that is experienced by the participant group. Whilst there is an increasing body of research

that addresses linking Aboriginal and Torres Strait Islander culture and their health and wellbeing (Anderson and Kowal, 2012; Bourke et al, 2018; Salmon et al, 2018), there is a gap in this literature base that incorporates marginalisation and social isolation as an additional variable. This research expands upon previous research by exploring the impact of Aboriginal and Torres Strait Islander culture as a moderating force to social exclusion. How the research results were derived through the evolution of a genuine participatory methodology of research (Freire, 1970; Barnes 2003; White et al 2004; Hanley, 2005; Albert and Harrison, 2006; Genova, 2014) , and what this means for the empowerment of marginalised and ‘hard to reach’ population groups through research, are as significant as the research findings in relation to the social inequality that Aboriginal and Torres Strait Islander people with disability experience.

1.2 The research problem and aims

The prevalence of disability amongst the Aboriginal and Torres Strait Islander population has been estimated at least twice the rate of other Australians (ABS, 2016a, 2016b). Whilst the gravity in the comparative prevalence of disability between Indigenous and non-Indigenous people is a pointer to underlying social inequalities, little is known about the full extent and nature of disability and the social circumstances by which Aboriginal and Torres Strait Islander people live. Instead of comprising a body of work, research on disability amongst Aboriginal and Torres Strait Islander people has been sporadic since it first appeared in the research literature (Bostock, 1991; Gething 1994, 1995, 1997), and almost every researcher that has conducted studies in the field has lamented a lack of a solid research base relative to its need (Llewellyn, 2014; King et al, 2014; Gilroy et al, 2016).

The absence of a research base has had implications for the application of Australian public policy in addressing the specific needs of Aboriginal and Torres Strait Islander people with disability. Whilst the support needs of Aboriginal and Torres Strait Islander people with disability are diverse across their lifespan, the two core social policy frameworks through which social programs can be provided to Aboriginal and Torres Strait Islander people with disability are the *Closing the Gap Framework* (Coalition of Australian Governments, 2007) and the *National Disability Strategy* (Coalition of Australian Governments, 2010). Both of these policy frameworks operate

unilaterally to either the Indigenous population, or to the population of people with disability. Neither policy framework acknowledges the accumulated, intersectional disadvantage that comes with being a member of the two marginalised groups.

The absence of Aboriginal and Torres Strait Islander people from policy creates a phenomenon that Bostock, himself an Aboriginal person living with a disability, referred to as a “double disadvantage” that Aboriginal and Torres Strait Islander people with disability were subjected to (Bostock, 1991). The absence of research, data and knowledge on the social outcomes for Aboriginal and Torres Strait Islander people constrains the capacity of social policy to deliver programs to those people whose support needs are greatest, but who, due to their chronic marginalisation, have proven to be the hardest to reach in terms of providing access to programs which could support them. Bostock (1991) captured the barriers embedded in the hierarchies of a unilateral policy and program architecture that Aboriginal and Torres Strait Islander people with disability must penetrate in order to access support for their disability. He noted, “when we look at access and equity to service agencies and access to the workforce, Aborigines are at the lowest rung of the servicing ladder” (Bostock, 1991, p.6).

The absence of research, data and knowledge on the prevalence and nature of disability amongst the Aboriginal and Torres Strait Islander population promotes the first aim of the study, which is to generate some foundational statistical data and knowledge to inform the development of social policy. The desired outcome of this aim is to foster a greater understanding of the scale and scope of disability in Aboriginal and Torres Strait Islander communities, as well as the specific access barriers that marginalised and socially isolated people face, which in turn will drive systems of support that are commensurate to their need.

In addition to producing a statistical profile on the social status of Aboriginal and Torres Strait Islander people with disability, a second aim of the research is an interrogation of forces that have created and sustained the social marginalisation of Aboriginal and Torres Strait Islander people with disability. If, as Bostock suggests, the hierarchy of priorities within social policy and service delivery has positioned Aboriginal and Torres Strait Islander people as the “lowest rung” on the ladder (Bostock 1991), then this is a social stratification that has been documented as in

existence since at least the early 1990's. If further, the profile on the status of Aboriginal and Torres Strait Islander people with disability shows pervasive social inequality, then their position within the social hierarchy has not altered in three decades, despite the gravity of the social justice issue that affects a marginalised community within Australia. The second aim of the research is to understand why the marginalisation of Aboriginal and Torres Strait Islander people with disability presents itself with reference to the empirical observations of social inequality produced within the first aim of the research. In essence, this aim is a theoretical and conceptual framing of the social marginalisation of Aboriginal and Torres Strait Islander people in terms of power relativities compared to other groups in Australian society, as evidenced by data.

The third aim of the research addresses the schism between the understanding of disability that exists as a form of wisdom within the Aboriginal and Torres Strait Islander disability community, and that which is acknowledged within a scientific research base and ultimately in the formulation of social policy. To achieve this aim, a 'community-directed' approach to research was devised, guided by principles that came directly from a community-based organisation that represented the First Peoples disability community where the research was located. The community organisation that hosted this research was the First Peoples Disability Network, an Indigenous disabled peoples' organisation which is operated by a Board comprised in its entirety of Aboriginal and Torres Strait Islander people with disability. They undertake systemic advocacy and rights advocacy for Aboriginal and Torres Strait Islander people with disability, and a succession of its community leaders have been acknowledged as speakers at human rights forums internationally, as advisors to various Australian government agencies, and as advocates within Australian social policy forums.

Whilst the first three aims of the research intend to understand how social inequality is created and sustained amongst a marginalised group, the fourth aim of the research changes tone by looking at how a culture that is inclusive of Aboriginal and Torres Strait Islander people in their communities acts as a moderating force to the social inequality and isolation that they otherwise experience in other aspects of their lives. This aim explores the cultural beliefs and values of social inclusion that exist in Aboriginal and Torres Strait Islander communities, in contrast to deficit-based

constructs of ‘disability’ that have emerged in western civilisations. This culture of inclusion that is observed in Aboriginal and Torres Strait Islander communities can be traced to ancient times through artefacts from Aboriginal cultures that are emblematic of a culture of inclusion, namely ancient footprints dated at 20,000 years of a one-legged man on a hunt with his tribe (Webb, 2007). The exploration of a culture of inclusion is then followed through a review of research on social construction of disability conducted in Aboriginal communities that observed that there is no word for disability in Aboriginal languages (Ariotti, 1999; King et al, 2014). Finally, the exploration of an Aboriginal and Torres Strait Islander culture of inclusion reconnects with the empirical approach to data outlined by the first aim of the research by examining the participation by Aboriginal and Torres Strait Islander people with disability in cultural and community events, as evidenced through the personal testimony of the participants and statistically-based indicators of their participation within their community.

The combination of the four aims collates an overarching approach to the research in balancing dimensions which are empirically-based (aim 1); theoretical (aim 2); methodological (aim 3); and culturally specific to Indigenous peoples (aim 4). The breadth of the four aims reflect the research’s intention to act as an exploratory scoping study, upon which future research can build upon, in a discipline of study that has been largely neglected.

1.3 Expanding research aims into research questions

The four aims are transformed into research questions which the study addressed. Within each aim there is an overarching research question; under each there sits a number of derivative questions. In line with the approach to the study being an exploratory study, the research questions are intended to be broad reaching and tempered against being overly rigid.

The first research question, which is to capture the empirical observations on disability amongst the Aboriginal and Torres Strait Islander population, is transformed into the first overarching research question: ***What is the prevalence, nature and social impact of disability amongst the Aboriginal and Torres Strait Islander population?***

Within the line of inquiry relating to the prevalence, profile and impact of disability amongst the Aboriginal and Torres Strait Islander population, a number of derivative questions are considered:

- What is the prevalence of disability amongst the Aboriginal and Torres Strait Islander population?
- What is the profile of disability, with respect to disability diagnoses?
- What are the social, health and wellbeing outcomes experienced by Aboriginal and Torres Strait Islander people with disability compared to other population groups?
- What are the implications for the scope of disability and social status of Aboriginal and Torres Strait Islander people with disability of Australian Indigenous and public disability policy?

The second aim of the research is a theoretical and conceptual framing of the problems of social inequality that affects Aboriginal and Torres Strait Islander people with disability as people who intersect two marginalised populations groups. This research aim is transformed into the research question: ***How is the social inequality that is experienced by Aboriginal and Torres Strait Islander people with disability created and sustained?***

The derivative questions that sit under this line of inquiry are:

- What is the relationship between the inequality in the power relativities between Aboriginal and Torres Strait Islander people with disability and other population groups, and the inequality that they experience?
- What are the sources of power inequality that sustain the social inequality experienced by Aboriginal and Torres Strait Islander people with disability?

The third aim acknowledges that the research is being conducted within a marginalised population involving people who have experienced vulnerability. For the research to reliably reflect the experiences of Aboriginal and Torres Strait Islander people with disability, the methodology was to source testimony from people who have experienced isolation, discrimination and trauma. Previous empirically-based research

on Aboriginal and Torres Strait Islander disability has been conducted by non-Indigenous researchers in Aboriginal communities (Ariotti, 1999; King et al, 2014), or by institutionally-based researchers that have sourced their perspective on Aboriginal and Torres Strait Islander people with disability from service providers (Gilroy et al, 2016). The point that differentiates this research from prior research is that it was produced from within the Aboriginal and Torres Strait Islander disability community by a researcher who was embedded within that community. The uniqueness of this community-based approach to Aboriginal and Torres Strait Islander disability research required a research approach to be devised that was both informed of the vulnerabilities experienced by the population group, as well culturally compatible in Aboriginal and Torres Strait Islander communities. These two aspects of undertaking research involving people from Indigenous populations is distilled into the following research question: ***What is a model of research that actively promotes participation of Aboriginal and Torres Strait Islander people with disability through the direct testimony of their lived experience?***

This aim incorporates participatory research that both acknowledges the entrenched social isolation of the participant population and respects the cultures of Indigenous peoples. The derivative questions accommodate social isolation and cultures of Indigenous peoples in promoting participatory research:

- What are the research governance practices which establish trust with people in Aboriginal and Torres Strait Islander people with disability and their communities?
- What are the discourses of research practice that improve the acceptance of research activities amongst Aboriginal and Torres Strait Islander people with disability and their communities?
- How should experiences of vulnerability from within the participant population, including exposures to trauma and discrimination, inform the ethical conduct of research involving Aboriginal and Torres Strait Islander people and other vulnerable populations?

The fourth and final aim is to look at the role of Aboriginal and Torres Strait Islander cultural beliefs and values of inclusion of people with disability and their affirming

influence on their health and wellbeing. It aims to integrate an Indigenous standpoint theory (Nakata, 1998, 2007; Rigney, 2000; Foley, 2003) of cultural and community knowledge in all stages of research, including: its philosophical foundations; the research setting; researcher's standpoint; design and methods; the selection and utilisation of data sources; analysis; and knowledge translation. By taking an Indigenous knowledges approach to the problem of social exclusion of people with disability, this study is differentiated from other disability research which has been undertaken through a comparatively different ontology and value-base. This is distilled into the research question: ***Is there an Aboriginal and Torres Strait Islander 'cultural model of inclusion' that actively promotes the social participation of people with disability?***

Taken as a whole, the four research questions of this study were:

Question 1: What is the prevalence, nature and social impact of disability amongst the Aboriginal and Torres Strait Islander population?

Question 2: How is the social inequality that is experienced by Aboriginal and Torres Strait Islander people with disability created and sustained?

Question 3: What is a model of research that actively promotes participation of Aboriginal and Torres Strait Islander people with disability through the direct testimony of their lived experience?

Question 4: Is there an Indigenous 'cultural model of inclusion' that actively promotes the social participation of Aboriginal and Torres Strait Islander people with disability?

1.4 The research setting and context

This section builds upon the issues raised in identifying the research problems to provide a greater understanding of the setting and context in which research takes place. Whilst the research context described in this section is built upon progressively in the remainder of the thesis, an introductory overview is required from the outset,

particularly for other researchers who are unfamiliar with the uniqueness in the trauma experiences of Aboriginal and Torres Strait Islander people with disability living as a marginalised minority group in their country.

There are three dimensions to the setting and context that are covered by this section. The three aspects come from different, but cascading, perspectives:

- (i) first, from the perspective of Aboriginal and Torres Strait Islander people with disability as a distinct population group;
- (ii) second, from the perspective of Aboriginal and Torres Strait Islander people with disability as a self-determining community; and
- (iii) third, from the personal perspective of the researcher, who is an Aboriginal man who is also profoundly deaf, and hence an active member of the Aboriginal and Torres Strait Islander disability community to whom this research relates.

This first dimension of the research context comes from the perspective of Aboriginal and Torres Strait Islander people as a sub-group within the Australian population. It focusses predominantly upon the ongoing impact of colonisation of Indigenous peoples by a western power. In addition to the cultural disruption caused by colonisation, this aspect will also consider the disruption to the social order which has affected the power and social status of Aboriginal and Torres Strait Islander people living with a disability. In understanding their disempowerment as having its origins in colonisation, the research focuses on social inequality that they experience relative to other groups in Australian society.

The second dimension of the research context comes from the perspective of Aboriginal and Torres Strait Islander people as a self-determining community. It outlines how the research was located within the First Peoples Disability Network (Australia), which is a national, non-government community organisation that is governed in its entirety by Aboriginal and Torres Strait Islander people with disability. Locating the research within a community-based Aboriginal and Torres Strait Islander community organisation differentiates it from all previous disability related research

on Aboriginal and Torres Strait Islander people, which by contrast has emanated from research institutions. The rationale for locating the research within a community organisation that is representative of the community group that the research relates to, as contrasted to principally affiliating with a research institution, is to provide an authenticity in the ‘voices’ of Aboriginal and Torres Strait Islander people with disability on the issues to which the research speaks to.

The third dimension of the research setting and context comes from the researcher’s personal perspective. This perspective is significant to how the research was conducted, as the researcher is an Aboriginal man who is profoundly deaf and is a recognised member of the Aboriginal and Torres Strait Islander disability community. The researcher’s personal perspective addresses how having a researcher embedded within the Aboriginal and Torres Strait Islander disability community has contributed to the grounded approach used in the research. The tacit understanding of community protocols held by the researcher has aided in building the trust of the community and its members to facilitate their participation in the research. It will also outline how the cultural obligations of the researcher back to the community of which he is a member have augmented institutional models of research ethics, resulting in a more robust ethical approach to research that is culturally compatible to Indigenous communities, and is sensitive to the vulnerabilities that they experience as people who have been socially isolated.

1.4.1 The impact of colonisation upon Aboriginal and Torres Strait Islander people with disability

The research takes place in the Aboriginal and Torres Strait Islander communities, who are the Indigenous peoples of Australia. At the time of the 2016 population census, the Australian Aboriginal and Torres Strait Islander population was estimated at 798 365, or 3.3% of the total Australian population (ABS, 2018). As elaborated further in Chapter 6, obtaining precise data-based estimates on disability prevalence amongst the Aboriginal and Torres Strait Islander population is problematic, but it is understood that disability occurs at prevalence rate that is twice the prevalence rate of disability amongst the population who are not Aboriginal and/or Torres Strait Islander (ABS 2016a, 2016b, 2017a). Depending on the survey instrument used, approximately 7.3% to 7.9% of the Aboriginal and Torres Strait Islander people are living with severe and

profound disability (ABS, 2016a, 2016b, 2017c). When the Aboriginal and Torres Strait Islander population and disability prevalence estimates are combined into a single estimate of the population of Aboriginal and Torres Strait Islander people with disability, the likely population of Aboriginal and Torres Strait Islander people with disability is somewhere between 0.8% and 1.5% of the total Australian population. The population estimate as a percentage of the total of is reduced further once severity of disability is taken into account, with Aboriginal and Torres Strait Islander people with severe or profound disability is likely to constitute a mere 0.25% of the total Australian population. The implication of Aboriginal and Torres Strait Islander people with disability being a numerically small minority group within the total Australian population is that it is an impediment to publicly driven social change that can be effected by the weight of population numbers alone.

In setting an historical context for this study, Aboriginal and Torres Strait Islander people are 'First Peoples' in a colonised nation, having suffered a sudden disruption to their Indigenous societies and cultures. The oppressive effects of colonisation upon Aboriginal and Strait Islander people are enduring, although the nature by which colonisation continues to impose itself has continued to adapt since the process of colonisation commenced in the late 1700s (Moreton-Robinson, 2003, 2015).

European colonisation caused catastrophic shocks in Aboriginal and Torres Strait Islander societies (David et al, 2006), and since its commencement in the late 1700's, the processes of colonisation has had multiple and continuing impacts on the Aboriginal and Torres Strait Islander population (Johnston, 1991; Trudgen, 2000). First, massacres and the introduction of foreign diseases drastically reduced the Aboriginal population in the first decade following European contact. Second, the imposition of guns, alcohol, tobacco and sugar as agents of colonisation resulted in hugely increased levels of disablement among the surviving population and their future generations, which has had a long-term impact on population health status. Third, the colonisation itself was founded on the imperial legal doctrine of 'terra nullius', literally meaning 'nobody's land' (Frost, 1981; Reynolds, 1987). To morally justify the dispossession of the native inhabitants from their land, Aboriginal and Torres Strait Islander people were treated as subhuman and viewed as inferior by their European conquerors. The humanity of Aboriginal and Torres Strait Islander people was effectively denied, and the impact of racial discrimination affecting the rights,

inclusion and social structure of Aboriginal and Torres Strait Islander people is still evident in Australia today.

Colonisation had a particular impact upon Aboriginal and Torres Strait Islander people with disability, centring them at a convergence of armed aggression dispossessing them from their land as Aboriginal people, alongside their continuing social isolation as people with disability, a phenomenon which some disability scholars refer to as ‘othering’ (Mik-Mayer, 2016). European colonisation of Australia’s Indigenous lands and peoples commenced in period in history known as ‘the Enlightenment’, an intellectual and political movement which emerged in Europe in the late 18th and early 19th century, characterised by scientific thought, reasoning, and the promotion of personal liberty (Reeves, 2010). An influential thinker in Britain at the time was Scottish economist Adam Smith (1776), whose book the *Wealth of Nations* included a theory of market economics. Amongst the key ideas of the theory of market economics is a concept of ‘human capital’, which equates people to physical resources in a production process. A corollary of ‘human capital’ is the notion of a ‘disabled person’, an idea that was socially constructed to categorise those people that were perceived to be unable to participate in the market economy, or as raw materials in a production process and discarded as not meeting a standard specification. These were the emergent ideas at the time and became the foundation for the social and political economy of the new colony of New South Wales, in the country that now is known as Australia.

Hence, upon colonisation by a European power, the native population of Australia faced cultural upheaval on multiple fronts. In addition to violent dispossession from their land by force (Hollinsworth, 2006; Reynolds, 2013), social hierarchy was imposed that was antithetical to their cultural values of diversity and inclusion. Some Aboriginal people, already subjugated by armed force (Reynolds, 2013) and the pejorative influences of the early colonial press (Gilroy, Ragen et al, 2018), also acquired a new label of ‘disability’, adding another dimension to their dehumanisation, further marginalising them even amongst their own people. In the two and a half centuries since, Aboriginal and Torres Strait Islander people with disability have been vulnerable to the most insidious aspects of social engineering policies and practices that have been imposed upon them since the commencement of colonisation: whether it is the over-incarceration of Aboriginal and Torres Strait people (Johnston, 1991); the

institutionalisation of people with disability in mental asylums and institutions, and the structural violence that occurred within them (Sweet, 2017); the removal of children from their families during the Stolen Generations and beyond (Human Rights and Equal Opportunities Commission, 1997; McGlade, 2012); or their exclusion from participating in a market economy (Hunter, 2000).

The magnitude of the impact of colonisation upon Aboriginal and Torres Strait Islander people with disability is beyond the scope of this introductory section, nor is it intended for colonisation to be the focal point of this research. It is, however, important to note here the history of colonisation and its impact on Aboriginal and Torres Strait Islander people with disability as detailed from the body of literature that is cited in this section. In essence, the ‘trauma story’ of Aboriginal and Torres Strait Islander people with disability is an impairment uniquely experienced by Aboriginal and Torres Strait Islander people who have been dispossessed from both Country and body.

1.4.2 Locating the research in the Aboriginal and Torres Strait Islander disability community

The research aimed to optimise the participation of Aboriginal and Torres Strait Islander people with disability through a model of research that was designed, conducted and driven by the community group to which the research related. A core strategy to achieving an authentic model of community-based research was to locate the research within a community-based Aboriginal and Torres Strait Islander disability organisation. Locating the research in an organisation answerable to a community-controlled disability governance structure was instrumental in keeping the research program grounded to the needs, values and decision-making practices of community. In research practice, this meant that the researcher was embedded within a community organisation and presented as a representative of community. As a model of research based in community, it is a contrast to models of research where the researcher’s principal affiliation is with an academic institution independent to the community being researched.

The community host for the research was the First Peoples Disability Network. First Peoples Disability Network is a non-government non-profit Indigenous Disabled Peoples Organisation that is governed by a board of directors comprised in its entirety

of Aboriginal and Torres Strait Islander people with a lived experience of disability, either personally or through a close family or community connection. As a national representative body for Aboriginal and Torres Strait Islander people with disability, their families and communities, it has its origins in a national gathering of Aboriginal and Torres Strait Islander people with disability in 1999, and formally incorporated as a national body in 2009. To maintain its independence as a representative voice for and on behalf of Aboriginal and Torres Strait Islander people with disability, it is not a service provider and hence is not conflicted by advocating for an ongoing commercial interest. Its governance structure as an Aboriginal community-controlled disabled peoples' organisation embodies the dual right of self-determination of Indigenous peoples as articulated in the United Nations Declaration of the Rights of Indigenous Peoples (United Nations, 2007), and the right to participatory decision making by people with disability as articulated in the Convention on the Rights of Persons with Disabilities (United Nations, 2006).

Over the course of the research, the researcher was embedded as a community-based researcher within the First Peoples Disability Network. This position was formalised through employment of the researcher by the First Peoples Disability Network in a research and policy advocacy role. The effect of this arrangement was to establish agency for the research in a community organisation in which all stages of the research were legally, culturally and philosophically accountable to a board comprising members from the community that was the focus of the research. In research practice, the researcher was presented as acting on behalf of the First Peoples Disability Network, and therefore the community, in the eyes of the participant group and other stakeholders in the research translation, rather than as an independent researcher from an academic research institution.

Whilst the principal affiliation was with a community organisation, an affiliation with an academic institution was established and acknowledged. The affiliation with an academic research institution provided a mechanism through which the research could be subjected to recognised conventions for research practice and ethical conduct. Adherence to the recognised standards for research was vital in controlling the perception of insider bias that might arise when conducting the research from within the community involved in the research (Corbin Dwyer and Buckle, 2009). Taken together, an affiliation with a community organisation and an academic institution

worked to complement each other in a community-directed model of research co-production, which is elaborated upon further in Chapter 3. Complying with community values and protocols provided the authenticity, whilst adhering with institutional practices and ethics provided the legitimacy.

1.4.3 *The researcher's 'standpoint' within the First Peoples disability community*

An attribute of the research is its application of Indigenous Standpoint Theory (Nakata, 1998, 2007; Rigney 2000; Foley, 2003). Nakata describes Indigenous Standpoint Theory as a process of constructing knowledge in which an Indigenous scholar works at the “cultural interface” between Indigenous knowledges and systems, and non-Indigenous knowledges and systems to make sense of Indigenous existence within the social order (Nakata, 1998). Indigenous Standpoint Theory draws a distinction between ‘lived experience’ and ‘reflexivity’, in that an Indigenous scholar cannot claim a special knowledge or authority by the sole virtue of being Indigenous. Instead, the significance of an Indigenous scholar researching at the cultural interface comes not merely in drawing from their personal experiences, but as Pohlhaus (2012) describes as them being “socially positioned” to delimit knowledge and conduct a critical analysis of the social relationships through which knowledge is produced. Nakata (1998) condenses the significance of the social positioning of an Indigenous researcher as “knowing where to look” (Nakata, 1998, p.218).

Indigenous Standpoint Theory is elaborated on further in Chapter 2 in relation to the power relativities that Aboriginal and Torres Strait Islander people encounter within Australian social structures. For the purposes of this introduction however, the significance is the acknowledgment of the researcher’s standpoint, in being an Aboriginal researcher with a disability conducting this research. A critical criterion for research that applies Indigenous Standpoint Theory is that the researcher must be Indigenous (Foley, 2003). This research was undertaken by me as someone who is not only Aboriginal, but also profoundly deaf, and as embedded within a community-based Aboriginal and Torres Strait Islander disability organisation working at a cultural interface between community, research and policy. Hence, the standpoint of the researcher intersects three aspects - Indigenous, disability, and community.

The researcher's positionality as an Indigenous disability community-based researcher has afforded privileged insights during the research, as tacit knowledge coming to the research from within the First Peoples Disability Network has meant, using Nakata's summation (Nakata, 1998, p218), that the researcher has known where to look. At a practical level, being an Aboriginal person who is profoundly deaf was instrumental in generating a bond with the participant group based on a mutually shared set of experiences. Being seen as 'one of us' enabled a deep reaching access to people's testimonies that might not have been possible by someone who was viewed as coming from outside community.

Alongside the privileged access to insights and access to knowledge that is afforded to a researcher positioned within the Indigenous disability community, there are reciprocal cultural obligations and responsibilities that researchers from this standpoint accrue. There are community and cultural protocols, often unwritten, that an Indigenous researcher must adhere to in collecting data and undertaking the research. To an outsider to the community, these protocols can be bundled under generic concepts of 'trust' and 'respect' (Dew et al, 2018), but within Indigenous cultural practice, they present a more sophisticated way of doing business. One such example is an Indigenous cultural value of recognising a person's story as central to their connection to time and place, their land and their community. Whilst a person's story can be referred to as 'testimony' and can be treated as qualitative data for the purposes of research, limiting a person's story to its analytical qualities loses the sacredness of their story. Undertaking analyses of personal testimonies is akin to acting as a curator of artefacts in a museum. These are the cultural values and obligations that filter through every aspect of this research, from its design, conduct and reporting.

The structure of the thesis respects the distinction between 'reflexivity' and 'lived experience' as entailed within Indigenous Standpoint Theory by separating the two. The body of the thesis is an outcome of insights, critical analysis and reflections as an Indigenous disability community-based researcher positioned at the 'cultural interface' of public Indigenous and disability policy.

1.5 The social policy context of the research

This research takes an intersectional approach by looking at the social inequality Aboriginal and Torres Strait Islander people with disability experience as a unique group traversing two other marginalised groups; one group being Aboriginal and Torres Strait Islander people, and the other group being people with disability. The intersectional approach in this research contrasts with the approach of contemporary Australian social policy that sectionalises Aboriginal and Torres Strait Islander people and people with disability as two discrete populations and addresses the social issues that affect them through separate and unconnected policy frameworks.

Within the Australian federated system of government, there is a multiplicity of policy initiatives, frameworks and plans that impact upon the lives of Aboriginal and Torres Strait Islander people with disability. To highlight the degree of fragmentation of public policy affecting Aboriginal and Torres Strait Islander people with disability policy, Australia has nine governments at the federal, state and territory level, as well as 546 local governing bodies. Issues affecting Aboriginal and Torres Strait Islander people with disability transcend numerous policy domains, from Indigenous affairs to disability, health, law and justice, education and employment, transport, and housing. The number of government agencies managing one (or more) aspects of Aboriginal disability policy is in excess of fifty government agencies. In each of these agencies, Aboriginal and Torres Strait Islander disability issues are incidental to the core policy program.

The purpose of highlighting fragmentation of the policy framework affecting Aboriginal and Torres Strait Islander people with disability is to situate the approach of Australian public policy in contrast to the intersectional approach taken by this research. At the national level, there are two main social policy initiatives of the Australian Commonwealth Government which affect Aboriginal and Torres Strait Islander people with disability. One policy is the *National Indigenous Reform Agreement*, more commonly known as *Closing the Gap Framework* (Coalition of Australian Governments, 2007) that aims to improve health and social outcomes of Aboriginal and Torres Strait Islander people. A second separate and unconnected strategy is the *National Disability Strategy* (Coalition of Australian Governments, 2010) that is an overarching national policy approach to improving access to support

services and social outcomes for people living with disability, their families and carers. The establishment of a National Disability Insurance Scheme is a key policy initiative of the *National Disability Strategy* (Coalition of Australian Governments, 2010), and amounts to a \$28 billion undertaking to provide increased access to disability services by people with severe and profound disability. A specific discussion of issues emerging from the implementation of the National Disability Insurance Scheme in Aboriginal and Torres Strait Islander communities is in the findings presented in Chapter 7.8 of the thesis.

Addressing inequalities through the *Closing the Gap Framework* and the *National Disability Strategy* as unconnected policies may be regarded a *sectional* policy approach, drawing a comparison to the intersectional approach of this research. Within the Indigenous policy domain, the *Closing the Gap Framework* includes specific targets for equality between Aboriginal and Torres Strait Islander people and other Australians in the areas of: life expectancy; child mortality rates; school attendance; literacy and numeracy; year 12 level education attainment; and employment outcomes (Coalition of Australian Governments, 2007). The significance of a policy target under the *Closing the Gap Framework* is that it is under-pinned by a partnership agreement between the Commonwealth Government and State and Territory Governments that have a funding commitment towards programs to attain equality in outcomes for that targeted area.

Since its inception, there has been no target within the *Closing the Gap Framework* which acknowledges the impact of disability as a factor in attaining equality within their targeted policy area across the entire population. For example, achieving equality in educational attainment for the entire Aboriginal and Torres Strait Islander population does not acknowledge the peculiar barriers that Aboriginal or Torres Strait Islander children with disability might face to attaining equality in access to their education, over and above their status as Aboriginal or Torres Strait Islander children. Consequently, social equity programs provided through Indigenous education policy focus upon cultural inclusion, but ignore disability inclusion. As another example, the target to attain equality in employment outcomes for Aboriginal and Torres Strait Islander people does not factor in how disability related discrimination in employment practices may coincide with race-based discrimination to curtail the prospect of attaining equality in employment across the entire population.

Part of the oversight of the impact of disability within Indigenous policy may be attributable to an absence of the research and data that demonstrate the heightened level of social inequality that Aboriginal and Torres Strait Islander people with disability encounter compared to Aboriginal and Strait Islander people without disability. This was the case at the commencement of the research. The significance of this research in producing this data and analysis is detailed later in this chapter. The central plank of Australian public disability policy is the *National Disability Strategy* (Coalition of Australian Governments, 2010) that aims to improve the quality of lives of people with disability. The *National Disability Strategy* has identified six policy priority areas with distributed responsibilities across various government agencies, including: inclusive and accessible communities (including the physical environment, transport, communications, social and cultural life); rights protection, justice and legislation (including anti-discrimination and interaction with justice systems); economic security (including employment and income support); personal and community support (including provision of disability support services); learning and skills (including early childhood and education); and health and wellbeing (including access to health, interaction between the health and disability services).

In 2017, the Australian Government took a step towards acknowledging the unique needs of Aboriginal and Torres Strait Islander people with disability through the release of an *Australian Government Plan to Improve Outcomes for Aboriginal and Torres Strait Islander People with Disability* (Commonwealth of Australia Department of Social Services, 2017). The Plan is an audit of current government activities affecting Aboriginal and Torres Strait Islander people that might have incidental benefit to people with disability, but few meet the criteria of targeting the specific needs of this group. Notably, there are no future policy initiatives detailed within the Plan that have been costed, nor has there been any reference to the prevalence or profile of disability amongst Aboriginal and Torres Strait Islander communities upon which demand for disability services, and requirements for a disability workforce servicing Aboriginal and Torres Strait Islander people, can be determined. In this respect, the Plan is better viewed as a statement of intent which recognises Aboriginal and Torres Strait Islander people with the *National Disability Strategy*, than as a coherent strategy or action plan for community development that drives improvement in social outcomes.

A key pillar of the *National Disability Strategy* is the establishment of a National Disability Insurance Scheme, which aims to increase the accessibility of disability supports and services for people with severe and profound disability. It establishes a market-based model for the provision of disability services in which participants in the NDIS are afforded a notional quantum of money, referred to as a ‘package’, with which they can purchase services. In other words, it focuses exclusively on personal agency, paraphrased as ‘choice and control’ (Commonwealth of Australia, 2013), to drive a market-based allocation of disability support services.

There are limitations to the market model of the National Disability Insurance Scheme when it is implemented in Aboriginal and Torres Strait Islander communities. In many Aboriginal and Torres Strait communities, there are gaps in the basic public infrastructure that are needed to make a market function effectively. As this research has affirmed, many issues that inhibit access by people with disability are structural. The structural barriers to access include public infrastructure deficits such as an absence of footpaths, accessible housing and transport. In the hierarchy of community need, addressing fundamental issues of survival, such as homelessness and chronic hunger, take precedence over the capacity of the National Disability Insurance Scheme to make an impact at the personal level. However, the responsibility for addressing the structural issues is beyond the remit of the National Disability Insurance Scheme, and it instead resides in another, unconnected arm of government.

An application of this research is to connect the unilateral aspects of the Australian Government’s Indigenous policy and disability policy through an intersectional approach. This is discussed further in the section below on the significance of the research, and again in Chapter 10.

1.6 Overarching approach to research

The overarching purpose of this research is to elevate and promote the voices of Aboriginal and Torres Strait Islander people with disability within research and policy. From within its base in the First Peoples disability community, it is methodologically designed as an exploratory study using an authentically grounded approach. The

approach to the research was not an application of one single theoretical approach, but instead informed by a broad range of theoretical frameworks and constructs that were applied in the research design as well as used to construct conceptual frameworks to explain the results. Some of the theoretical and methodological approaches are Indigenous in origin (Tuhiwai Smith, 2012; Nakata, 1998; Rigney, 2000), others are derived from a Westernised research epistemology. The influences upon the research approach include:

- (i) Foucauldian approaches to discourse and power (Foucault, 1972, 1980), with respect to understanding the power relativities that create and sustain social inequalities;
- (ii) Critical feminist approaches to ‘intersectionality’ (Crenshaw, 1991) to explain the relative power inequalities that Aboriginal and Torres Strait Islander people experience as a group traversing two or more marginalised groups, as it applies in the interactions amongst social groups of differing power status (Crenshaw, 1991; Choo and Ferree, 2010; Cho 2010), and in population-based health inequalities (Kapilashrami and Hankivsky, 2017; Green et al, 2017);
- (iii) Freire’s ethos of emancipatory research and a ‘pedagogy of the oppressed’ (Freire, 1970), responding to the historical and multi-faceted marginalisation of the participant group;
- (iv) Contemporary approaches to participatory action research which have been utilised in the community-based disability research internationally (Barnes, 2003; Albert and Harrison, 2006; Hanley, 2005);
- (v) Charmaz’ principles of grounded theory (Charmaz, 2006), reflecting a philosophical desire to build the research from the community up;
- (vi) Indigenous Standpoint Theory (Nakata, 1998, 2007; Rigney 2000; Foley, 2003), as referenced above, and other Indigenous research philosophies (Wilson, 2008), acknowledging the privileged positioning of the researchers within the community involved in the research, and the

reciprocal cultural obligations back to the community and their implications for research ethics; and

- (vii) De-institutionalising research methodologies, in reference to Indigenous research within the context of colonisation (Tuhiwai Smith, 2012), and as a strategy for driving social change (Phillips et al, 2004; Hardy and Maguire, 2010; Hardy and Thomas, 2014).

Whilst the influences upon the research approach were many and varied, the construction of a distinctive approach for this research was driven exclusively by what would be safe, culturally compatible and effective in the First Peoples disability community. The vision for authentically grounded participatory research was operationalised into research practice through five design principles:

- **Principle 1:** The research is philosophically, methodologically and operationally aligned to the control and direction of the First Peoples disability community.
- **Principle 2:** The research advances the rights-based movement of the First Peoples Disability Network in advocating the rights of Aboriginal and Torres Strait Islander people with disability.
- **Principle 3:** The research is inclusive of all people who wish to participate, subject only to their self-identification as a member of the First Peoples disability community.
- **Principle 4:** The research is discrimination and trauma informed, acknowledging the unique sensitivities of conducting research that includes people who are both Aboriginal and/or Torres Strait Islander and have disability.
- **Principle 5:** The research meets both (i) international standards of ethical research practice and quality, and (ii) ethical standard for conducting research in Aboriginal and Torres Strait Islander communities.

As an exploratory scoping study, its principal purpose was to canvass issues and generate ideas from Aboriginal and Torres Strait Islander people with disability. In adhering to an authentically grounded approach, the core research question that was presented to participant groups was distilled into four words: “What is your story?” In keeping with the participatory aims of the research, Aboriginal and Torres Strait Islander people with a lived experience of disability were deemed the people most qualified to answer this question.

1.7 Significance of the research

The innovation in the community-directed research methodology, and the richness in quality of the data produced through the participatory research processes, mean that the research is broad and varied. At its most central point of impact, this research can be directly applied to a future research and policy agenda to address the social inequalities experienced by Aboriginal and Torres Strait Islander people with disability. Beyond the impact realised by the First Peoples disability community as the immediate participant group, many of the principles in participatory research methodology and techniques are relevant to research that is undertaken involving other population groups that are marginalised and experience vulnerability.

Given the breadth of potential impact that is emerging from this research, this section focuses on two key points of impact. The first point of impact discussed is the application of intersectional approaches to add nuance to Australian social policy. The second point of impact discussed is the empowerment of vulnerable populations through their participation in genuine participatory research.

1.7.1 A foundation for applying intersectional approaches to Australian social policy

An aim in presenting the scope, nature and impact of disadvantage experienced by Aboriginal and Torres Strait Islander people with disability through the research is to connect more closely the current sectional approaches to social policy within government through an intersectional approach. A key message from this research is that reversing social inequality is better served through an intersectional response, in

which personal agency models of disability are coordinated with structural responses to Indigenous disadvantage.

Whilst there are numerous public policy frameworks which affect Indigenous people and disability as discrete demographic cohorts, there is presently no focused public policy framework which focuses on the unique circumstances experienced by people who are Aboriginal or Torres Strait Islander *and* have disability. As referenced earlier in the Chapter, this may be attributable in part to an absence of data and research that has pinpointed the inequalities that Aboriginal and Torres Strait Islander people experience as a standalone demographic cohort, even when compared to the two marginalised populations that they traverse.

Demonstrating the ‘intersectional inequality’ (Avery, 2018, pp. 107-150) experienced by Aboriginal and Torres Strait Islander people with disability is the first point of impact of this research. The evidence of ‘intersectional inequality’ is presented in three ways. First, statistical data on the social, health and wellbeing outcomes for Aboriginal and Torres Strait Islander people from the Australian Bureau of Statistics is disaggregated by disability status, and shows that Aboriginal and Torres Strait Islander people with disability experience social inequality at a higher rate than Aboriginal and Torres Strait Islander people without disability for every indicator that related to systems that intended to support their disability. This is the first time that statistical data has been used to quantify ‘intersectional inequality’ at the population level, and this data can now be used in the development of costed policies and programs to support the needs of Aboriginal and Torres Strait Islander people with disability as a unique population group.

The second way that the social inequality experienced by Aboriginal and Torres Strait Islander people with disability is demonstrated is through their personal testimonies. The personal testimonies were obtained through interviews conducted with Aboriginal and Torres Islander people with disability. This is the first time that direct narrative testimony from Aboriginal and Torres Strait Islander people with disability has been used to articulate ‘intersectional inequality’ and multi-faceted discrimination. This model of participatory research distinguishes this research from other research which has sought the perspectives of Aboriginal and Torres Strait Islander people with disability through intermediaries, such as service providers (Gilroy et al, 2016), carers

(DiGiacomo et al, 2017), or non-Indigenous researchers (Ariotti, 1999; King et al, 2014). The personal testimonies obtained through this research reveals the human impact of accumulated exposure to inequality and discrimination, that other non-participatory approaches to research have not been able to fully capture. Revealing the gravity of the impact that ‘intersectional inequality’ and discrimination have at the human level presses the case for social reform which addresses ‘intersectional inequality’ as a human rights issue.

The third way that ‘intersectional inequality’ is demonstrated is through the construction of a conceptual framework that explains how social inequality is created and sustained. This is achieved by synthesising the critical feminist theory of ‘intersectionality’ (Crenshaw, 1991) with neoclassical micro-economic principles (Frank and Bernanke, 2013) to relate the empirical observations of social inequality with their ongoing economic disempowerment. This analytical framework illustrates how the social policy practices that pursue relatively easily obtainable policy objectives, or ‘low hanging fruit’, at the expense of addressing access barriers which are perceived to be more difficult, places Aboriginal and Torres Strait Islander people with disability in a state of perpetual disempowerment and vulnerable to experiencing ongoing inequality. The impact of this third dimension of the research is that provides a theoretical basis by which the behaviours and incentives within the public administration of social programs can be critically reviewed. Whilst it is a theoretical model that has been designed from the standpoint of the First Peoples disability community, its concept and principles have relevance to other groups who experience vulnerability by facing differential barriers to their accessing of social equity programs.

1.7.2 Participatory research as a process of healing

A second point of impact relates to effectiveness of the participatory research methods in gaining access to the first-hand experiences from people who have suffered isolation and exclusion, both at the personal level and as a community. The raw testimony provided by the participant-disclosed personal encounters of discrimination, and in some cases trauma, in graphic detail. At one level, this speaks to the desire of people who have been subjected to isolation and trauma to have their stories heard and acknowledged. At another level, it speaks to respectful approaches to research which

create a safe space in which participants can tell their story on their terms, without judgment or boundaries, and in their own time and place. The ability of this research to make the voices of the participant group central to the research enabled access to the wisdom of their experiences in a richness of detail that that had not previously been captured through other approaches to research.

This research commenced with an ambition to undertake the research within the most optimal model of emancipatory and participatory research that could be achieved. The research was striving to illustrate a culturally considerate way of doing research with the First Peoples disability community, as well as to generate insight into the issues. The pathway that the research followed from its grounded beginning has been recorded and reflected upon. This research process was not transactional. Instead, it was deeply embedded in the relationships between the person participating, the researcher, and the community who was hosting the research activity. In effect, creating a safe space in which people who have experienced trauma and isolation were able to tell their story, be acknowledged and believed, has had an affirming effect upon their sense of being included and connected to a broader movement of social change. These are learnings that can apply not just to a future researcher, but also disability service providers, clinicians, teachers, lawyers and other professionals and practitioners who work with people from vulnerable communities.

A deeper consideration of how participatory research can connect a person experiencing vulnerability to a larger community, and can contribute to personal healing, is included in the discussion section of this thesis.

1.8 Organisation of the thesis

This thesis is organised into four parts. It comprises eleven chapters, as well as a prologue and epilogue.

Part One covers central questions addressed by the research, its setting and context, and a conceptual framing of the research problems and how it is addressed in this research. It contains the first three chapters:

- Chapter 1 is an introductory chapter that provides an overview to the motives for the research, the approach, and central messages.
- Chapter 2 explores how issues of disability amongst the Aboriginal and Torres Strait Islander population have been considered within the scientific literature. Chapter 2 also provides an exploration of the theories on Foucauldian approaches to power, social hierarchies and discourse; intersectionality; emancipatory and participatory research; and Indigenous knowledges from the literature that have influenced the research design and methods.
- Chapter 3 provides an introduction to key terms and concepts that are used throughout the research. It explains how various theories and concepts introduced in the preceding chapter are synthesised into a bespoke conceptual framework that has been constructed for the purposes of doing this research and understanding the findings. The conceptual elements of the research are introduced at this point to aid the interpretation of the methods and the findings in the chapters that follow.

Part Two addresses the methodology used for the research. It contains two chapters:

- Chapter 4 constructs a conceptual model that was devised specifically for research to facilitate the participation of Aboriginal and Torres Strait Islander people with disability. Synthesising the researcher's positionality with a broad theoretical foundation that was built in Chapters 2 and 3, this chapter describes the component of an authentic community model of research that comprises: a unique model of 'narrative' that privileges the testimony of Aboriginal and Torres Strait Islander people with disability; a model of research production that inverts the traditional relationships between the researcher and the participants; and the adoption of a discursive approach to facilitate participation in research by an historically marginalised group.
- Chapter 5 builds upon the construction of a conceptual model of community-directed research by detailing how the model was operationalised in the research. This chapter describes the quantitative and qualitative data sources,

and further illustrates how through a mixed methods approach, the statistical data and personal testimonies are aligned in the presentation of the findings to generate a cohesive narrative that is derived from Aboriginal and Torres Strait Islander people with disability. It then outlines the pathway of the research over the stages of the development from its grounded beginnings through the various stages of the research: from obtaining community and personal consent to participate; the recruitment of participants; the interview style and technique; the exercise of trauma informed safety protocols; the reporting of results; and optimising research impact amongst the First Peoples disability and its related stakeholders.

Part Three presents the findings of the research. It contains four chapters.

- Chapter 6 presents an analysis of statistical data generated from the Australian Bureau of Statistics to estimate the prevalence of disability amongst the Aboriginal and Torres Strait Islander population, which has not been undertaken in any prior research or government report. It uses the statistical data to profile the complexity of disability that occurs amongst the Aboriginal and Torres Strait Islander population. It then draws from personal testimony to highlight where statistical data is limited in understating the full nature of disability, due to issues including an under-disclosure of disability, and the non-availability of disability diagnoses in certain circumstances.
- Chapter 7 presents statistical data and personal testimony on the social inequality that is experienced across a range of indicators compared to other population groups, including Aboriginal and Torres Strait Islander people without disability, and people with disability who are not of Aboriginal or Torres Strait Islander origin. The analysis shows that Aboriginal and Torres Strait Islander people were found to have experienced higher rates of social inequality compared to other population groups in every indicator that was considered for analysis, leading to a key finding on the existence of ‘intersectional inequality’. Drawing from intersectionality theory (Crenshaw, 1991) ‘intersectional inequality’ is a term that the researcher devised to describe the empirical observation of inequality that is heightened for Aboriginal and Torres Strait Islander people with disability as a group

intersecting two marginalised populations. The social, health and wellbeing indicators that are selected for analysis include: accessible communities; justice and personal safety; educational attainment; employment outcomes; access to health care services; and mental health outcomes.

- Chapter 8 chronicles the experiences of social isolation, discrimination and trauma that Aboriginal and Torres Strait Islander people with disability encounter in their everyday lives. It describes different ways through which the race-based discrimination (racism) and disability related discrimination (ableism) appear in lives of Aboriginal and Torres Strait Islander people with disability, both of which have an acutely detrimental impact on their mental health and wellbeing. Finally, it introduces a concept of ‘apprehended discrimination’ (Avery, 2018, p. 102-106), a term which was devised by the researcher to describe the cognitive response by people who have been repeatedly exposed to discrimination. Citing examples drawn from personal testimonies, ‘apprehended discrimination’ shows the pathway from discrimination to avoidance, whereby Aboriginal and Torres Strait Islander people move from an intuitive fear of discrimination, through to a rational expectation of discrimination, and towards an ultimate response of avoidance in which they exclude themselves into further social isolation.
- Chapter 9 departs from the findings relating to inequality and discrimination by shifting the focus to one of inclusion. It presents evidence that Aboriginal and Torres Strait Islander people with disability participate in their own Indigenous community and cultural events at the same rate as Aboriginal and Torres Strait Islander people without disability. Parity of participation expressed in this indicator is the sole categorical exception to the findings of social inequality presented in Chapter 6. This finding has profound implications for how inclusive disability support systems could be constructed from an Indigenous culture of inclusion of people with disability.

Part Four are reflections and concluding observations. It comprises two chapters:

- Chapter 10 is a deeper consideration of the issues arising, implications and extended applications of the research. It commences with a consideration of the research and its prospect for driving social change through an intersectional approach within Australian Indigenous policy and public disability policy. It then moves to deeper consideration on the impact of the research, not just through the presentation of data and research findings not previously accessible, but how the participatory research processes used for research involving a vulnerable population group contributed to attaining these results. It offers deeper reflection on the research impact for the community and the people who were involved as participants and its role in a healing process for a marginalised people. It posits whether there is a converse to the present experience of ‘apprehended discrimination’, in which inclusion becomes the expectation. Looking towards a positive future for Aboriginal and Torres Strait Islander people with disability, it asks whether ‘apprehended inclusion’ can be made possible.
- Chapter 11 includes concluding comments which bring together the key messages from this research, with reference to the research questions addressed, and implications for a future research and policy.

The legacy of this research is a model of research that addressed questions of social inequality that are experienced by acutely marginalised groups of people. Its focus on inclusion, in both its content and its methodology, has reached beyond the First Peoples disability community and resonated with other groups who have experience vulnerability. The thesis concludes with a message on the power of inclusion as a mechanism for personal, community and social transformation.

2. Issues affecting Aboriginal and Torres Strait Islander people with disability identified in the research literature

2.1 Introduction

A detailed discussion of the social inequality and inclusion of Aboriginal and Torres Strait Islander people with disability commences in this chapter with a review of how issues affecting Aboriginal and Torres Strait Islander people have been reflected within the research literature. This chapter outlines the systematic strategy using a meta-narrative review (Greenhalgh et al, 2005; Wong et al, 2013) to identify research relevant to this study, and describes secondary search strategies used to address limitations in the systematic approach to literature searches. There is then an historical account of the research base relating to disability amongst Aboriginal and Torres Strait Islander people, with the purpose of highlighting the key themes that are covered within the academic research base, and also its omissions. The meta-narrative review approach will then incorporate additional research that were not detected through a systematic searching method of academic literature database. This aims to chronicle what Greenhalgh refers to as an “unfolding ‘storyline’ of a research tradition over time” (Greenhalgh, et al, 2005, p417), emphasising the seminal publications from the research that have advanced scholarship in Aboriginal and Torres Strait Islander disability studies.

The composition of the literature relevant to the research is organised into four parts, each part relating to each research question in Chapter 1.3. The first section addresses literature relevant to the question, ‘What is the prevalence, nature and social impact of disability amongst the Aboriginal and Torres Strait Islander population?’ The second section relates to the question, ‘How is social inequality that is experienced by Aboriginal and Torres Strait Islander people with disability created and sustained?’ The third section relates to the question, ‘What is a model of research that actively promotes participation of Aboriginal and Torres Strait Islander people with disability through the direct testimony of their lived experience?’ The fourth section relates to

the question, ‘Is there Indigenous cultural model of inclusion that actively promotes the social participation of Aboriginal and Torres Strait Islander people with disability?’

2.2 Research literature search strategy

2.2.1 *Justification of a meta-narrative review*

The literature search strategy chosen for this study was a meta-narrative review (Greenhalgh et al, 2005). A meta-narrative review is an emerging form of systematic literature review within social sciences research that seeks to illuminate complex and heterogeneous topics by highlighting contrasts through which researchers of different standpoints have researched a similar topic (Wong et al, 2013). The concept of a meta-review is to develop “storylines” in the narrative of the research (Greenhalgh et al, 2005) which is useful in multi-disciplinary and complex areas of study that involve large and diverse sources of data.

The theory of a meta-narrative review is developed from Kuhn’s concept of ‘paradigms’ (Kuhn, 1962). Different standpoints on how different researchers see the world mean that their ‘paradigms’ can differ conceptually, theoretically, methodologically, and instrumentally. A meta-narrative review enables ‘storylines’ of research to emerge that paradigmatically depart from strictly rigid systematic reviews. Greenhalgh’s finding that “scientific revolutions were identifiable in which breakaway researchers had abandoned the prevailing paradigm and introduced a new set of concepts, theories and empirical methods” (Greenhalgh, 2005, p417) has provided a liberating inspiration to incorporate Indigenous cultural and emancipatory philosophies into this study in a way that institutionalised ways of research have not previously recognised.

A meta-narrative review was deemed the most suitable search strategy in this study for two reasons. The first reason is the complex and ambiguous realm of the study topic, particularly when the ambiguities in describing the Aboriginal and Torres Strait Islander population intersected with the ambiguities in defining disability and impairment within research writing. The second reason is that a prevailing scientific ‘paradigm’ in literature search strategies embeds rigid rules that privilege institutionally-generated forms of knowledge whilst excluding community-generated

forms of knowledge. These reasons are elaborated further in the limitation of the structured search process of academic databases below. A meta-narrative review allows the 'storyline' of Aboriginal and Torres and Strait Islander people with disability to be infused into the knowledge base to overcome the limitations of being excluded from institutional models of research. This enables a shift in 'paradigm' to elevate and promote the voices of Aboriginal and Torres Strait Islander people with disability, this giving effect to the overarching aim of the research.

2.2.2 *Components of the meta-narrative review*

The meta-narrative review applied Greenhalgh's three-phase search process. Due to the grounded nature and the multi-faceted aspects of this research, these phases were conducted iteratively over the course of the research, rather than in one sequential step-wise process. The three phases, as defined by Greenhalgh, were:

- (i) An initial scan of relevant literature, that is led by intuition and sector networking, to obtain the various perspectives or 'paradigms' to the research problem;
- (ii) A search for seminal papers within each research 'paradigm' in the research topic and an evaluation of its contribution to the development of the body of research; and
- (iii) A search for empirical papers using electronic searching databases, manually searching academic databases, and 'snowballing' additional references from reference lists in seminal publications. (Adapted from Greenhalgh et al, 2005, p402).

The positionality of the researcher, acting in a policy position for a community-based First Peoples disability organisation, provided a multitude of opportunities for network-based referrals to research and literature that otherwise would have escaped a rigidly structured search of academic literature. There are two notable examples that highlight this. One example is the narrative of a one-legged Mungo man on a hunt. The researcher was alerted to this narrative by a staff member of the Australian Museum with whom he had been discussing his research at a networking function early in the

research. This chance networking encounter had led to further discoveries of scientific and grey literature that a conventional search strategy on Aboriginal and Torres Strait Islander disability would not have detected. Over the course of this research, this narrative has been expanded upon and through this research has become a seminal narrative of an Indigenous culture of inclusion.

A second example in the value of a meta-narrative review to this research is the location of a seminal publication by Bostock (1991). This publication is entitled 'Access and equity for people with a double disadvantage', and notably does not include a reference to key words 'Aboriginal and Torres Strait Islander people' nor 'disability', and again escapes the ambit of conventional search strategies. The researcher was alerted to the existence of this work directly by the author, who was also an esteemed Aboriginal Elder of the First Peoples disability community of which the researcher was a member. This resource was not available electronically, and the researcher was required to order it from a library retrieval system. Over the course of this research, Bostock's concept of 'double disadvantage' has evolved into a seminal paper, setting an historical marker in the narrative of 'intersectionality' (Crenshaw, 1991) as it applies to Aboriginal and Torres Strait Islander people with disability in an Australian context.

2.2.3 *Outcomes of a structured search of academic literature databases*

As valuable as networking and the researcher's positionality was in locating research and literature to cultivate a more comprehensive narrative of the research, the meta-narrative analysis was not exclusively reliant upon those strategies. These intuitive and network search strategies were complemented with a structured search of relevant academic literature databases. The purpose of undertaking a structured search of academic literature was to access alternative research perspectives and paradigms beyond the researcher's sphere of networking, providing a balance to what was obtainable through community-generated resources. Accessing research locatable through academic databases also enabled this research to be positioned as a distinct community research 'paradigm' in contrast to alternate institutionally-based research 'paradigms'.

A systematic search of relevant academic databases included searches of: ProQuest Health and Medicine; Medline (OVID); Humanities and Social Sciences Collection (Informit); Indigenous Collection (Informit); and PubMed (accessed via the Lowitja Institute 'LIt.Serach' function). The key words used in the search were 'Aboriginal' or 'Indigenous', used in conjunction with 'disability' or 'impairment'. This resulted in four permutations in the keyword search, which were done as discrete searches within each academic database. This was to gain some insight into the way in which issues of Aboriginal and Torres Strait Islander disability were summarised in the research literature. The four permutations in the keyword search were:

- 'Aboriginal' with 'disability'
- 'Aboriginal' with 'impairment'
- 'Indigenous' with 'disability', and
- 'Indigenous' with 'impairment'.

The abstracts of articles retrieved were then reviewed for relevance to the scope of this research. A principle-based criterion outlined in Table 2.2.3.1 was used as a guide for determining which publications were included or excluded within the scope of the meta-narrative review. Given the complexities and ambiguities within the topic area, if it was uncertain from its abstract whether an article was in scope and relevant to the meta-narrative review, it was included by default.

Table 2.2.3.1: Inclusion criteria for determining the scope of the systematic literature search in the meta-narrative review

Principle	Included in scope	Excluded from scope
The article addresses 'intersectionality' by considering Aboriginal and Torres Strait Islander people with disability as a unique population group.	• Must include an exclusive focus, that is Aboriginal and Torres Strait Islander and disability.	• Studies and papers where Aboriginal and Torres Strait Islander people are incidental in a whole of population study. • Studies and papers where disability is incidental to

		other aspects health and wellbeing.
Addresses social dimensions of 'disability'.	• Scope of study makes unlimited reference to disability. • Scope is within a general categorisation of a disability type (i.e. physical, mobility, sensory, intellectual impairment, cognitive impairment).	• Studies and papers that address disability in terms of a medical condition (cardio-vascular disease) or morbidity (frail and ageing). • Studies and papers that are limited to a narrow disability diagnosis (e.g. fetal alcohol spectrum disorders). • Studies and papers that are specific to the prevention of disability and / or injury.
The setting is relevant to Australian Aboriginal and Torres Strait Islander people	• The study or paper is set in Australia • The study or paper addresses Indigenous peoples in general, but has application in an Australian setting	• The setting for the study relates to an Indigenous peoples group outside of Australia.

The following table presents the outcome of the systematic literature search as part of the meta-narrative review. These results are presented for each academic database collection that was searched for each of the four keyword permutations. This table show both the number of articles that were retrieved ('R'), and the number of articles that were considered as in scope for the review ('IS') once the inclusion criteria in Table 2.2.3.2 were applied.

Table 2.2.3.2: Results of systematic literature search - articles retrieved ('R') and articles in-scope ('IS') by academic search collection (Current as at 8 March 2019).

Keyword #1	'Aboriginal'				'Indigenous'			
Keyword #2	'disability'		'impairment'		'disability'		'impairment'	
	R	IS	R	IS	R	IS	R	IS
Medline (OVID)	139	16	72	0	233	14	178	1
ProQuest Health and Medicine	226	17	105	2	356	16	236	2
Humanities and Social Sciences Collection (Informit)	26	3	7	0	30	4	4	0
Indigenous Collection (Informit)	33	14	11	0	19	4	6	2
PubMed (accessed via the Lowitja Institute Lt.Serach)	167	13	109	2	(This search incorporated keywords 'Aboriginal' and 'Indigenous' within one collection)			

2.2.4 Categories in the Academic Literature

Within the articles detected through the systematic search of academic papers, there were four general categories in the type of publication. There are categorised below:

- **Ethnographic studies in Aboriginal community settings:** Two studies were ethnographic studies where the researcher was embedded in a defined Aboriginal community (Ariotti, 1999; King et al, 2014). In both cases, the researcher identified as being non-Indigenous.

- **Aboriginal and Torres Strait Islander disability through intermediated perspectives:** Other publications were empirical studies where findings relating to Aboriginal and Torres Strait Islander people with disability used methodologies that sampled intermediaries to Aboriginal and Torres Strait Islander people with disability, rather than Aboriginal and Torres Strait Islander people with disability themselves. These intermediary groups included carers (DiGiacomo, 2017) and predominantly non-Indigenous mainstream service providers to Aboriginal and Torres Strait Islander people with disability (Gilroy et al, 2016).
- **Methods papers without empirical findings:** One publication was a methods paper that presented what the authors refer to as a “decolonising methodology” for disability research project with the Anangu and Yarnangu peoples of Central Australia (Gilroy, Dew et al, 2018). The project methodology involved interviews with a mix of 62 Anangu and Yarnangu Aboriginal people with disability or their carers, and 47 workers in service agencies providing support to Aboriginal people. No academic paper on the findings of this study has been published as yet. However, in support of the meta-narrative review methodology selected for this research, a companion report to the academic paper was self-published by the Aboriginal community organisation (Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women’s Council, 2018) who partnered the academic team on this project. The report produced by the community organisation was not located by the systematic research process, but was instead emailed directly to the researcher by the Aboriginal community organisation that produced it.
- **Systematic literature reviews detailing need for more research:** There were a number of systematic literature review publications or secondary data analyses that did not include primary research involving Aboriginal Torres Strait Islander people with disability. This category of papers tended toward findings that were exclusively conceptual and were across a broad range of topics. These topics included: a need for a workforce development strategy for services to Aboriginal and Torres Strait Islander people (Gilroy et al, 2017): technical definitions of ‘disability’ used in data instruments that collect

disability statistics (Colman et al, 2018); conceptualisations of disability from media and policy discourses (Ravindran et al, 2017); and access by Aboriginal and Torres Strait Islander people to the National Disability Insurance Scheme (Phuong, 2017).

What is notable about in the analysis of the papers that were detected through a systematic search of academic literature is what is absent. No paper was found that replicated this study's methodology that exclusively interviewed Aboriginal and Torres Strait Islander people with disability within a self-contained study. Some research had aspects of these principles, but the participatory principles were diluted through the inclusion of intermediaries speaking on behalf of Aboriginal and Torres Strait Islander people. There were only cursory references to the issues of social isolation and inequality that are the focus of this study. No study made a direct reference to 'discrimination', 'racism', 'ableism' or 'inequality' in their abstract. Only one study referenced 'access barriers' (Gilroy, 2016), and only one study made a direct reference to researching with Aboriginal and Torres Strait Islander people with disability as an intersectional cohort (Green et al, 2018).

The lack of recognition, particularly of community-generated forms of knowledge, points to a broader chasm between knowledge produced through academia and knowledge produced within community. This chasm proved significant in this study, and being a community-directed project, it has benefited from accessing community forms of knowledge in providing an entry point insight into what issues might arise from the participants, and how to prepare adequately for the interview and field work stage.

Even after incorporating community-generated publications with those unearthed by the search of the academic research databases, there was no research or paper identified that was comparable to the type of grounded research that facilitated the direct involvement of Aboriginal and Torres Strait Islander people as the core participant group. This necessitated a meta-narrative review method. The remainder of this chapter reverts to the intuitive and snowballing literature search methodologies to targeting broad based theories and concepts that could be synthesised and reconstructed into a methodology that was culturally safe and suitable for conducting research involving the First Peoples disability community.

2.3 Seminal developments in the literature relating to Aboriginal and Torres Strait Islander people with disability

This section traces the development of literature as it relates to the first question for this research thesis, which is ‘what is the prevalence, nature and social impact of disability amongst the Aboriginal and Torres Strait Islander population?’ It shows how the historical development of research from when the issues of Aboriginal disability first emerged within the research base in the early 1990’s (and later to include Torres Strait Islander people with disability).

At the commencement of this research, disability amongst Aboriginal and Torres Strait Islander people was a neglected area of research. The chronology in the development of the research base shows that as an area of research, Aboriginal and Torres Strait Islander disability is underserviced relative to its need. No other research identified through the systematic search of academic literature has incorporated the direct involvement of Aboriginal and Torres Strait Islander people in a participatory methodology as this study has done, nor has any research presented disaggregated statistical data for the Aboriginal and Torres Strait Islander people to quantify the level of social inequality that they experience relative to other population groups.

2.3.1 *Primary research referencing Aboriginal and Torres Strait Islander people with disability*

In the early 1990’s, a theory of ‘intersectionality’ was being framed by Crenshaw (1991) as a theoretical base to explain the accumulated disempowerment experienced by groups who traverse two or more oppressed population groups. The concept of ‘intersectionality’ is discussed further within a power relations context below. In the Australian setting, a concept of ‘double disadvantage’ was being introduced in Australian Indigenous and disability policy discourse, as a way of describing the multiple and accumulated inequalities that occur within Aboriginal communities (Bostock, 1991). The concept of ‘double disadvantage’ was initially described in broad terms to constitute the disadvantage that was experienced by Aboriginal people with disability over and above the disadvantage associated with their disability. Gething (1995) built upon Bostock’s conceptualisation of multiple forms of discrimination by highlighting that Aboriginal people with disability in remote areas could experience

‘triple discrimination’ by acknowledging the limitations to access and inclusion for those people living in remote communities (Gething, 1995). In describing double disadvantage, Bostock made two critical observations. The first was that the issues affecting the disadvantage experienced in Aboriginal communities more broadly were so paramount that they dwarfed the particular issues affecting people with disability who lived within them. The second observation was that in reference to access and equity in disability services, “Aborigines are at the lowest rung of the servicing ladder” (Bostock, 1991). Both of these empirical observations made within the Australian Aboriginal and Torres Strait Islander disability context are compatible with the theoretical framing of intersectionality through the lens of power relations between and within vulnerable groups.

A small number of papers based on consultations and case studies investigating reasons why there was so little statistical data available for Aboriginal people with disability, cite a combination of factors including a lack of sophistication in data collection systems, a reticence of Aboriginal people to disclose their Indigenous status, and cultural differences in how questions were framed and interpreted (Gething, 1994; 1995). After a burst of policy attention abated in the mid 1990’s (Gething, 1995), Aboriginal and Torres Strait Islander disability reverted to being a neglected domain of policy and research. Intermittently, studies have advanced culturally derived understandings of ‘disability’ by Aboriginal and Torres Strait Islander people and its implications for disability services in their communities (Ariotti, 1999; King et al, 2014; Gilroy et al, 2016).

Ariotti (1999) published a seminal paper on disability as it is socially constructed in an Aboriginal community. Ariotti’s observational study of the Anangu Aboriginal people of central Australia found an inclusive culture in which there was no word for ‘disability’ in their native language groups. Instead, there were a number of words and phrases that referenced specific impairment types, none of which were used in a pejorative way as to invoke stigmatisation of the person with an impairment. Ariotti’s finding of an Indigenous culture that is inclusive of people with disability is supported by King (2014). King self-identifies in her paper as a “white Australian women”, whose ethnographic study as an immersed researcher at an Indigenous community respite centre for people with diabetes, found that the Aboriginal participants asserted their identity as “Indigenous first, disabled second” (King et al, 2014, p744) as a way

to positively negotiate the impact of colonisation as it affected them and their community.

Between 2004 and 2005, Bostock and Griffis (2005) undertook a broad-based community consultation on the needs of Aboriginal and Torres Strait Islander people with disability, culminating in a report entitled *Telling it Like it is*. This consultation activity was led by Bostock and Griffis in an official capacity on behalf the Aboriginal Disability Network (New South Wales), an Aboriginal community-controlled disability organisation and precursor to the First Peoples Disability Network (Australia). Bostock and Griffis visited 33 Aboriginal communities in New South Wales to document high levels of unmet need, a lack of service provision and extreme poverty in Aboriginal communities. Despite producing the most compelling evidence of disadvantage affecting Aboriginal people with disability and communities at its time, its origins from within a community-based organisation, coupled with a lack of academic interface, meant that the report lacked penetration within research and government policy despite the gravity in social inequality that the report spoke to. The values of *Telling it Like it is*, centering community in research activity as espoused by Bostock and Griffis (2005), have been carried on in this study.

From an academic standpoint, Gilroy (2016) applied Indigenous Standpoint Theory in his research on factors that influenced the participation of Aboriginal people in disability services. In his positioning as a self-identified Aboriginal disability researcher, Gilroy interviewed 64 disability service workers, seven of whom were Aboriginal and 57 who were not Aboriginal, on their perspectives on why Aboriginal clients chose to participate or not in disability services. Gilroy's research found that disability service providers reported a large number of factors that influenced the decision of Aboriginal people with disability to participate in the disability service system. The factors perceived to be of influence were: a different conceptualisation of disability by Aboriginal people compared to people who are not Aboriginal; a belief that Aboriginal people were "too proud" to accept support; experiences of trauma relating to colonisation; a lack of trust in generic or mainstream services that were not Aboriginal owned and operated, which extended to a lack of trust in workers; experiences of racism; and a complexity in the service delivery systems that was difficult for Aboriginal people to navigate.

Whilst the majority of the study's participants are non-Aboriginal disability service providers, Gilroy's research is significant in that it represents a resurrection of Aboriginal and Torres Strait Islander disability issues within a research setting. Gilroy has subsequently collaborated with other researchers to produce research on the influences of early colonial media on the stigmatisation of Indigenous people through disability tropes (Gilroy, Regan, and Meekosha, 2008), and as an academic partner in co-produced research with the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council (2018), which is an Aboriginal community-controlled disability and social services organisation in central Australia. A methods paper on this co-produced project has been published (Gilroy, Dew et al, 2018), but the findings from the research are yet to be published. Whilst the prolific nature of these writings has elevated issues of Aboriginal and Torres Strait Islander disability in research, there are methodological concerns from a community standpoint that the research base is being populated by the perspectives of powerful stakeholders such as service providers, rather than the First Peoples disability community themselves. This is a critical methodological difference that the current study has addressed.

Concurrent with primary research on disability within Aboriginal and Torres Strait Islander communities, there are some critical analyses which have linked colonisation with disability (Meekosha, 2008; 2011). Hollinsworth's (2013) critical analysis on the history of racism in Australia draws a logical, but not empirical, parallel between the de-humanisation of Australia's Indigenous peoples and people with disability to argue why disability studies must address race, culture, and gender. Hollinsworth's critique then argues the "racist representations of Indigenous people and their consequent treatment disabled virtually all Indigenous Australians, regardless of any specific impairment" (Hollinsworth, 2013 p607). This analysis requires careful interpretation, as it breaks the nexus between impairment and 'disability'. Analyses inferring that being Aboriginal in and of itself is a disability must be treated with extreme caution as to not overreach the point of the argument. It is not satisfactory to advance the equality of Aboriginal and Torres Strait Islander people through a discourse that maintains disability as a deficit point of reference. As this study will show in Chapter 8, the forces of racism and ableism can traumatise people and populations independently of each other and concurrently. As racism and ableism are different in nature and present differently to the people who experience discrimination, they should not be conflated, notwithstanding the traumatic effect upon health and wellbeing that they both induce.

2.3.2 *Secondary research and systematic reviews*

Another category of publication in the research base are meta-analyses of disability in Aboriginal and Torres Strait Islander community. An audit of disability research in 2014 (LLewellyn, 2014) located 39 papers in scientific literature and 30 papers in ‘grey’ literature. The majority of the papers detected through the disability research audit constituted bio-medical disability research conducted in Aboriginal and Torres Strait Islander communities. As with the systematic search of scientific research database, the audit of disability research used criteria that failed to incorporate the knowledge of the First Peoples disability community and its leaders, again highlighting the gaps in scientific searching techniques to identify research activities and the priorities identified by the community.

From mid 2018 came a spate of publications that have an applied relevance to disability in Aboriginal and Torres Strait Islander communities. One methods paper outlined a comparative model of research co-production in an Indigenous disability project in Central Australia, called ‘Walykumunu Nyinaratjaku: To Live a Good Life’, that was conducted at the same time as this research (Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women’s Council, 2018; Gilroy, Dew et al, 2018). The model of research constructed for the ‘Walykumunu Nyinaratjaku’ project involved a research team in which the lead researchers affiliated with an academic institution worked under the direction of an Aboriginal community-controlled organisation. There is commonality between ‘Walykumunu Nyinaratjaku’ and this study in that they are both underpinned by “Indigenous decolonising research methodology”, as described by Gilroy et al (2018, p2). However, how the principles of an Indigenous decolonising research methodology are executed is a key point of difference between this study and the ‘Walykumunu Nyinaratjaku’ study. Whereas the lead researchers in the ‘Walykumunu Nyinaratjaku’ study are affiliated with an academic institution, the researcher in this study is affiliated with a community organisation. The principal affiliation with community by the researcher in this study maintains an absolute philosophical alignment to the concept of community control of the research.

Also from mid 2018, there was a series of 11 papers on ‘Intersecting Indigeneity, Colonisation and Disability’ in a special issue of the *Disability and the Global South* journal (Soldatic and Gilroy, 2018). This special issue contained a mix of personal

reflections and theoretical pieces critiquing the impact of colonisation within an Indigenous disability context. Whilst this special issue has added to a critical understanding of Indigenous disability from colonialisation theory, a common attribute of the authorship is the institutional affiliations of the authors and relative absence of community voices. The current research adds to the standpoint of Indigenous disability scholarship by adding ‘community’ as a third dimension. In effect, this research enables differentiation in standpoints between research that is done *on* Indigenous disability, and research that is done *from within* Indigenous disability.

2.3.3 *The contribution of this research to the evidence base*

As stated above, none of the prior research has incorporated a participatory methodology which has authentically captured the views of Aboriginal and Torres Strait Islander people directly. Whilst noting that the applications of this study are broad, these are two focused contributions that this study aims to make.

In that respect, there have been a number of research and applied policy publications that have already emanated from this research and have contributed to the existing research base. In February 2016, the paper ‘Intersectional Dimensions on the Right to Health for Indigenous Peoples – A Disability Perspective’ (Avery, 2016a) was part of a United Nations study by the Expert Mechanism on the Rights of Indigenous People (EMRIP) on the ‘Right to health and Indigenous peoples, with a focus on children and youth’ (United Nations Human Rights Council, 2016). That submission to the EMRIP study articulated that the composite rights for Indigenous people with disability existing when a cultural right of inclusion as an Indigenous person intersects with social inclusion as a person with disability (Avery, 2016a, p4). It also outlined the cumulative impact of intersectional risk across the life course of an Indigenous person with disability which has been expanded into a ‘matriculation pathway into prison’ (Avery, 2016, p. 9; Avery 2018 , pp. 37-44) which is referred to in Chapters 7.4 and 10.3 of this thesis. The EMRIP study also cited the paper’s references to the concept of ‘institutionalised ableism’ in health care, when symptoms of a medical conditions are attributed to disability rather than to a separate illness, leaving people with disability at risk of having serious illness undiagnosed and untreated (United Nations Human Rights Council, 2016, p18). The concept of institutionalised discrimination in health

care to Indigenous people with disability, introduced conceptually in 2016, has been validated by this research, with empirical evidence of prejudice in health systems and clinical practice leading to adverse health risks that have been drawn from personal testimonies of Aboriginal and Torres Strait Islander people with disability.

In April 2016, ‘Aboriginal And Torres Strait Islander Perspectives On The Recurrent And Indefinite Detention Of People With Cognitive And Psychiatric Impairment’ (Avery, 2016b) was released. The monograph was an outcome of a community-led initiative which drew together otherwise unconnected researchers who have partnered with First Peoples Disability Network in other projects to highlight a grievous social justice issue in which Aboriginal people with cognitive impairment have been imprisoned without conviction due to their unfitness to plea, in some cases for over a decade.

In July 2018, the research book entitled *Culture is Inclusion: A narrative of Torres Strait Islander people with disability* (Avery, 2018) was published. Written and produced foremost as a gift to the First Peoples Disability community and exercising the principle of reciprocity in Indigenous research, this book is a cornerstone publication of the research study upon which this thesis expands. It presents an overview of the concepts, research models, and findings from this research in a format designed to be accessible by members of the disability community and by government agencies in both the Indigenous and disability policy sectors. *Culture is Inclusion* infiltrates this thesis in three ways. The first way is through the presentation of the research findings, which are re-presented and analysed in Chapters 6 to 9. Second, the publication is designed as a discursive text to disrupt the prevailing discourses of disability and inclusion. This is discussed, applying Foucauldian principles of power and discourse which the following section addresses. Thirdly, this thesis concludes with a critical reflection of the research embodied by *Culture is Inclusion* as it has affected the community that participated in the research, over and above the impact within academia and research.

2.4 Research literature on the perpetuation of inequality through power relativities in social hierarchies

2.4.1 *A Foucauldian analysis of power and discourse*

This section addresses the second aim of the research, which is ‘how is social inequality that is experienced by Aboriginal and Torres Strait Islander people with disability created and sustained?’ Answering this question requires centering on ‘power’, and in particular the power relativities amongst groups within a social hierarchy. In the first instance to frame the empirical observations of social inequality as connected to the power relativities of Aboriginal and Torres Strait Islander people as an acutely marginalised population group, or more precisely, their ‘disempowerment’ with the broader Australian society. Once a connection between social inequality and disempowerment has been established, it will then look at how social inequalities are sustained over time through institutionalised processes of disempowerment.

Subsequent chapters of this thesis will construct a conceptual and theoretical framework to illustrate how the disempowerment and social inequality experienced by Aboriginal and Torres Strait Islander people as indicative of a vulnerable population is not a static phenomenon, but is instead the outcome of a social hierarchy that is constantly reinforced through institutionalised processes which favour those with relative power against those who are disempowered. Before moving to the construction of this theoretical framework, this section provides a primer on the key theories and concepts that have influenced its construction.

Any considerations of power and its relationship with social inequality starts with Foucault’s theories of power and discourse (Foucault, 1972, 1980). Analyses of Foucauldian approaches to power and discourse are diverse and lengthy. The purpose of this section is not to cover the full realm of literature on the power and discourse, which is beyond the scope of this research. Instead, this section catalyses aspects of Foucault’s theories with other critical discourse analyses to compile a logical connection between social inequality and a process of disempowerment as it can be applied to interpret and explain the marginalisation of Aboriginal and Torres Strait Islander people with disability.

The logical flow connecting social inequality with disempowerment is generated through a number of steps. The first step is in understanding how power is enacted through discourse, and conversely, with relevance to this study, how disempowerment is enacted through an absence of discourse. In this analysis, ‘discourse’ is defined as the collection of ‘texts’ and practices that systemically forms a field or domain (Foucault, 1972). Within this definition, ‘texts’ exist not just in written form, but can also exist as symbolic representations that have a physical medium, and hence can be transmitted and accessible to others (Taylor and Van Emery, 1993). Foucault then describes ‘power’ as the circulation of discourse through an inter-related cluster of social networks of relations, through which the discourse provides meaning about an ‘object’ (Foucault, 1972; 1980), and in turn generates the production of knowledge about that domain (Hall 1992). Hardy and Maguire (2010) further contend that the discourses about an object are not confined to that knowledge generated from within a particular field, but are influenced by broader social factors and shaped from discourses emanating from outside the domain to which the discourse relates.

In translating these observations to this study, the discourses that are relevant to this study are the texts and practices that portray Aboriginal and Torres Strait Islander with disability, which in Foucauldian terminology constitutes the ‘object’. As shown in the earlier part of this chapter, discourse that emanates from within the domain of Aboriginal and Torres Strait Islander disability is negligible, which has had the effect of rendering Aboriginal and Torres Strait Islander people with disability invisible within public discourse. The vacancy of discourse specific to Aboriginal and Torres Strait Islander people is instead populated by general public discourses, either on Aboriginal and Torres Strait Islander people, or on people with disability. As shown in Chapter 1, both of these discursive streams have been pejoratively formed to disempower Aboriginal and Torres Strait Islander people with disability through the processes of colonisation.

Phillips, Lawrence and Hardy (2004) integrate Foucault’s theories of power and discourse to institutional theory, and this extension helps understand how the institutions that generate inequality are produced and maintained. For clarity, in this analysis, an ‘institution’ is taken to mean a collation of practices, norms and self-reinforcing behaviours, as opposed to physical structures. Institutions influence behaviours by counter-acting against practices or behaviours that are construed as

deviating from the accepted norms and practices which are embodied by the institutions (Jepperson, 1991). The nature of institutional forces being as generalised as they are, these practices may not be consciously formed, but instead applied as taken for granted. An example of how this might present in practice is a ‘devil’s advocate’, a common colloquial expression asserted by a person or process in order to question or challenge proposals for social reform against established conventions of policy production. Unfettered, institutionalisation means that the way it is, is the way it shall be.

This is where Bostock’s observation that Aboriginal and Torres Strait Islander people are at “the bottom rung of the service ladder” is pertinent (Bostock, 1991).

Notwithstanding that a grave social inequality had been identified over a quarter of century ago, it has not penetrated public consciousness and discourse as an issue of social injustice. The observation that a status quo of acute social inequality has been maintained over such a long period aligns with understandings provided through general theories of power, discourses and institutionalisation. Hence, not only has colonisation created a power inequity that has marginalised Aboriginal and Torres Strait Islander people with disability, the forces of institutionalisation work to keep them marginalised in perpetuity. This concept of institutionalised disempowerment is illustrated further in Chapter 3, where the various theories referenced in this chapter are connected in a targeted explanation of how institutionalised forces perpetuate the social exclusion of vulnerable populations, even within social programs that specifically aim to address the social disadvantage that they face (refer ‘low hanging fruit’ in Chapter 3).

Whilst this analysis thus far paints a pessimistic explanation for why Aboriginal and Torres Strait Islander people experience social inequality, power and discourse analysis does provide an outlet for change through strategies for resistance. Foucault points out that power is not only used as a force of oppression, it is also used for production of new domains, knowledges, and “rituals of truth” (Foucault, 1980). In this sense, the opportunity for ‘power’, or a shift from disempowerment to empowerment, is accessible to all, even the most vulnerable and marginalised. Strategic change can be executed from within existing power relations through resistance mechanisms that produce novel discourses or undermine existing discourses (Hardy and Thomas, 2014). These insights provide a segue to emancipatory and

participatory research as a tactic for disrupting the power inequities and initiating social change.

The foundational theories for emancipatory and participatory research are covered later in this chapter. Before moving onto the philosophical foundations and methods of emancipatory and participatory research, this review will next delve into a deeper analysis of power relativities through the theory of ‘intersectionality’ (Crenshaw, 1991). This discussion will explain the intersectional effect of being a marginalised group within two larger marginalised populations upon the power and positioning of Aboriginal and Torres Strait Islander people with disability within the Australian social hierarchy.

2.4.2 *Intersectionality*

Whereas the Foucauldian analyses above provides a general analysis of power relationships that exist within *between* groups, the theory of ‘intersectionality’ is an extended critical theory that addresses imbalances of power that occur *within* marginalised groups. Where multiple aspects of oppressed ‘minority’ identities intersect, imbalances of power are multiplied. Intersectionality was originally advanced in the early 1990’s by critical social theorist Kimberlé Williams Crenshaw (1991), who had argued that the unique role of gender in race relations had been largely ignored. Writing within the context of violence against women, Crenshaw observed that whilst racism and sexism readily intersected in the lives of African-American women, they rarely did so in the practices or discourses of feminism and anti-racism. Instead, she observed that efforts to advance the rights of African-American women occurred within “mutually exclusive terrains” (Crenshaw, 1991).

Crenshaw argued that there is a hierarchical power situation in which there exist marginalised peoples *within* otherwise marginalised populations. In the examination of violence against African-American women, the intersection of racism and sexism cannot be captured wholly by looking at the race or gender dimensions of those experiences separately. Ignoring the power hierarchy and difference within groups, Crenshaw argued, contributes to tension amongst those groups. Because their intersectional identity as both women and of colour are shaped as one or the other, Crenshaw observes that women of colour are marginalised within both groups.

Since Crenshaw's early work, intersectionality has developed into a theoretical and methodological frame of enquiry to "spark further inquiry into the dynamics of intersectionality both as an academic frame and as a practical intervention in a world characterized by vast inequalities" (Cho et al, 2013, p807). Intersectional theory has been used within disability studies as a sensitising approach to explain the impact of social dynamics adversely affecting people with disability on issues including: their interface with the law and process-driven legal frameworks (Lundberg and Simonsen, 2015) and "complex interplay" of race, gender disability within family violence (Cramer and Plummer, 2009). It has also been used to understand the dynamics in the power relations between and within vulnerable populations compared to those who have privilege and can exercise power to create and sustain inequality (Choo et al, 2010).

Applying intersectionality as a model through which the effects of relational privilege and power can be understood is distinctly different to using intersectionality as a process through which vulnerable populations can be identified and further sub-categorised. As an additional complexity, it is the categorisation and sub-categorisation of vulnerable populations that generate the social distinctions which can reinforce power relativities between and within vulnerable groups (Crenshaw, 1991). In applying intersectionality theory into practice, care needs to be taken to ensure that the intra-population tensions such as those identified in Crenshaw's study are not accentuated in a further stigmatisation of vulnerable people in vulnerable groups, by merely stratifying their social status into ever refined categories (Kapilashrami, Hill and Meer, 2015). This concern is addressed in a discussion on the application of intersectional approaches to population-based health inequities in the following section.

2.4.3 *Intersectional approaches to population health inequities*

Intersectional approaches have emerged as a basis for addressing health inequality at population level over the past decade. Much of the research to date has contributed to the theorising of how intersectionality theory can contribute to an increasingly sophisticated approach to understanding the forces driving health inequalities between population groups (Kapilashrami and Hankivsky, 2017; Green, Evan and Subramanian, 2017). In presenting the potential for intersectional approaches to provide greater nuance to population health research, Hankivsky, et al (2017)

highlights the contrasting epistemologies of biomedical approaches to health research, described as a ‘reductionist approach’ that understands health through the physiology of the human body and its composite parts on one hand, with the approaches of social sciences which, on the other hand, see health through its social determinants. In recognising the limitations of the respective epistemologies of biomedicine and social science as stand-alone perspectives on health, Hankivsky et al (2017) argue that synergies that reconcile the two approaches in health research and that are explicitly intersectional will generate more precise evidence for effective policies to reduce health inequalities between population groups.

In this respect, explicitly intersectional research is contrasted with research which is solely inter-categorical (McCall, 2005), or that which is limited comparing outcomes between different population groups. As stated by Wemrell et al (2017), “intersectionality theory is not adequately applied through mere efforts towards fractioning the population into smaller taxonomic units [but] the object of interest is in how interacting systems of power drive disease incidence” (Wemrell et al, 2017, p214).

In taking the point of difference between intersectional and inter-categorical research further, Dhamoon and Hankivsky’s (2011) application of intersectional theory to global health research draws a distinction between aspects of a person’s identity (including for example: race; Indigeneity; functioning or disability status; ethnicity; gender; sexuality; geography; and age) and the forms of systemic oppression (including racism; ableism; sexism; homophobia; and ageism) that are deterministic in the social positioning of marginalised population groups. Dhamoon and Hankivsky’s differentiation of intersectionality as relating to the ‘systemic oppression’ that marginalised people are subjected to, beyond the intersecting attributes of a person’s identity, is significant to the application of population-based health research, both in its design and in giving it a sense of purpose. Methodologically, it means the inherent attributes of identity cannot be reduced to stochastic variables in an equation to assess health risks or outcomes of a population group. Instead, attributes of identity must be viewed more deterministically as to their social positioning. This approach also provides a more optimistic outlook than seeing health inequalities a consequence of inherent health risk factors. As Bauer (2014) points out, “a quantitative intersectionality focused purely on intersecting identities or positions would run the

risk of continuing to reinforce the intractability of intersectionality, albeit in a more detailed or nuanced way” (Bauer, 2014, p11). The strength of power-based intersectional approaches to health is that if attributes of identity are deterministic of health inequality, then social processes and policies may be implemented to alter the determinism in a manner that advances population health equality.

Despite the emerging interest in applying intersectionality to population-based health research, there has been little published research to date that has fully embodied an intersectional approach to assessing layered health inequalities that affect marginalised groups within marginalised populations. One exception is Wemrell et al (2017), who found significant correlations between the age-adjusted risk of ischemic heart disease and intersections of gender and social stratification based on income. Whilst Wemrell’s study of inequality intersecting gender and social strata is limited to one bio-medical health indicator, it does affirm the theory of intersectionality as it applies to population-based health inequalities.

This study builds upon the application of intersectionality theory in understanding health to undertake a critical analysis of power relations and social determinants that drive the inequities, as expressed in the second aim of the research. To reinforce the point of differentiating identity from the social forces that drive inequality, this research does not view inequality or vulnerability as inherent in the identity of Aboriginal and Torres Strait Islander people with disability. Instead, Aboriginal and Torres Strait Islander people are placed into vulnerability through the interaction of social forces that drive their inequality, which include exposures to racism, ableism, and their interactions.

In addressing these dual aims, this research advances the aspirations for a fuller explanation of health inequality amongst populations expressed by the intersectional health researchers referenced in this section. The use of intersectionality to quantify the variations in health equality experienced by groups within populations, as well as explain why health inequality is created and sustained, positions this research amongst the frontier of global health research.

2.5 Research literature on emancipatory and participatory research

This next section of the literature review addresses the third aim of the research, which is to derive a model of research that actively promotes participation of Aboriginal and Torres Strait Islander people with disability through the direct testimony of their lived experience. This aim is the next iteration in the logical progression in defining the overall research problem of social inequality and exclusion experienced by Aboriginal and Torres Strait Islander people with disability. If, as the above sections allude, social inequality is not inherent in identity but instead conditioned through social forces, and if approaches to research that take an ‘outsider’ perspective are inadequate in explaining how and why exclusion occurs, then the next question is whether research that emanates from within the marginalised community will provide greater insights to the phenomena of social exclusion and what can be done to address it. As outlined earlier in the chapter, participatory models of research have not previously existed in this population and must be constructed from the ground up.

This review of literature relating to participatory models of research which will inform the development of a community-directed research methodology in Chapter 4 starts with an observation on the historical source of philosophical development of intersectional disadvantage and inequality. Whilst the concepts of ‘intersectionality’ (Crenshaw, 1991) and ‘double disadvantage’ (Bostock, 1991) were developed in different parts of the world without cross reference to each other, what is strikingly similar is that the conceptual development of understanding the social inequalities as a consequence of layers in social oppression were in both cases advanced by people with a shared personal identity with the community to which their observations related. In the case of ‘intersectionality’ (Crenshaw, 1991), an African-American female scholar drew upon the lived experiences of African-American women to explain the intersection of gender and race in social power inequalities that lead to their heightened exposure to violence. In the case of ‘double disadvantage’, an Aboriginal man with disability (Bostock, 1991) drew upon experiences of Aboriginal people with disability to highlight the compounding nature of discrimination experienced by people who were both Aboriginal and had a disability.

Whilst this is not intended to be a definitive observation, it does point to the potential for leadership in the conceptual development on social access and inclusion research

and policy that comes from within the community who are marginalised. Freire (1970) describes the ethical and philosophical leadership that can *only* come from a lived experience of social disadvantage as a ‘pedagogy of the oppressed’, in which he states the truism:

“the pedagogy of the oppressed cannot be developed or practiced by the oppressors. It would be a contradiction in terms if the oppressors not only defended but actually implemented a liberating education” (Freire, 1970, p54).

What Freire is saying in this quote is that whilst ‘the oppressors’ can sympathise or even empathise with ‘the oppressed’, they can never replicate their knowledge that comes from their experience of living with oppression. The challenge then for this research is how Freire’s ‘pedagogy of the oppressed’ can be operationalised to capture the knowledge of lived experience that comes from being part of the First Peoples disability community.

A movement toward participatory action research with disability groups emerged in the United Kingdom in the 1990’s. Locating disability as a form of social oppression (Albert and Harrison, 2006), and observing the unequal power relationship between the researcher and researched (Hanley, 2005), emancipatory disability research methods aimed for “the empowerment of disabled people through the transformation of the material and social relations of research production” (Barnes, 2003).

On the spectrum of participation by people in vulnerable positions in research, ‘emancipatory research’, which White et al (2004) defines as the full participation and complete control over the research process, provides the optimal form of participation and control. There have been some case studies of emancipatory research involving peoples with disability. In 2000, the United Kingdom’s Department for International Development funded a Disability Knowledge and Research Program (‘DKaR’) for participatory action research projects in a range of countries from the Global South, all of which embraced an emancipatory research framework and employed a social model understanding of disability. An evaluation of DKaR included findings that the interaction of disability and technology in a community development context was best understood as dynamic social processes. These understandings that were generated through an emancipatory research processes were differentiated to static formations

that were usually employed in Global North disability discourses; for example: where ‘disability’ is taken solely to mean ‘impairment’; or when ‘technology’ is taken to mean ‘equipment’ or ‘infrastructure’ (Albert and Harrison, 2006). Another study in the European Union in which the views of 58 young people with disabilities were collected through a consultation process called the ‘theatre of the oppressed’ (Genova, 2015, p1045) which involved the engagement of young people with disability emancipatory disability research tool. The design of this study was aimed at production of knowledge through the empowerment of young people with disability. The emancipatory methods in this research generated through the ‘voices’ of young people with disability, which told of how physical access barriers interacted with more challenging cultural and institutional barriers, produced a more sophisticated understanding of the access barriers to inclusive education than could be otherwise be produced. It is this purist approach to emancipatory disability research, albeit culturally attuned to an Indigenous population, which this research seeks to implement.

2.6 Research literature on Indigenous disability and inclusion in Indigenous cultures

This fourth and final aspect of the literature review addresses the fourth aim of the research, which is whether there is a distinctive Indigenous ‘cultural model of inclusion’ that actively promotes the social participation of Aboriginal and Torres Strait Islander people with disability. This aspect of the research acknowledges that conceptualisations of social inclusion and disability for Aboriginal and Torres Strait Islander people are just not subjugated by social forces that marginalise populations into positions of vulnerability, but also is affected by influences that stem from their Indigenous cultural beliefs and values.

The pursuit of an Indigenous specific model of inclusion initially stemmed from the researcher’s positioning as a community-based researcher embedded within an Indigenous disability community organisation. What was tacitly observed by the researcher in how people with disability were accommodated within the social relationship structures within Aboriginal and Torres Strait Islander communities presented a stark difference to the isolating social practices of western society. The discovery of a line of single footprints amongst archeological remains in the Mungo

National Park (Webb, 2007), as explained by Aboriginal custodian of the land as the one-legged Aboriginal man actively participating in a hunting group (Markey, 2016), is emblematic of the diversity and inclusion in First Peoples cultures. It is derived from a belief system and worldview of humanity in which biological, physical and intellectual differences are accepted as part of the fabric of society.

The small amount of published research on disability in Aboriginal communities all settles on a conclusion that ‘disability’ is not a concept that readily translates in Aboriginal languages and cultures. Ariotti’s study observing the Anangu people of the Northern Territory describes a community where there is no word for ‘disability’ in their native Pitjantjatjara language (Ariotti, 1999). Instead, there are words in the native language which describe various impairments, such as blind (‘kuru pati’), deaf (‘pina pati’), to hobble around (‘lurpani’) or to have back pain (‘witapijara’). It was observed that the Anangu people did not use these words in a pejorative sense. Instead, these words are factual references to a person’s functioning capacity within in a community in which there is an acceptance of diversity and difference.

Another study by King et al involving Aboriginal people working in an urban Indigenous-specific respite centre for people with diabetes-related disability speaks of the “invisibility of their disability experience” (King et al, 2014, p740). This phrase makes reference to a society in which the centrality of Indigenous culture, being a person who is Aboriginal, overshadows the physical, objective nature by which an impairment may be viewed. Accordingly, the Aboriginal people involved in the study did not readily accept the categorisation of being a person with disability, as disability was viewed as a non-Indigenous concept. The hierarchy of Aboriginal identity above disability in an Aboriginal person’s sense of belonging is paraphrased by a participant in the study as being “Indigenous first, disabled second”. Gilroy et al (2016) studied services providers’ attitudes towards Aboriginal and Torres Strait Islander people with disability and concluded that there were diverse conceptualisations of disability in the Aboriginal population, often described as “normal” and “part of living”, and that an acknowledgement of disability, or lack thereof, was a key influencing factor in whether Aboriginal people accessed disability services (Gilroy et al, 2016).

There are parallels to Aboriginal and Torres Strait Islander people’s worldview of human capability and diversity with other Indigenous peoples worldwide. Culturally,

there were no equivalent words in the Māori language for disability or many diagnostic labels that apply, such as autism. The *Te Pou o te Whakaaro Nui* (2016) is a project to update and create Māori language used in the mental health, addiction and disability sectors with language that is not judgmental, and uses Māori words ‘whaikaha’, meaning ‘to have strength, otherly abled’ as an equivalent for ‘disabled’; and ‘takiwatanga’, meaning ‘his or her own time and space’ as an equivalent word for ‘autism’ (Te Pou o te Whakaaro Nui, 2016). In another hemisphere, the Navajo Indigenous people of North America lacked a word for ‘disability’ until an acculturation through western influences, instead living by a concept of ‘Honzo’ to describe someone who is walking in harmony with all that is around them (Kapp, 2013).

First Peoples expressions of humanity and diversity are more than just observances of functional linguistics. They speak of a belief system that values a person’s centeredness over biomedical and physical differences, and acceptance of difference as within the natural order of the world. It is a belief system that governs their behaviours, and comes with such a long-standing track record that it need not be consciously taught, rather it is modelled through Indigenous people’s attitudes towards other members of their community.

The contemporary dilemma for Aboriginal and Torres Strait Islander people is that their culture and belief system of human functioning and diversity is so radically different from the Western construct of disability dominant in Australia and other Westernised nations, which constructs disability as a deficit against a perceived ‘normal’ level of functioning, and “an individual deficit/problem that has to be fixed, rehabilitated or prevented.” (Berghs et al, 2016). Philosophical reflections aside, the cultural dichotomies present a contemporary dilemma for Aboriginal and Torres Strait Islander people. ‘Do you have a disability?’ is a question that is culturally insensible for Indigenous peoples, and an issue that this research attempts to reconcile.

2.7 A summary of issues from the literature review

This literature review has served three purposes. The first purpose is to position this research as a novel methodology which applies a purist model of emancipatory research to understand social inequality and the inclusion of Aboriginal and Torres Strait Islander people with disability. The second purpose of this review is to enable a theoretical framing of the research problem as has been observed empirically, following a reasoned logic. The third purpose is to establish the basis of a research strategy, combining the elements of theories and concepts described in this chapter which can be synergised and reconstructed into a research strategy that is fit for the purpose of investigating social inequality and inclusion in Aboriginal and Torres Strait Islander communities.

The following chapter will detail how the elements of the literature presented in this review are reconstructed into a conceptual framework that explicitly examines the power relationships and social forces driving inequality experienced by Aboriginal and Torres Strait Islander people. Before proceeding to the conceptual framework of this study, this chapter concludes by summarising the key messages that contribute to the theoretical reframing of the research problem, and a logical sequencing of the research strategy.

2.7.1 *A theoretical framing of the research problem*

- I. There are empirical observations which show that Aboriginal and Torres Strait Islander people are marginalised and face social inequality.
- II. Foucauldian analyses of power and discourse can be used to correlate social inequality of marginalised population groups to their position within a social hierarchy. Hence, the social inequality of Aboriginal and Torres Strait Islander people with disability is a function of their disempowerment relative to other population groups.
- III. ‘Intersectionality’ shows that Aboriginal and Torres Strait Islander people with disability are exposed to heightened vulnerability due to their traversing two marginalised populations.

- IV. An absence of discourse coming from within the domain of Aboriginal and Torres Strait Islander disability is a source of their disempowerment, effectively rendering them ‘invisible’ within the broader public discourse.
- V. The vacuum of discourse on Aboriginal and Torres Strait Islander people with disability means that social understandings are formed through broader public discourses that come from outside the domain, either through discourses of Aboriginal and Torres Strait Islander people, or by discourses about people with disability. As illustrated in Chapter 1, both of these streams of public discourses have been formed pejoratively through the processes of colonisation.
- VI. Forces of institutionalisation sustain the disempowerment of Aboriginal and Torres Strait Islander people with disability and preserve their invisibility. Through the correlation of disempowerment and inequality, institutionalisation also entrenches the social inequalities that they are subjected to.

2.7.2 *A strategic response to activating social change*

- VII. Understanding power and discourse as permeable and accessible to even marginalised people provides a strategy for social change. Social change can be activated by disrupting public discourse.
- VIII. Disruptive discourse can be enacted through two strategies. The first is through the production of novel discourses that emanate from within the domain of Aboriginal and Torres Strait Islander disability. The second is to challenge the pejorative discourses that emanate from outside that domain and the institutional processes that sustain them. This provides a theoretically-based justification for the aim of ‘promoting and elevating the voices of Aboriginal and Torres Strait Islander people with disability’ that is articulated in this research.
- IX. A prescription of ‘authenticity’ strategically positions those with a ‘lived experience’ as the producers of discourse to drive their re-empowerment.

- X. Emancipatory and participatory research is a tactical measure to authenticate the discourses as coming from within the domain of Aboriginal and Torres Strait Islander disability.
- XI. The additional application of Indigenous Standpoint Theory and research methodologies situates emancipatory and participatory research within a cultural context.
- XII. Strategies to initiate social change and empowerment through discourse must also be cognisant of the institutional forces that will naturally act to preserve a status quo.
- XIII. Hence, producers of discourses that come from a state of disempowerment must have their discourses legitimised for them to have social impact. This means that when disruptive discourses are generated through research, the research methods used must be sufficiently robust to withstand outside contestability.
- XIV. The impact of disruptive discourse is enhanced when it can be projected widely through social networks. Therefore, the modes and manner through which discourses are communicated can positively affect the re-empowerment of marginalised groups as a separate force in addition to the messaging content contained within the discourse.

The next chapter (Chapter 3) follows this logical sequence to construct a conceptual framework that relates to the social inequality and inclusion experienced by Aboriginal and Torres Strait Islander people with disability as the explicit domain of this research.

3. A theory of social inequality experienced by Aboriginal and Torres Strait Islander people with disability

3.1 A theoretical framing of the research problem and strategy

The previous chapter outlined the background theories including concepts that are relevant to this research. One outcome from the review of prior research and scientific literature is that whilst there are elements of a theoretical approach to inform the problem of social inequality, there is no cogent theoretical construction of how and why social inequality exists and is sustained that is concordant with to the experiences of Aboriginal and Torres Strait Islander people with disability. The aim of this chapter is to provide a framing of the research problems by synthesising the theories and concepts introduced in Chapter 2 into a framework that is fit for the specific purpose of this research. This will address the second aim of the research, which is to understand how social inequality experienced by Aboriginal and Torres Strait Islander people with disability is created and sustained.

The construction of a theory which explains how social inequality for Aboriginal and Torres Strait Islander people is created and sustained follows a three step logic. The first step in the logical development of the theory is to apply the general theory of intersectionality (Crenshaw, 1991) to the situation of Aboriginal and Torres Strait Islander people. It will highlight how as a group traversing two marginalised populations, Aboriginal and Torres Strait Islander people with disability face heightened access barriers to their social inclusion. The second step in the logical development of the theory is to evaluate the impact of economic assumptions that underpin the neo-liberal approach to social policies, and that characterise the current implementation of Australian social policy. In adapting the economic principle of ‘low hanging fruit’ (Frank and Bernanke, 2013) to a social policy setting, this step will demonstrate that market-based approaches to the administration of social policy regresses to an equilibrium mid-point within a targeted population, and do not facilitate greater access to social inclusion for those who already carry an historical

legacy of socially exclusion. The third step in the logical process is to combine steps one and two, synthesising intersectionality theory with the economic principle of low hanging fruit. Connecting these two theoretical streams will show that sectional and neo-liberal approaches to social policy do not address the inequality experienced by Aboriginal and Torres Strait Islander people with disability as a group traversing two marginalised populations, and that perversely their inequality is heightening compared to other groups. This is described as a ‘paradox of low hanging fruit’ in the concluding section of this chapter.

The construction of a theory in this chapter will provide a concise explanatory framework upon which the empirical results of this research can be interpreted in subsequent chapters.

3.2 ‘Intersectional discrimination’ - applying intersectionality in the context of Aboriginal and Torres Strait Islander people with disability

The first step in establishing a theoretical base for understanding how social inequality is created and sustained involved applying intersectional theory to the specific circumstances of Aboriginal and Torres Strait Islander people with disability. The critical approach to intersectionality is discussed in Section 3.2, before it is combined with the discussion of political and economic forces undertaken in Section 3.3, to compile a composite analysis of how social inequality arises and is perpetuated in neo-liberal economies. The composite analysis of the social and economic forces of inequality is presented in Section 3.4.

Chapter 2 introduced ‘intersectionality’ (Crenshaw, 1991) as an explanatory framework for how relativities in the power relationships amongst groups of people within marginalised populations can explain social outcomes and inequalities, that cannot be exclusively explained through uni-dimensional analyses of power relationships across population groups. As a foundational framework for this research, intersectionality shows that to fully understand the unique experiences of Aboriginal and Torres Strait Islander people with disability, the research must recognise that they are a discrete group at an intersection of two marginalised populations. Crenshaw’s observations of intersectionality showed that an explanation of race or gender in

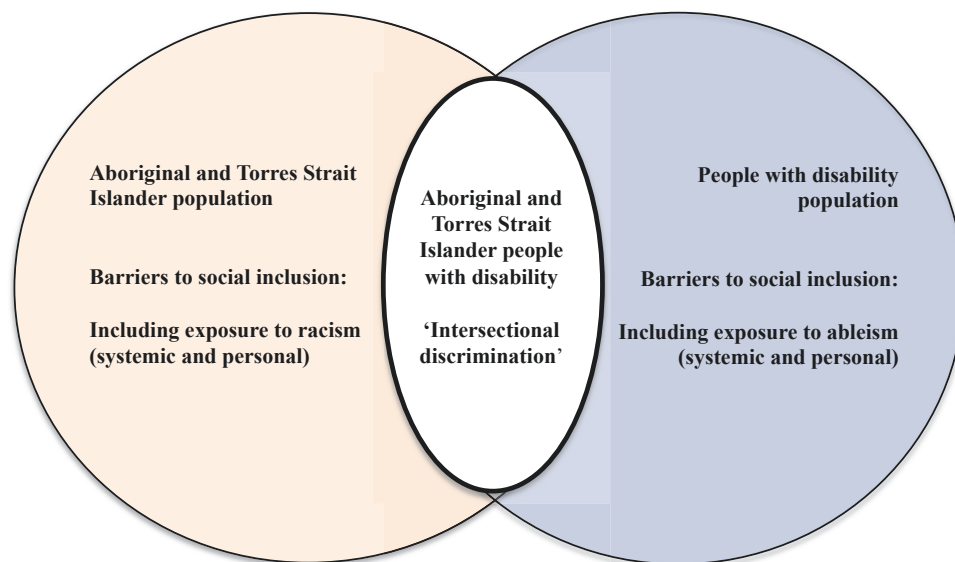
isolation from each other did not fully describe the experiences of African American women in their exposure to violence; rather they constituted a marginalised group within a marginalised population. This chapter will argue that a similar theoretical approach can be used in this study by taking Crenshaw's racial demographic setting in an African American population and applying it to Aboriginal and Torres Strait Islander people with disability who also constitute a marginalised sub group that traverse two marginalised populations.

Bostock's (1991) concept of 'double disadvantage', derived from the Aboriginal disability community, aligns with the theory of intersectionality. As people with identities traversing two marginalised groups, Aboriginal and Torres Strait Islander people with disability experience both racially-based discrimination ('racism') and disability-related discrimination ('ableism'). The prevalence of racism and its adverse impact upon health and wellbeing of Aboriginal and Torres Strait Islander people is well documented (Larson et al, 2007; Paradies et al, 2008; Priest et al, 2014; Ferdinand, 2012) in which the psychosocial impact of racism has been shown as "enough to make you sick" (Larson et al, 2007).

In addition to racism and ableism as forms of discrimination that act independently of each other, the personal testimonies revealed a third hybrid category of discrimination that could not exclusively be explained by racism or ableism alone. This third category of discrimination is referred to in this research as 'intersectional discrimination' (Avery, 2018, p. 35 and pp. 98-101), so named as it aligns with Crenshaw's theory of intersectionality. 'Intersectional discrimination' was observed as a unique interaction of race- and disability-related discrimination experienced by people who are both Aboriginal and/or Torres Strait Islander *and* have disability. One example drawn from the testimonies from the participant group for this research, recounted further in Chapter 7 but included here to illustrate the concept, is an account of an Aboriginal man with cognitive impairment who is harassed at a shopping centre by security guards who assume he is drunk. In this real-life scenario, ableist prejudices that conflate intellectual disability with drunkenness are magnified by racist prejudices about the prevalence of alcohol consumption by Aboriginal and Torres Strait Islander people, interacting to produce a vulnerability to discrimination that is not adequately explained by racism or ableism alone.

The representation of the Aboriginal and Torres Strait Islander population with disability as intersecting two marginalised groups is diagrammatically represented in the figure below, with reference to the forces of discrimination that they are exposed to (racism, ableism, and ‘intersectional discrimination’). This diagram will be expanded upon during the chapter as a basis for a theoretical approach to explaining social inequalities that affect intersecting populations.

Diagram 3.2: Aboriginal and Torres Strait Islander people with disability as intersecting two marginalised populations¹



3.3 ‘Low hanging fruit’ - Neo-liberal approaches to social policies that affect Aboriginal and Torres Strait Islander people with disability

The thesis now departs from its discussion of intersectionality as a critical approach to a discussion of how neo-liberal approaches are implemented and practised in Australian social policy. This part of the theoretical analysis considers social forces related to the political economy in which the personal experiences of discrimination and access barriers experienced by Aboriginal and Torres Strait Islander people with

¹ As noted in the Glossary, ‘intersectional discrimination’ can conceptually apply when there are intersections in population groups who experience marginalisation, including by race, disability, gender, sexuality, age and education. This diagram and the subsequent analysis focuses on the intersection of the Aboriginal and Torres Strait Islander population and the population of people with disability, which is the emphasis of this research.

disability are situated. Understanding the economic forces that underpin neo-liberal public policy will show how the application of free market principles in the administration of social programs creates generalised forces that produce and sustain social inequality. An analysis of the social forces that sustain inequality within a neo-liberal political economy is formulated as a separate stream of thought to the discussion of intersectionality in above Section 3.2, with a view to converging the two streams of analysis into a composite theoretical construction analysis in Section 3.4 below.

Neo-liberalism in this analysis refers to a political philosophy in which control of economic forces within public policy are transferred from the public sector to the private sector control. The analysis in this section is limited to a review of the neo-classical economics principles that are associated with neo-liberal approaches to public policy, specifically the operation of free market principles to determine an efficient use of resources allocated to social purposes. The purpose of this analysis is to demonstrate that when applied to social policy affecting vulnerable population groups, market-based economic principles perpetuate the inequality of population groups whose access barriers are relatively high compared to other population groups.

Within the broad gambit of neo-classical economic theory, there are two economic principles which form the focus of this analysis. These are: first, the law of diminishing returns; and second, the principle of low hanging fruit. The law of diminishing returns, which has its origins in the economic writings of the eighteenth century French physiocrat Anne Robert Jaques Turgot (Brue, 1993), states that under certain circumstances, the returns to a given additional quantity of labour must diminish (Cannan, 1892). The law evolved from a concept which is intended to explain relative returns from marginal increases in assets into a strategic decision-making principle referred to as ‘the low hanging fruit principle’. This principle states that “in expanding the production of any good, first employ those resources with the lowest opportunity cost, and only afterward turn to resources with higher opportunity costs” (Frank and Bernanke, 2013, p49). The principle of ‘low hanging fruit’ is so named in reference to a parable in which the most accessible fruit is picked first, and this colloquial phrase has entered common usage to describe an approach which seeks to optimise early returns for initiative by pursuing the most accessible opportunities in the first instance.

The principle of low hanging fruit can be extended from its conventional use in a commercial context to a broader application of Bourdieu's concept of 'social capital' which encompasses not only economic concepts of capital, but includes the capital that relates to the generation of social relations and social commitment (Bourdieu, 1985). Coleman's rational-choice approach to social capital (Coleman, 1994) provides a bridge between concepts of social capital and free market rational thinking. In this analysis, demand is driven by the consumer, who in this example is a person with a disability. Unlike many commercial transactions involving the purchase of goods, the purchase of disability services is not a discretionary spend. A person does not choose to have a disability, and hence the support services they require are not a matter of personal choice. Whilst there may be some pricing differential between competing suppliers of disability services, these price differentials are immaterial compared to a minimum expenditure required for support services. To illustrate this point, a profoundly deaf person requiring a cochlear implant may have a choice between two competing suppliers of the cochlear implants, but this price differential is insignificant compared to *any* expenditure relating to requiring a cochlear implant. Hence, demand-side considerations of the consumer (the person with disability) are immaterial in understanding how economic power is sustained through free market mechanics in social programs. Accordingly, this analysis focuses upon the supply side, in particular the impact of decision-making behaviours by the social program manager.

In applying the law of diminishing returns to social programs which support people from marginalised groups, there are incentives to first provide support to those individuals with relatively low accessibility barriers, compared to others within their group, as they are the easiest to reach and most likely to produce a demonstrable outcome for the social program manager. As resources within the social programs are further deployed, the outcomes (measured by increases in social capital) diminish incrementally. There comes a point where the marginal gain will equal the marginal cost of securing access to the program. At this point, the return upon the social investment is optimized, after which the economic incentive to pursue further opportunities to increase access diminishes, and diminishes at an exponential rate.

The effect of the low hanging fruit principle can explain how relative inequality emerges within marginalised groups. Intersectionality highlights that in addition to inequalities *between* population groups (such as Indigenous populations versus non-

Indigenous populations *or* alternatively people with disability versus people without disability), there are stratifications of inequality *within* population groups (such as the intersection of the Indigenous population and people with disability). The variation in inequality within population groups is reflected in the data above which compares the social and economic outcomes experienced by the Australian Aboriginal and Torres Strait Islander population who have disability to both the Aboriginal and Torres Strait Islander population and the population of people with disability as discrete population cohorts.

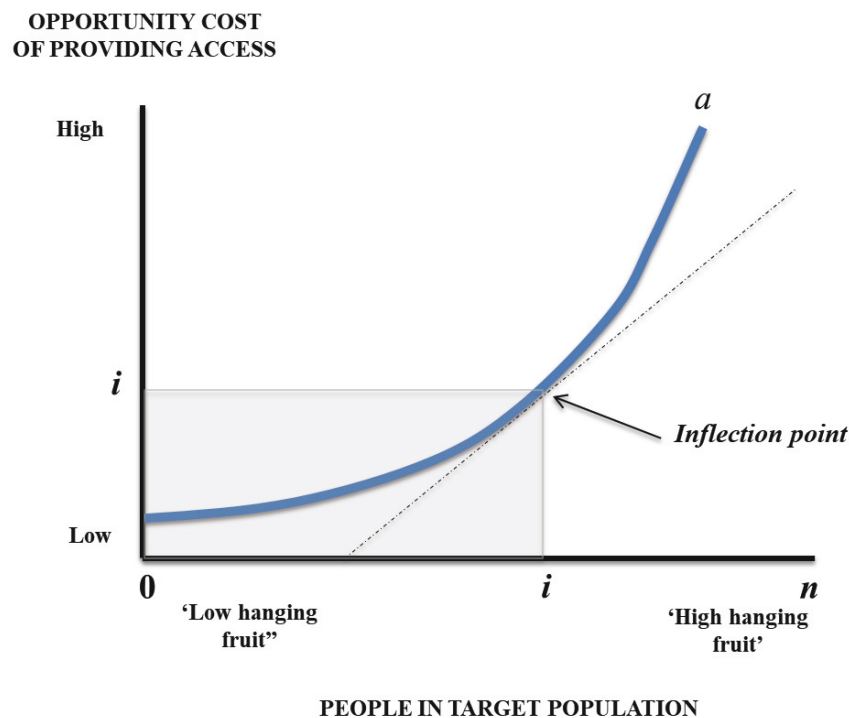
The variation in inequality within populations may be a consequence of the number, acuity and interaction of the systemic barriers that a person has faced over the course of their life which impedes an equitable interaction within society. In this analysis, identifying as a member of a marginalised population cohort, such as identifying as Indigenous or as a person with disability, does not in itself determine a person's vulnerability. It is the exposure to systemic barriers and their impact upon that person's social exclusion. People may face social exclusion by disengagement in different forms of social activity; exclusion from accessing community services on the basis of coverage or costs; and/or by having limited economic resources (Saunders et al, 2007). Identifying as a member of a marginalised population group includes the likelihood of being exposed to systemic barriers, and identifying as a member of multiple intersecting population groups increases the likelihood exponentially. Further, marginalisation from social life perpetuates itself (Bossert et al, 2007). Social exclusion can self-manifest when, because of their own personal experiences, people can relate more to societal patterns of discrimination and disadvantage than to optimism and hope, and so over time, lose trust and disengage. Not all people will be start from an equal footing in regard to access, and hence the cost of restoring trust will be differential.

In the parlance of this economic framing, 'low hanging fruit' is symbolic of people within vulnerable populations where the accumulated impact of systemic barriers to their accessing the benefits of the social program (and hence the opportunity cost in securing their participation) is relatively low when compared to other members of their vulnerable population cohort. This does not diminish the inequality they experience compared to the population as a whole, merely their relative opportunity cost of

accessing the benefits of social programs compared to others within their vulnerable population cohort.

At the other end of the access spectrum, ‘high hanging fruit’, a term which is chosen here as a point of contrast, is representative of people who have been exposed to serious or complicating systemic barriers affecting their participation in social life, and hence the opportunity cost in securing their participation is relatively high when compared to other members of their population group. In effect, ‘high hanging fruit’ represent the most marginalised citizens within the most marginalised population groups in society. Thus the ‘rational’ administrator (policy maker, social program manager) is faced with a spectrum of the population with variable opportunity costs in securing their participation. Seeking to optimise the benefit of the social program (and subject to meeting key performance indicators for the success of the program for which they have responsibility), the administrator has the incentive to devote resources to secure the participation of low hanging fruit in the first instance, then devote resources to people where the opportunity cost for their participation on the program is greater. The effect of the principle of ‘low hanging fruit’ within the provision of social programs is reflected diagrammatically below in Diagram 3.3.1.

Diagram 3.3.1: Access to social programs by relative opportunity cost



In Diagram 3.3.1 representing the number of people who access a social program by its increasing opportunity cost ('access curve' a):

- The vertical axis refers to the relative opportunity cost of providing access to a scheme from relatively low systemic barriers ('low hanging fruit') to relatively high and complex interaction of systemic barriers ('high hanging fruit'). In effect this is a scale of vulnerability within a defined population that a social program is intended to benefit.
- The horizontal axis represents the total number of people (n) within a population that a social program is intended to benefit.
- The *access curve* (a) is the social program's equivalent of a supply curve, which plots the marginal opportunity cost, as measured in changes to political capital, or the rate at which cost increases as the number of people on the social programs increase.
- The inflection point (i) is the theoretical point at which the marginal return (measured in political capital) equals the marginal cost of providing access to the social program.

The access curve is initially highly elastic, reflecting the relative low opportunity cost of providing access to 'low hanging fruit' onto the program. In practical terms, this is characterised by response rates to low-cost, high yield social marketing strategies such as television and social media advertising.

After an initial phase of recruitment into the social program, the rates of increase of access tapers off, as it approaches the inflection point i . At the inflection point, the benefits of providing access break even with the opportunity cost, and the elasticity of the access curve changes from elastic (responsive) to inelastic (increasingly unresponsive). After the inflection point, the incentive to provide further access to the social program dissipates as the marginal opportunity cost of exceeds the marginal benefit of providing access to each additional person onto the social program. Hence the access curve tapers off and levels out once 'low hanging fruit' are saturated, and

more cost intensive strategies are required to provide access to those people who experience higher systemic barriers.

The inflection point *i* represents a critical marker in administrators' decision making, In the light of the diminishing incentives, does the administrator continue to provide access to people experiencing high systemic barriers to their inclusion, or do they instead cease to provide access to people experiencing high systemic barriers and, to use another frequently used term, consign the task to the 'too hard basket'?

Within the framing of this problem using social exchange theory, a *rational* decision to discontinue access to social programs for people facing high access costs does not necessarily need to be a conscious decision; the decision could be unconscious decision attributable to what is referred to in social exchange theory as 'generalized and reinforcing factors' (Homans, 1961), which supposes that the past experiences of decision makers are carried forward into their future decisions. Observations from the field of behavioural psychology on the tendencies which perpetuate decision making are supported by recent developments in neuroscience, with one recent study finding that the physical effort it takes to achieve a positive outcome can influence behavioral decisions, not just for the task at hand but also for perceptual decisions beyond the context of the specific action (Hagura et al, 2017). Hence, the perceived difficulty of undertaking a current task is influenced by experiences of past difficulty (the cost to act) when comparable tasks have been previously attempted. These insights are material as they open up considerations as to whether institutionalised implicit bias towards 'the too hard basket' is a contributing factor to social programs not reaching those who are the most marginalised within society.

3.4 The effect of intersectionality within neo-liberal approaches to social programs

Section 3.2 above established the theoretical analysis by applying intersectionality theory to the context of Aboriginal and Torres Strait Islander people with disability. Section 3.3 then outlined how the economic principles that underpin neoliberal approaches to social policy can sustain social inequality by not reaching those groups who face relatively higher barriers to their access to social inclusion. The final step in

the analysis covered in this section is to integrate the social theory of intersectionality with the microeconomic principle of the ‘low hanging fruit’. Here we use the scenario of social programs for Aboriginal and Torres Strait Islander people with disability as a practical illustration on how the two concepts can be integrated, in order to explain how intersectionality accentuates the inequalities in social and economic outcomes they experience compared to other groups of the population.

As outlined in Chapter 1, Aboriginal and Torres Strait Islander people with disability are potential beneficiaries of social programs from within both an Indigenous policy and a disability policy framework. Historically within the Australian policy framework, neither Indigenous policies nor disability policies, have taken an intersectional approach to target the unique circumstances which affect Aboriginal and Torres Strait Islander people with disability. In other words, Indigenous policies and disability policies have been implemented without connection to each other. Access to services by people with disability has been incidental to access to services by the Aboriginal and Torres Strait Islander population as a whole. Reciprocally, access to Aboriginal and Torres Strait Islander people has been incidental to the provision of access to the population of people with disability as a whole.

Within the terminology of this analysis, Aboriginal and Torres Strait Islander people with disability are representative of ‘high hanging fruit’. People in this group, by virtue of their being concurrent members of two marginalised groups (at least) accumulate multiple forms of inequality over the course of their lives. As a result, the systemic barriers that prevent them accessing social programs are greater than other groups of the population face. In other words, and in economic terms, this means that the average marginal opportunity cost of providing access to a social program for an Aboriginal and Torres Strait Islander person with disability from the administrators’ perspective is greater than the average marginal cost of providing access to either an Indigenous person without disability or person with disability who is not Aboriginal or Torres Strait Islander.

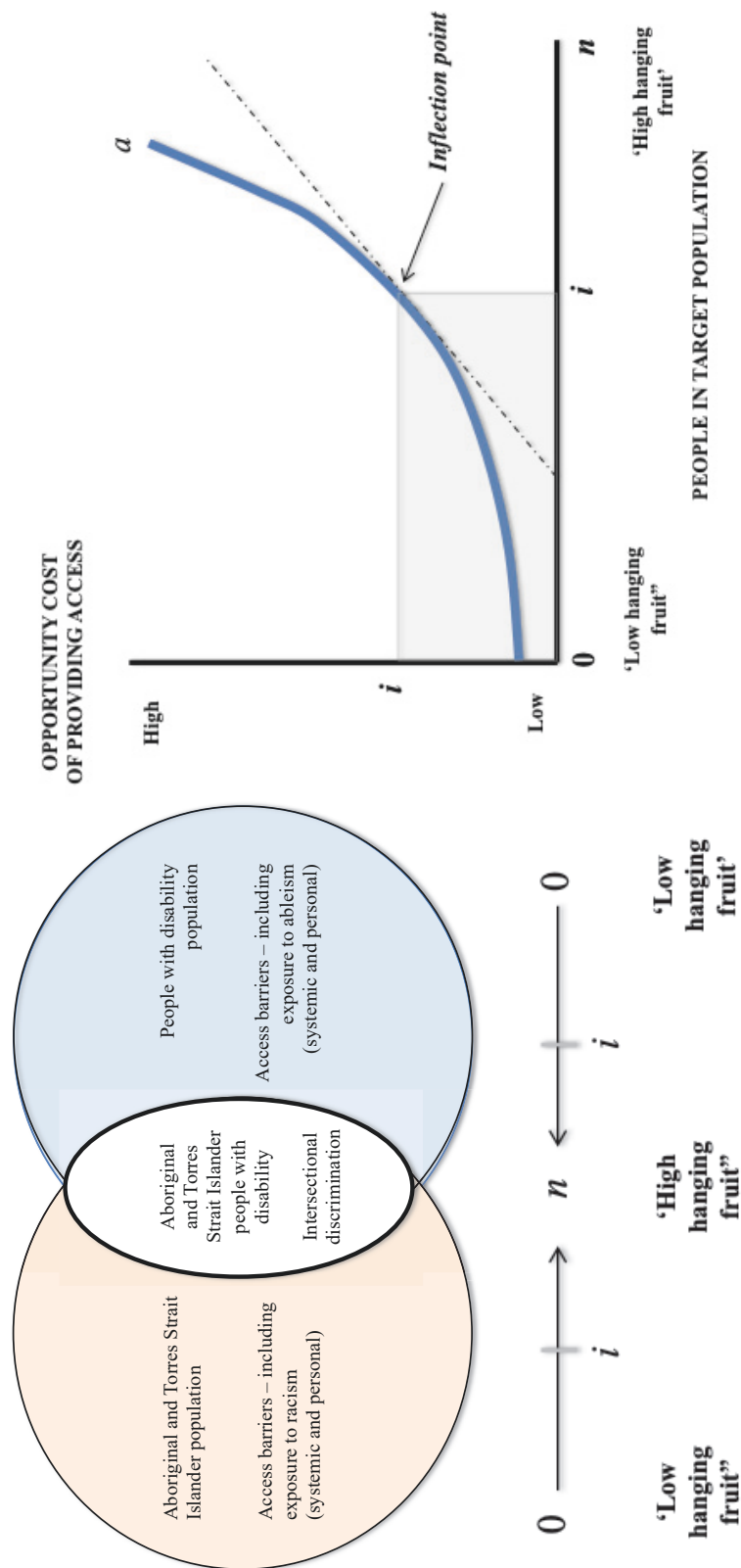
Section 3.3 considered the principle of ‘low hanging fruit’ within the implementation of one policy framework (i.e. Indigenous or disability). An intersectional perspective involves examining the interaction of policies from within both Indigenous and disability policy frameworks. In the scenario, Indigenous programs and disability programs are run concurrently to address inequality experienced by those population

cohorts when compared against the population as a whole. Consistent with historical practice, the scenario assumes that Indigenous programs and disability programs are implemented without either providing specific reference to the relatively higher access barriers facing Aboriginal and Torres Strait Islander people with disability as a cohort intersecting both target populations. The effect of the concurrent implementation of both programs is illustrated by interposing the figures used above to illustrate intersectionality and the principle of ‘low hanging fruit’ against each other in Diagram 3.4.1 below.

Figure 3.4.1 shows that the incentive in each program is to optimise benefit by providing access to those with low access barriers in the first instance. This is for both the Indigenous programs and disability programs. As the number of people provided access to each program, reflected in the movement from 0 towards n (which in Figure 3.4.1 is the arrow direction from left to right under Indigenous program, and the arrow direction from right to left under disability programs), the opportunity cost of providing for each additional person increases in line with the systemic barriers that they face.

As the number of people with access increases towards n , they will reach the inflection point i , after which the opportunity cost exceeds the benefit in terms of political capital. The manager of the social programs is faced with increasing disincentives to provide access. The rational economic incentive is to discontinue further access to the social program beyond the inflection point where the opportunity cost exceeds benefit. This corresponds to the zone where the Indigenous population and disability population intersects.

Diagram 3.4.1: Intersectionality and ‘Low Hanging Fruit’ Social Policy



What the mechanics of this implementation process means to the relative inequality experienced by vulnerable populations is that people facing relatively low systemic barriers will gain access to the program and receive its benefit. As a result, the inequality in social outcomes they experience relative to the entire population will improve. As this occurs, the average inequality as measured across the target population (i.e. the Indigenous population or disability population) as a whole will also improve. However, those with high systemic barriers to access will not access the program, so their social outcomes will stay constant. This creates a ‘paradox of low hanging fruit’, which is a paradox whereby the more successful the early-stage implementation of social programs for a vulnerable population, without factoring intersectional vulnerabilities or other differences in barriers to access, the greater will be the inequalities experienced over the long term within a vulnerable population.

3.5 The significance of a theory of social inequality experienced by Aboriginal and Torres Strait Islander people with disability

The significance of this chapter is that it provides a theoretical foundation for interpreting the empirical observations of social inequality that Aboriginal and Torres Strait Islander people with disability experience, as presented in the results chapters of this thesis. The formulation of a theoretical basis helps apprehend that the social inequality, and exclusion that comes with it, is not either a random or ‘point in time’ phenomenon, but is instead an vulnerability to inequality that is perpetually reinforced through the mechanics of market-based economics, in what is described in Section 3.4 as a ‘paradox of low hanging fruit’. Further, this analysis has drawn explicitly on conventional neo-classical economic theory to logically frame a theory, in an analytical approach that is distanced from neo-liberalism as a political philosophy.

Drawing on general theories outlined in Chapter 2, this chapter has shown that by synthesising intersectionality with neo-classical economic principle of ‘low hanging fruit’, social inequality is a phenomenon that is reinforced through market-driven approaches in the provision of social support structures. This answers the second aim of this research, which was to ask why and how social inequality is created and sustained.

This theory has practical significance in contemporary Australian social policies that are characterised by market-based approaches to supporting Aboriginal and Torres Strait Islander people with disability. The application of this theory to Australian social policy is covered more extensively in the discussion section of this thesis.

With a theoretical understanding of social inequality established, Chapters 6 to 9 present empirical evidence using statistical data on social, health and wellbeing outcomes, and personal testimony from Aboriginal and Torres Strait Islander people with disability to demonstrate that this theory holds true in practice. Before proceeding to a presentation of the empirical evidence of social inequality, the next chapter will outline the methodology and methods by which the data was obtained.

4. An epistemology of community-directed research

4.1 Introduction to the chapter

The previous chapter used theories of power (Foucault, 1972) and intersectionality (Crenshaw 1991), introduced in Chapter 2, to conceptualise an explanatory framework for how social inequality experienced by Aboriginal and Torres Strait Islander people with disability is created and sustained. This chapter builds upon these concepts and applies them to the power relationships that exist within a research setting. As a conceptual approach, this chapter focusses upon the third aim of the research: that is, to create a framework for emancipatory and participatory research that considers the marginalisation and vulnerability that is experienced by Aboriginal and Torres Strait Islander people with disability, while working from within the community's own processes of generating and sharing knowledge. The conceptual model of participatory research is a precursor to Chapter 5, which details how the concepts and principles of a community-based participatory research model are operationalised in the methods used in this research.

The model of community-directed research is constructed through five sections. This first section in Section 4.2 is a critical reflection on the influence of the researcher's position in the design of a research model and methods, when researching within Aboriginal and Torres Strait Islander, and disability communities. The second section, in Section 4.3, outlines the research principles that have governed the research, all of which have emanated from the values and beliefs of the First Peoples disability community. The third section, in Section 4.4, presents a conceptual model of community-based research that inverts the traditional relationships in research by positioning the participants in the prime position of empowerment relative to other players involved in the research (including the researcher), aiming to apply Freire's concepts of emancipatory pedagogy (Freire, 1970) in the context of this research. The fourth section, in Section 4.5, describes a model of 'narrative' that privileges the testimony of Aboriginal and Torres Strait Islander people with disability in research, and is complemented by the presentation of statistical data which affirms that validity of the issues raised through the participants' testimony across the population group.

The use of testimony is deliberate and serves to differentiate the process and the purpose of data collection from that of collecting stories. This will be discussed in further detail in Chapter 5. The fifth and final section, in Section 4.6, revisits Foucault's theories of power and discourse (Foucault, 1972) and disruptive discourses (Phillips, Lawrence and Hardy, 2004; Hardy and Thomas, 2014) to develop a strategy to disrupt the alienating and disempowering discourses of institutional research, in favour of a discourse that enfranchises the participant group, and conceivably other population groups that experience vulnerability.

These concepts taken together constitute a community-based epistemology of research that is authentic to the community's values, beliefs and knowledge processes. Designing a model of research from its inception grounded in community has enabled the underlying principles and values of that community to be carried forward without compromise through all stages of the research. The discipline of adhering to a community-directed epistemology through the entirety of the research has culminated in a philosophy of research that is distinctly differentiated from alternative institutionally-based philosophies to research, and is capable of producing research outcomes that institutional approaches to research of themselves have been unable to attain.

4.2 The influence of the researcher's positionality in developing the research model

The triumvirate of being a deaf, Aboriginal, community-based researcher doing research within the Aboriginal and Torres Strait Islander disability community is an intersectional position that is unique compared to work conducted by previous researchers. The notion of 'positionality' allows for a reflection on how the values and standpoint within the social context of a study might generate biases that might be carried into the research (Finlay, 2002). Rather than seeing positionality as implicit and therefore not worthy of reflection, the researcher viewed his unique positionality as an asset in innovating a community model of research that is consciously distanced from institutionalised influences. Hence, the researcher asserted the positionality in creating the research design, over and above devising strategies to defend it against criticisms of 'insider' research lacking objectivity. In other words, the researcher's own 'lived

experience' as an Aboriginal person with disability, and the tacit knowledge that has been accumulated through over a decade's experience as a social policy advocate and researcher, was consciously introduced as an asset to the research design. It is this intersectional positionality that is unique when compared to prior research, and that has allowed this research to draw upon learnings from personal experiences beyond those which could be drawn from theory and prior research alone.

The broad objectives of asserting positionality affirmatively in the research design were twofold. Firstly, the researcher's personal affinity to the community involved in the research provided insights into designing an approach to research that would resonate with the participant group. Secondly, the researcher's prior and extensive professional experience in community-based advocacy at the interface of research and policy has allowed first-hand experiences on what social change strategies are effective on one hand, and what strategies are contested on the other hand, within the Aboriginal and Torres Strait Islander disability policy domain. There were four core dimensions of the researcher's positionality that have motivated the development of this research.

As an Aboriginal researcher:

As outlined in the introductory chapter, the setting for this research is within a nation in which the assertion of Aboriginal and Torres Strait Islander rights, cultures, and therefore research philosophies, are suppressed by a dominant westernised culture, politics and research philosophies. The processes of colonisation have diminished the power and standing of Aboriginal and Torres Strait Islander people within Australian society. The overarching objective of asserting the voices of Aboriginal and Torres Strait Islander people (with disability) through research is disruptive to power relativities that have created and sustained their marginalisation.

As a theoretical base, Section 1.4 of the thesis introduced Indigenous Standpoint Theory (Nakata, 1998, 2007; Rigney 2000; Foley, 2003), as defining a standpoint in which an Aboriginal researcher using Indigenous methodologies doing the research from within the community to which the research relates. In addition to identifying as an Aboriginal person from the Worimi people of New South Wales, the researcher has had eight years' experience in working as an applied social policy researcher embedded within two Aboriginal community-controlled organisations in which the

board and management are entirely comprised of Aboriginal and Torres Strait Islander people. The first organisation was the National Congress of Australia's First Peoples, a self-determining body representing Aboriginal and Torres Strait Islander peoples; and secondly, the First Peoples Disability Network, a self-determining Indigenous disabled peoples' organisation who acted as community host for the duration of the research.

The researcher's immersion within an Aboriginal and Torres Strait Islander community setting has provided grounded insights into ongoing manifestations of colonisation, including racism, discrimination, and social inequality that Aboriginal and Torres Strait Islander people experience compared to other Australians. These 'insider' insights have been brought to bear in the conceptual framing and analysis of the nature and impact of social inequality, as it relates to the second aim of the research.

The researcher has benefited from the constant exposure to Aboriginal and Torres Strait Islander culture as routinely asserted and practised within proud Aboriginal and Torres Strait Islander peoples' organisations. In addition to garnering insights into the social issues as referred to in the above paragraph, it has motivated the infusion of the intangible qualities of Aboriginal and Torres Strait Islander culture in the research as presented. The researcher summarised this in determining that this research needed not just to 'be' Aboriginal, it had to 'look' Aboriginal. Examples of how Indigenous culture is asserted within this research are: the use of 'yarning pieces' to bring life into the presentation of the participants' testimony; the framing of a 'cultural model of inclusion' (Avery, 2018. P. 190-191) in response to the fourth aim of the research; and the use of Aboriginal art and imagery to convey key messages of the research in its translation.

As a deaf person:

This dimension relates to the status and standing of people with disability within society. Implicit in the contestability is a prejudice that people with disability of any kind have an impaired capacity to participate and require protecting during the research; or in the researcher's case, limited capacity to competently execute the research. Intersecting Aboriginal and Torres Strait Islander disability research presents a heightened risk. As shown by the state of the evidence base in Chapter 2, Aboriginal

and Torres Strait Islander disability research is in its infancy, whereas the structures for its ethical review exist within an health and medical research paradigm. The social dimensions of disability are not well accommodated within a medical paradigm of health research. Hence a model of research that asserts the participatory right of people with disability, as is the ethos of this research, could potentially come into conflict with institutionalised prejudices that view the participation of people with disability as a risk.

In this research practice, being profoundly deaf created an affinity between the researcher and members of the participant group based on their shared life experiences of hearing impairment. Being viewed as ‘one of us’ by the Aboriginal and Torres Strait Islander disability community eased the story telling which was the fundamental research method. Being profoundly deaf as a talking point in community settings also initiated an introduction to deaf and hearing impaired people who might otherwise not have participated in the research. This was particularly evident in some of the remote Aboriginal sites visited during the research where people were unaccustomed to seeing cochlear implants as worn by the researcher, which then became a talking point to introduce a discussion around disability.

The researcher’s personal experiences of being deaf during the research journey contributed to the critical reflections on the nature of disability. One such example is the researcher’s interviews with the Deadly Deaf Mob, all of which were conducted in Auslan sign language. Here, many of the Deadly Deaf Mob, all of whom identified as culturally and linguistically Deaf and were proficient in Auslan, had assumed that because the researcher wore a cochlear implant, he was also proficient in Auslan. This is not the case, and in this environment the researcher was the sole person with the communication impairment due to an inability to sign. As a critical reflection, this experience reinforced to the researcher that what constitutes a ‘disability’ is situational.

As a social policy researcher embedded in a non-government community organisation:

The third dimension to the researcher’s positionality that has influenced the design of the research is the tacit experiences that have been gained as a social policy researcher within a non-government community organisation. The researcher made a strategic

choice at the outset to principally locate this research within a non-government community organisation, the First Peoples Disability Network (Australia). This applied a logic that the philosophies and theories of emancipatory research would be applied at their strongest when the research, and the researcher, were located within the community involved. The close proximity of the researcher to the community meant that the research was constantly guided by community protocols and standards. However, the community setting of the research meant that any incompatibility between community values and the institutional rules of research production had to be negotiated and reconciled. This reconciliation process typically took place via a succession of micro-battles in which the research values and principles of the First Peoples disability community were asserted in an institutionalised environment. On the positive side, the community setting acted as a safe haven for the researcher to retreat to when the pressures to conform the research to institutionalised ways and means became onerous.

As the previous chapters have explained, marginalisation and disempowerment are a consequence of power relationships amongst groups in society; then a logical strategy for the re-empowerment of marginalised people requires by necessity an alteration of power relationships between groups. It is the alteration of power relationships that is potentially confrontational to those groups who currently hold positions of power. In considering strategies to promote and defend the research within a contested policy space, the researcher was able to draw on prior professional experiences in advocating for social change at the interface of community and government policy. Specifically, the researcher understood and expected that community-based research would be positioned against a hegemony of institutionally-based research that, in relation to Aboriginal and Torres Strait Islander disability research, has shown to be ill-equipped to recognise and value knowledge that has been produced from within community. It was further understood and expected that policy bureaucrats within the domain of the research would contest research that addressed issues of social inequality, possibly positioning the research exclusively upon its advocacy origins as lacking in rigour (expressed by the “you would say that” dismissal), or disengaging from the research and its outcomes entirely.

The expectation of contestability drove a number of design attributes of the methodology. It was a principal reason why the researcher selected a mixed methods

approach. Noting the value placed upon quantitative data by policy bureaucrats, and an appreciation of the power that numbers carry in policy discourse, statistical analysis was incorporated into the methodology as reinforcement to the testimonial data that aimed to give voice to Aboriginal and Torres Strait Islander people with disability. As an additional strategy to secure the legitimacy of the research, the research also established a layered review process, integrating an independent academic review process and a process for technical review of statistical methods, both complemented by an ongoing community review process.

4.3 Research principles defined by the First Peoples disability community

This research was initiated as an exploratory scoping study with a purpose to promote the voices of Aboriginal and Torres Strait Islander people with disability in research and policy. Its values and principles were set at the outset by an organisation representative of Aboriginal and Torres Strait Islander people based on their personal or ‘lived’ experiences.

Whilst the grounded approach drew upon well-established grounded theory (Charmaz, 2006), the research was initiated with firmly set values about how the research would be conducted as a community-directed approach to disability research, but without a pre-determined theoretical framework or hard-wired set of methods. The researcher’s positionality, mindful of the power relationships that exists between the researcher and the researched (Hanley, 2005), aimed to situate the power within the participant group. This required inverting the power relationships that characterised models used in previous research on Aboriginal and Torres Strait Islander disability, which as described in Chapter 2, had failed to capture the voices of Aboriginal and Torres Strait Islander people with disability themselves.

Through a process of obtaining community assent which involved Elders and leaders from the Aboriginal and Torres Strait Islander disability community, described in detail in the following methods chapter, a set of five research design principles were formulated that were reflective of the community’s values. These research design principles provided the strategic direction through which the research project was

operationalised. They are:

Principle 1: The research is philosophically, methodologically and operationally aligned to the control and direction of the First Peoples disability community.

Rationale: This statement of principle is an assertion of the rights which positioned the decision-making power within First Peoples disability community. In this respect, the researcher became an agent of the First Peoples disability community, vested with both the permission and obligation to ensure that all aspects of the research remained compatible with the community's values and cultural practices. The strategic significance of positioning the power and control over the research within the First Peoples disability community is that their direction would prevail in any issue when institutional research practices came into conflict with their values.

Principle 2: The research continues the rights-based movement of the First Peoples Disability Network to advance the rights of Aboriginal and Torres Strait Islander people with disability.

Rationale: This statement of principle embedded an over-arching purpose to the research by connecting it to the advancement of the right of First Peoples with disability. These rights are articulated through the collective right of Indigenous peoples to self-determination (*United Nations Declaration on the Rights of Indigenous Peoples*, 2007) and the right of participatory and inclusive decision making held by people with disability (*United Nations Convention of the Rights of Persons with Disabilities*, 2016).

Connecting this research to a 'movement' is also significant in that it gives life to a community-directed philosophy to research that extends beyond the limited scope that can be covered within this thesis. In outlining a philosophy of research that has emanated from a community of marginalised and vulnerable people, this study aims to act as a precedent to inspire the collective empowerment of marginalised communities through their ongoing leadership of research endeavours.

Principle 3: The research is inclusive of all people who wish to participate, subject only to their self-identification as a member of the First Peoples disability community.

Rationale: This statement of principle aims at asserting an Indigenous cultural approach to inclusion and disability described in earlier chapters with a focus upon inclusion. Creating a discourse of inclusion is specifically aimed at redressing the social isolation endemic within the First Peoples disability community. What is described as a ‘purposive and convenience sampling’ within the following methods chapter was translated to the participant group to say that the research would accept all-comers who saw themselves as part of the community, who would be invited to share their stories on their terms. The specification of self-identification as the defining parameter for inclusion was aimed at placing the choice to participate (or not) with the individual, free from imposed boundaries such as having a disability diagnosis. These inclusion parameters were only qualified to ensure that it was the voices of Aboriginal and Torres Strait Islander people with disability which was captured through the research, and was not inclusive of intermediaries who sought to speak on their behalf.

Principle 4: The research is discrimination and trauma informed, acknowledging the unique sensitivities of conducting research that includes people who are both Aboriginal and/or Torres Strait Islander and have disability.

Rationale: In undertaking the research involving a marginalised and vulnerable population, it was anticipated that some, if not many, of the participant group would have been previously exposed to traumatic experiences and discrimination, either personally or in close proximity to someone in their family or community. Rather than perpetuate the isolation that exposures to trauma and discrimination can induce, it was determined to make it a keynote feature in the design of the research through affirmative methods that encouraged the participation of people who have been socially isolated. This principle strived to a higher level of research competency for the involvement of traumatised and vulnerable populations, exceeding the ethical requirement of safely managing the risk of trauma and discrimination amongst the participants.

The principle was instrumental in the methodology employed during the interviews with participants. This included the creation of a safe space in which the participants could recount their testimony on their terms and in their time. This involved translating the research into a non-invasive interviewing technique that was distilled into four words: ‘What is your story?’ The details of how the trauma and discrimination informed approach are applied to the research methodology is described in the following chapter.

Principle 5: The research meets both:

- (i) international standards of ethical research practice and quality, and**
- (ii) ethical standards for conducting research in Aboriginal and Torres Strait Islander communities.**

Rationale: This principle sets an objective standard for the quality of research produced through a community-directed approach. A high standard of research rigour is essential in defending the legitimacy of the research produced, not just with this research but for the standing of community-directed approaches to research. This echoes Nakata’s tenet of Indigenous Standpoint Theory (Nakata, 1998, 2007) that ‘lived experience’ on its own is not enough, it must be also be accompanied by critical reflection.

This principle creates the nexus between the community research model and the academically formed research. Notably, this statement of principle is framed in terms of the standards of ethical research practice and quality. This is distinct from rules and protocols of research production through which standards are executed in an institutional setting. Distinguishing standards of research quality from the protocols of research production created latitude in which specific procedures defined within an institutional approach to research ethics and methods could be deinstitutionalised in instances where they were incompatible with community’s protocols or cultural practices, all whilst preserving the underlying purpose for which the procedure existed.

These five principles set the strategy through which this research became operationalised from its grounded origins. The relationship between these principles and the prior research theories and concepts presented in Chapters 2 and 3 is that whilst previous research, theories and concepts could inform the development of the research, they could not usurp the values and directions that had been assented to by the Elders and leaders of the First Peoples disability community.

The fifth principle, in which academic standards are integrated with community values, introduces the following section which describes how power relativities which affirm the control and direction of the First Peoples disability community in the research produced is encapsulated within a conceptual model of community-directed research.

4.4 A conceptual model of community-directed research

The previous section articulated the core values in research that emanated from an Aboriginal and Torres Strait Islander disability community organisation. The community processes through which these principles were articulated and refined into written form have provided clarity to what representative community organisation should aspire to in undertaking and engaging in respectful research relationships. These principles were articulated within community, free from the influence of external research stakeholders. Whilst the process of setting principles internally within community provided surety that community were authentically speaking on their own behalf, the power hierarchies between community and other research stakeholders were benign to these processes.

Considering the relative power relationships is a segue to this next section, which describes how the community principles of research are asserted in a model of research that moves outside the internalised processes of community, and brings into consideration other stakeholders in the research production. As the historical narrative resulting from the meta-narrative review presented in Chapter 2 has determined, the Aboriginal and Torres Strait Islander disability community has been on the disempowered end of the spectrum, to the point of being rendered voiceless in research. Thus, principles of research valued by community can only be implementable if the traditional power relationships between researcher and community are altered.

A model of ‘community-directed research’ that was used as the foundation for this research is figuratively demonstrated in Diagram 4.4.1. Within the relative power frames for this research, its purpose was to convert the wisdom that is prevalent in community (but not necessarily captured in a form that is acknowledged outside community), into a form of research output that is translatable. This purpose is illustrated by the arrows at the top of the diagram. Fulfilling this purpose has required the community to work in a process of research co-production with groups of stakeholders external to the community, namely the academic research community and technical advisors on statistics and policy. This diagram represents the relationship model through which community are positioned in the principal position of power relative to external stakeholders in determining what research is done and how it is conducted. Within this research, ‘community’ is represented by the First Peoples Disability Network (Australia) on behalf of their constituent community.

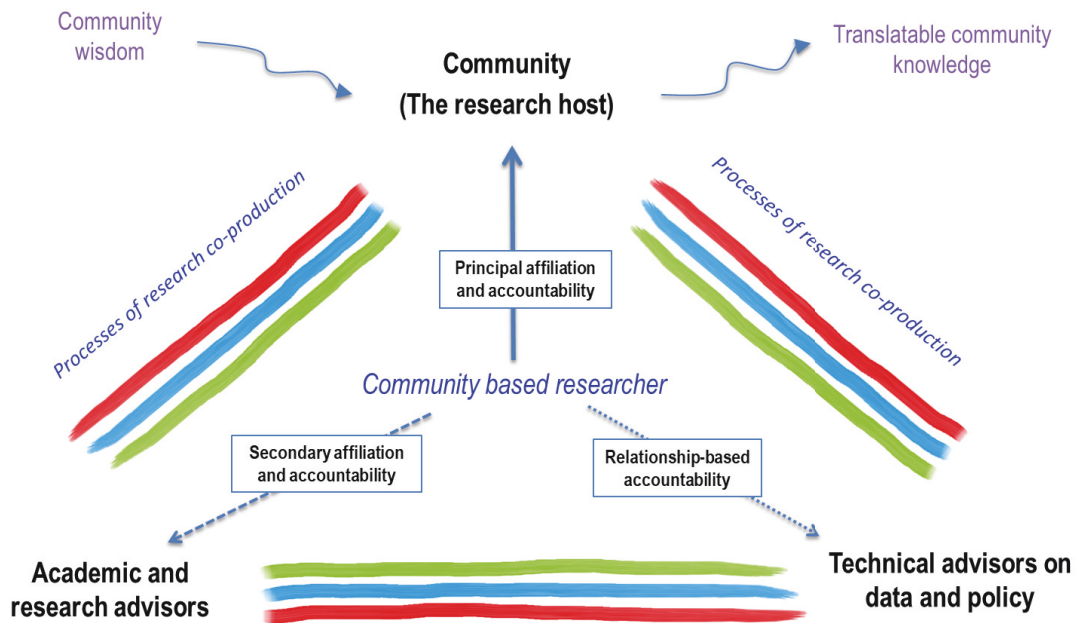
The academic research community and technical advisors play a valued role within this model of research in supporting community on technical matters of research methods, data management, academic rigour and quality, and knowledge translation. However, in contrast to traditional power hierarchies in research, they are advisors, not deciders. In signing up to become co-producers with community in research, the academic and technical partners agree to work respectfully within the model in which community values and principle are preferenced. In practice, the relationships between community and external research partners are negotiated iteratively as opposed to neatly organised processes that are conducted in a step-wise fashion. In acknowledging how these power relationships are negotiated through iterative discourses, the connectors between community and external stakeholders are represented in the model by lines that are drawn in freehand. The fulcrum point in the community-directed model is the community-based researcher. The role of the community-based position (represented by myself in this research) is the interface between the community, the academic and the technical advisors to the research. A significant feature of how this role is defined is by asserting that its principal affiliation is to community, again inverting the power relationship. The community-based researcher also has a formal affiliation to an academic institution, as is essential in progressing community wisdom through recognised rules of research production. However, the community’s value system takes precedence over institutional value systems. It is incumbent upon the community-based researcher to assert the community’s values in negotiating any areas

of conflict in the respective value systems, rather than accept institutional values by default. This power inversion may be viewed controversially within the orthodoxy of research, and can cause personal tension for the community-based researcher in having to navigate community values within the parameters of institutional research. Asserting a principal affiliation to community was nonetheless viewed as a vital distinction for the community-based researcher to optimise trust with a participant group in regard to their exposure to vulnerability.

Rounding out the community-directed model is the relationship with the technical advisors, which in this research was represented by the Australian Bureau of Statistics. The arrangement between the researcher and the Australian Bureau of Statistics over the course of this research was entirely relational, in that there was no formal contractual obligation or memorandum of understanding between the two. The relationship was governed by goodwill to affect work that was of mutual interest. In this project, the advisory team at the Australian Bureau of Statistics provided technical advice that validated the data extraction techniques and analytical accuracy that was undertaken by the community-based researcher. Reciprocally, supporting this research served the Australian Bureau of Statistics' social charter in seeing that the survey data that they had collected was being applied in a practical, social context. Through this relationship, the researcher has made an ongoing contribution to development of Aboriginal and Torres Strait Islander disability data, including by an acknowledged contribution to an occasional paper published Australian Bureau of Statistics entitled 'Social and economic wellbeing of Aboriginal and Torres Strait Islander people with disability' (ABS, 2017c).

The combined elements of the community-directed model is diagrammatically represented in Diagram 4.4.1 below.

Digram 4.4.1: A community-directed model of research involving co-production with academic partners and technical advisors



Whilst this model of research was specifically designed to implement the research principles to foster the empowerment of a marginalised community, there is a broader application in relation to the self-determination rights of Indigenous peoples. Fundamental to its design is the right to self-determination for the Aboriginal and Torres Strait Islander disability community, as expressed by the *United Nations Declaration on the Right of Indigenous Peoples* as “the right [of Indigenous peoples] to freely pursue their form of economic, social, and cultural development” (United Nations, 2007). This model takes the right of self-determination for Indigenous peoples and asserts it within the research domain.

4.5 Facilitating participation in research through an empowering discourse

Having designed research principles and a model of research that promotes the empowerment of Aboriginal and Torres Strait Islander people with disability in research, the next phase in the conceptual design on community-directed research is a

methodology that is relevant to, and promotes the voices of, Aboriginal and Torres Strait Islander people with disability. This section outlines the theoretical foundations of a methodology which were later operationalised through research methods described in the following chapter. Central to this methodology is a novel conceptualisation of ‘narrative’, which is done by synthesising the personal testimony of Aboriginal and Torres Strait Islander people with disability with statistical data to provide both scope and context to the research question addressed by this thesis.

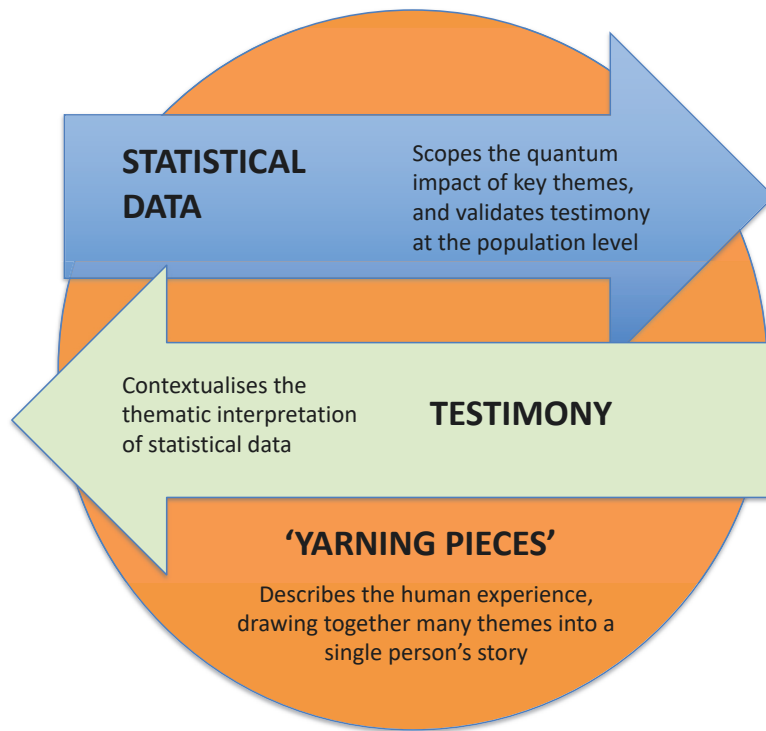
4.5.1 *The construction of a ‘narrative’*

‘Narrative’-based inquiry is a recognised method within clinical research (Greenhalgh, 1999; Greenhalgh and Hurwitz, 1999; Hudson Jones, 1999; Smith-Chandler and Swart, 2014) and mental health research (Launer, 1999), in which the overlapping stories of the patient, clinician or researcher, and other data come together to form an integrated interpretation of the phenomenon that is being explored. It is differentiated from a conventional scientific inquiry method that resides expertise solely in an impartial investigator who is separated from the investigated in order to establish an objective ‘truth’ (Greenhalgh, 1999). Narrative-based inquiry views the investigated as a knowledge holder, capable of contributing their knowledge towards a more comprehensive interpretation, or ‘narrative’, of what is occurring (Greenhalgh, 1999). Narrative-based inquiry also invokes ‘symbolic healing’, through which a patient’s wellbeing is improved through a sense of “mastery and control over their illness and symptoms” (Brody, 1994, p80). Recent studies have shown that narrative storytelling by people with traumatic brain injury is therapeutic when it is coupled with an altruistic opportunity for the narrator to become an advocate for others through sharing their personal story (D’Cruz et al, 2019).

The concepts of narrative inquiry within clinical research resonated with the purpose and aims of this research. This research searched for a ‘truth’ as recounted by the participants, rather than a ‘truth’ as asked and interpreted by an independent researcher. This is reflected in the formative question that asked participants: ‘what is your story?’. The concepts of synthesising many perspectives into a cohesive narrative have also resonated in shaping an understanding of the issues that affect them individually and socially. Within this research, the ‘narrative’ of First People with

disability has come together by synthesising three elements: statistical data, personal testimony, and ‘yarnings’, as represented in the model in Diagram 4.5.1, below.

Diagram 4.5.1: A model of ‘narrative’ comprising testimony, statistical data and ‘yarnings’



Testimony: The research collected first-hand oral testimony from Aboriginal and Torres Strait Islander people with disability on their life experiences of disability. This is achieved by asking Aboriginal and Torres Strait Islander people with disability: “What is your story?”, and allowing them to recount it at their own pace, on their own terms, and within their own safe space. No judgment was made, nor boundaries placed upon what they could or could not say.

The testimony was obtained through personal interviews with 47 people with disability, and through a forum of Elders. The testimony was given orally, or in the case of Deaf Aboriginal people via a verbal translation from Auslan, and recorded digitally. The oral testimony was then transcribed verbatim into text form for analysis. The testimony is presented as verbatim quotes used to provide context and illustration in the thematic analysis. The methodology by which testimony was collected is detailed further in Chapter 5.

Statistical data: The research was conducted on secondary analysis of statistical data collected independently by the Australian Bureau of Statistics. The two principal data sources used for obtaining quantitative data were the 2014-15 National Aboriginal and Torres Strait Islander Social Survey (NATSISS) and the 2015 Survey of Disability, Ageing and Carers (SDAC). The processes for analysing and presenting the quantitative data within the model of co-production developed for the research is described further in Chapter 5.

‘Yarning pieces’: Whilst the presentation of testimony with statistical data together provided both scope and context in the analysis of thematic issues covered by the research, these two elements of the narrative could not provide a complete picture in isolation. What was missing from the verbatim transcription of the testimony was the human experience, particularly how many of the issues come together in the life of each person. To complete the narrative, a concept of ‘yarning pieces’ was created to connect themes as they presented within the life of each person.

Whilst testimony and statistical data can be generated and analysed using westernised methodologies for quantitative and quantitative research, the yarning pieces draw upon a uniquely Aboriginal concept of ‘yarning’ through which oral histories are transmitted in harmony with time and place (Rogers, 2017; Bessarab and Ng’andu, 2010). The yarning pieces are not adjuncts that complement the testimony or statistical data, they are the mechanism through which otherwise disparate themes are drawn together in a cohesive narrative.

Drawing on the researcher’s field notes from the interviews, these ‘yarning pieces’ aim to provide a vignette on the life of an Aboriginal and Torres Strait Islander person with disability. They are designed and written in a way that aims to place the reader in the chair of the interviewer, watching and listening to the person’s story as it unfolds, and encompassing experiences beyond the spoken word.

4.5.2 *Democratising the language of research to facilitate inclusion*

One of the key barriers to research participation that was relayed to the researcher in preparation for the research was that many Aboriginal and Torres Strait Islander people with disability had said that they found that the prevailing language and terms used in research were alienating, confusing, and occasionally intimidating. One particular reservation that came up regularly was that many found proforma participant information and consent forms a lengthy legal document that diminished trust in the process. This feedback was instrumental in the approach taken in co-designing with a representative of the participant group a short form participant information and consent using a method that is described further in Chapter 5.3.

Building upon the participatory approach, the researcher made the conscious decision to talk about the research within community using language that made the participant group more comfortable with the research, and where possible making a linguistic connection to words and phrases that were commonly used by the participants. The approach of making the research discourse less alienating brought words and phrases such as ‘participant-owners’, ‘message stick’, ‘yarning pieces’ and ‘rock up recruitment’ into the research discourse. A list of key phrases and terms that were devised are defined in reference to conventional research phrases in the following Table 4.5.2.

Table 4.5.2: Terminology used to facilitate ownership and inclusion by the participant group

Practice / terminology used	Explanation
First Peoples disability community as ‘researcher’ and ‘host’:	At the highest conceptual level, it addresses the power imbalances that can occur in co-production between ‘researcher’ and ‘community’ (Filipe, Renedo and Marston, 2017) by fusing these roles into one. In this model, the ‘community’ is the ‘researcher’. This is operationalised in this research by the First Peoples Disability Network adopting the role of host organisation

	for the research, and designating a member of its community as lead researcher.
Participants as ‘owners’:	The participants involved in the research are more than just subjects of research, they are fully acknowledged as participant-owners of the research and its outcomes. Referring to participants as ‘owners’ is comparable to other examples where Indigenous governed models of care have conveyed a shared responsibility with their community and respect for the individual, such as the South Central Foundation model of Alaskan Native ownership in health care by ‘customer-owners’ (Dillard et al, 2018, p5). Having the research hosted by a community-based organisation that is established to safeguard their interests reinforces their stake in the research, and is a mechanism to preserve the cultural, intellectual and other rights that emerge from the research within the community.
The researcher is a ‘message stick’ for community wisdom:	A ‘message stick’ refers to an artefact in Indigenous cultures which is used to transmit communication between clans and tribes. The researcher has a custodial role over the testimony that is allocated by the participants. Community wisdom stays with the community, and cannot be appropriated by the researcher, even in its conversion into formal forms of knowledge. During the research, the researcher acts as an agent of the participants, or a ‘message stick’ upon which the participants could write their story.
The inclusion and recruitment strategy was called ‘rock up recruitment’ :	The convenience and purposive sampling method referred to in the following chapter was called ‘rock up recruitment’. This phrase was devised to convey an informal, non-invasive approach to participant recruitment in which the researcher would ‘rock up’ to a community site, and work organically within the community’s

	preferred communication systems to invite participation in the research.
Consent as a ceremonial form of permission:	The roles and relationship of the participant and individual researchers alters the nature of obtaining consent to participate. By contrast, consent takes on a role in which consent designates the passing of permission from the participant to share their wisdom and their testimony, to the researcher as a trusted custodian who accepts a responsibility to care for the testimonies as artefacts of the cultural history of Aboriginal and Torres Strait Islander people with disability.

4.6 Discursive strategies in knowledge translation to drive social change

4.6.1 *Devising a ‘generative number’*

The previous section described how theories of power and discourse were applied through a discursive strategy to facilitate participation in research by empowering the participant group in the research processes. This section describes how the same theories were applied to a different objective, this one an application of disruptive discourse to effect social change (Fairclough, 1996, pp197-233). Whereas the previous section focused on strategies to empower the participant group, this section focusses on strategies to inform and engage a broader audience of stakeholders in the research translation process.

The researcher’s positionality statement early in the chapter acknowledged the weighting that is placed upon statistical data in public policy discourse. The absence of statistical data that was configured in a way that could illustrate the need to address social inequality experienced by Aboriginal and Torres Strait Islander people with disability was an issue at the commencement of the research, and sourcing relevant data became this thesis’ initial aim. In developing the statistical analysis stream, the priority became to source and validate a ‘generative number’, so called in that it is a

single summary number or statistic that can be used to summarise the nature and extent of the research problem, and in turn generate further discussion. In this research problem, the ‘generative number’ that was prioritised was an estimate of number of Aboriginal and Torres Strait Islander people with severe and profound disability. The methods for its estimation are detailed in Section 5.2, and the results are presented in Section 6.2. The applied significance of this estimate as a ‘generative number’ is that it directly relates to the population of Aboriginal and Torres Strait Islander people with disability who are potentially eligible for the disability support stream of the National Disability Insurance Scheme (Commonwealth of Australia, 2013), the major national disability reform program being implemented by the Australian Government at the time of the research (Productivity Commission, 2017). The inability of any government agency to publish an estimate of the number of Aboriginal and Torres Strait Islander people with severe and profound disability, even within the *Australian Government Plan to Improve Outcomes for Aboriginal and Torres Strait Islander People with Disability* (Commonwealth of Australia, 2017) enabled an advocacy narrative around the indifference of government to a grave social injustice. Thus, the ‘generative number’ extended beyond its informative value by provoking policy makers into engaging on the scope of the problem uncovered by the research.

4.6.2 Reframing public discourse through ‘Culture is Inclusion’

In July 2018, the researcher published ‘*Culture is Inclusion: A narrative of Aboriginal and Torres Strait Islander Peoples with disability*’ (Avery, 2018)². The cornerstone publication from this research, *Culture is Inclusion* presented an overview of the research, its core concepts and findings. The publication was prepared principally for an audience within the Aboriginal and Torres Strait Islander and disability sectors, but also aimed to engage members of the general Australian public who have an interest in social justice. The following chapter will reference the methods through which *Culture as Inclusion* was deployed in knowledge translation, and future chapters will discuss its impact. The purpose of this section is to provide insight into how the theories of power and discourse outlined in Chapter 3, alongside the researcher’s positionality,

² Herein referred to by its abbreviated title *Culture is Inclusion*.

have provided a theoretical reference point to its design as publication which reframes public discourse.

Discourse theory principally influenced the research to consider how to assert Indigenous culture through the production of ‘texts’. Personal testimony was one form of ‘text’ that would be directly produced as a consequence of this research.

Considering the research problems in terms of power and empowerment provoked a deeper consideration of what additional ‘texts’ could be produced to reinforce the power to the participants’ testimony that had already been produced. This inspired the decision to incorporate additional ‘texts’ to complement the participants’ testimony that were generated in the form of Aboriginal artworks and of visual imagery that represented healing. The effect of this discursive strategy was to generate a high quality document that had a look and feel as coming from an Aboriginal and Torres Strait Islander disability organisation, both stylistically and tonally differentiated from a publication that a government or a university would typically produce.

As with discourse in the research processes, language was important in the research translation. The choice of summary title *Culture is Inclusion* was chosen for its double-barreled impact in asserting Aboriginal and Torres Strait Islander culture, whilst also placing its emphasis on inclusion and not disability. Further, the publication is spoken of in research engagement as a book, specifically a ‘thinking person’s coffee table book’, rather than a report. This is a discursive tactic to extend its reach beyond the community who live and work within the community involved, and to engage the broader Australian community on the research as a social justice issue affecting the nation. The impact of the discursive strategies used to produce *Culture is Inclusion* is discussed in Chapter 9 through testimonials on its impact from community and other stakeholders in this research.

4.7 An epistemology of community-directed research

Reflecting the grounded approach to this research, this chapter has described how a theoretical approach to research has emerged through interaction of various theories and concepts from the literature presented in Chapters 2 and 3 with the researcher’s personal experiences and positionality. The direction and leadership of the community involved in the research is a central theme to this chapter, as is the need to invert

traditional power relationships in research (Hanley, 2005). Both of these central themes are vital preconditions in conducting authentic emancipatory and participatory research that involves vulnerable population groups (Freire, 1970; Barnes, 2003; Albert and Harrison, 2006). These themes have been continued through the development of the conceptual methodology used in this research: starting with the ethical principles of research as articulated by community, through to a relationship model of research co-production which asserts the empowerment of community relative to other external stakeholders; the composition of a 'narrative' that elevates and promotes the participation of Aboriginal and Torres Strait Islander people in research through their testimony; and the use of texts and language to continue the empowerment of Aboriginal and Torres Strait Islander people with disability through a public discourse that centres on their culture and social inclusion. Taken together, these principles and concepts are packaged into an epistemology of community-directed research that is philosophically, technologically and culturally differentiated to alternative approaches to social policy research that are institutionally led.

Having established a theoretical frame for the methodology used in this research, the next chapter will detail how this conceptualised framework was operationalised in the research methods.

5. Research methods

5.1 Introduction to the methods chapter

This chapter builds upon the methodology theory outlined in Chapter 4 by detailing the methods that were used in this research. In applying the community-directed narrative model described in Section 4.4, a mixed methods approach (Leech and Onwuegbuzie; 2008; Creswell and Plano Clark, 2011; Bowers et al, 2013; Shorten and Smith, 2017) was used to synthesise quantitative and qualitative data. Accordingly, this chapter is written in two parts:

- Part A of this chapter, which is covered in Section 5.2, describes the data and analytical techniques used in the production of quantitative data. It describes the various datasets that were used in the analysis, and the processes of data co-production with the Australian Bureau of Statistics required to generate disaggregated Aboriginal and Torres Strait Islander disability statistics from a number of aggregated datasets.
- Part B of this chapter, which is covered in Section 5.3, describes the qualitative data that is defined as ‘testimony’, and was generated through interviews with forty-seven Aboriginal and Torres Strait Islander people with disability. This process describes how the narrative evolved in an authentically grounded approach which allowed the participants to narrate their testimony on their terms, and in their own time and place. It also describes how the interviewing technique was designed and conducted acknowledging the vulnerabilities of the population group being interviewed, and how the principles of trauma and discrimination awareness were translated into practical research interviewing protocols.

Drawing from the strengths of the researcher’s positionality embedded in a non-government Aboriginal and Torres Strait Islander disability organisation, an Indigenous cultural overlay has been applied to all aspects of the research. Whilst the cultural aspect can be explained through theories of Indigenous standpoint, in practice

it evolved from being a first-hand witness to Aboriginal and Torres Strait Islander people's 'lived experiences' of disability within a community organisation, and following through on the values, principles and ethics that were communicated by the community involved in the research.

This approach has generated a number of distinguishing features of this research. From a research governance perspective, it has meant that the research is principally accountable to the First Peoples disability community through its representative institution. Within the quantitative data analysis, the researcher's immersion enabled culturally innovative techniques to produce relevant disaggregated Aboriginal and Torres Strait Islander disability statistics. For the qualitative aspect of the research, the relationship of the researcher to a representative community group has enabled first hand access to the participant cohort of Aboriginal and Torres Strait Islander people with disability in a manner that has not been attained through the institutional-based approaches used in prior research. Further, the experiences of the researcher in coming into regular contact with the Aboriginal and Torres Strait Islander disability community in a non-research setting has informed the development of safe and culturally informed practices when translated into this research.

5.2 Data – Part A: Quantitative (statistical data)

5.2.1 *Analytic approach*

The quantitative aspect to the research involved a secondary analysis of datasets that are produced by the Australian Bureau of Statistics, which is the official Australian national statistical agency. There is no focused population-based instrument to capture prevalence, profile and outcomes data for Aboriginal and Torres Strait Islander people with disability. Accordingly, the statistical analysis required a poly-angulation of four datasets that contained data that relates to Aboriginal and Torres Strait Islander people with disability. The four datasets used in the analysis were: the 2014-15 National Aboriginal and Torres Strait Islander Social Survey (NATSISS); the 2015 Survey of Disability Ageing and Carers (SDAC); the 2014 General Social Survey (GSS); and the Aboriginal and Torres Strait Islander population estimates from 2016 Census of

Population and Housing (the Census). How each of these datasets were used in the analysis is outlined in Section 5.2.5 below.

Whilst each of these datasets are publicly accessible and contain data that is relevant to Aboriginal and Torres Strait Islander disability, the data were not configured to enable the disaggregation of Aboriginal and Torres Strait Islander disability statistics that was required for an intersectional analysis of social health and wellbeing outcomes. The necessary data was instead obfuscated within a number of unconnected datasets. For example, the NATSISS contains social statistics; it is designed to be completed by the Aboriginal and Torres Strait Islander population and includes a short form set of questions relating to disability, whereas the SDAC has a more detailed disability questionnaire but only contains a comparatively small cohort of Aboriginal and Torres Strait Islander respondents within a survey that is designed to be completed by people with disability and their carers, and is neutral to their Indigenous status. A more detailed description of the datasets and their limitations is outlined below in Section 5.2.4 below.

5.2.2 *Operationalising the community-directed model in the co-production of disaggregated Aboriginal and Torre Strait Islander disability statistics*

Section 4.4 described a conceptual model of community-directed research in which the community-affiliated researcher draws upon technical advice on statistical data. This conceptual model was operationalised in co-production of disaggregated Aboriginal and Torres Strait Islander disability statistics through a partnership between the Australian Bureau of Statistics and First Peoples Disability Network, for which the researcher was the designated representative. Working in co-production with Australia's official statistical agency was deemed important for legitimising the research in a contested policy arena as it has meant that the source of statistical data for this research is the same source that is used by government policy makers in formulating Australian Indigenous and disability policy.

The researcher's personal relationship with the Australian Bureau of Statistics was initiated through an expert advisory role which was formalised through appointments to a number of their Experts Advisory Groups which has included the NATSISS, the SDAC, the National Aboriginal and Torres Strait Islander Health Survey (NATSIHS),

and Aboriginal and Torres Strait Islander Population and Demographic Statistics. Acting as an expert advisor to the Australian Bureau of Statistics enabled the researcher to establish cross-functional relationships with the managers of the datasets that were used in this research. When it came to undertaking this research, the function of the expert advisor was inverted, with the dataset managers at the Australian Bureau of Statistics providing technical advice on the accurate disaggregation, presentation and interpretation of that data consistent with the respective methodologies used to collect the data.

5.2.3 *Key definitions in the statistical data*

Before proceeding further into how statistical data were disaggregated and analysed, this section provides a technical description of how the terms ‘disability’ and ‘functional limitation’ are used in the principal data sources. The Australian Bureau of Statistics’ working definitions for these terms are derived from the World Health Organization’s International Classification of Functioning, Disability and Health (‘ICF’) (World Health Organization, 2001) which sets a standardised framework for disability terminology that integrates the biophysical and social factors affecting a person. In adopting the ICF within the statistical data, the Australian Bureau of Statistics define ‘disability’ as:

“an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environment and personal factors)” (ABS, 2016a, Glossary).

As a point of contrast, ‘functioning’ within the ICF relates to the capacity to undertake a task as a consequence of having an impairment, and denotes the positive or neutral aspects of the interaction between a person’s health condition and their environmental and personal factors (World Health Organization, 2001). Whilst aiming to make health, and not impairment, the common metric of wellbeing between people with disability and people without disability (World Health Organization, 2002), the ICF framework nonetheless frames disability and human functioning within a limited concept of health. This means that other factors that may inhibit social participation, such as racial and other forms of discrimination, are outside its scope. This limitation

in scope presents another gap in its application to what are significant disabling factors affecting Aboriginal and Torres Strait Islander people.

In this respect, the Australian Bureau of Statistics disability related questions, in both the NATSISS and the SDAC, are self-reported responses to functional limitations experienced by the respondents to the survey. The Australian Bureau of Statistics categorises four levels of severity in their definition of ‘core activity limitation’:

- (i) **Profound** - the person is unable to do, or always needs help with, a core activity task.
- (ii) **Severe** - the person sometimes needs help with a core activity task, and/or has difficulty understanding or being understood by family or friends, and/or can communicate more easily using sign language or other non-spoken forms of communication.
- (iii) **Moderate** - the person needs no help but has difficulty with a core activity task.
- (iv) **Mild** - the person needs no help and has no difficulty with any of the core activity tasks, uses aids and equipment and has difficulty in general mobility. (ABS, 2016a, Glossary).

5.2.4 *Description of the datasets*

As stated above, the statistical analysis required poly-angulation of a number of datasets, as disaggregated Aboriginal and Torres Strait Islander disability statistics were not available in a single data source. This section provides an overview of the various datasets that were poly-angulated to provide a composite analysis on the prevalence, profile and social outcomes for Aboriginal and Torres Strait Islander people with disability in order to address the first aim of the research.

There were four Australian Bureau of Statistics datasets used in the statistical analysis: the NATSISS; the SDAC; the GSS and the Census. The two principal datasets used in the analysis of social statistics are the 2014-2015 NATSISS and the 2015 SDAC. Both

of the datasets use a self-reported sample survey approach to collect data. The NATSISS is designed to be completed by a sample cohort from the Aboriginal and Torres Strait Islander population and includes a short form disability module. In terms of geographical reach, the NATSISS has some, but not extensive, coverage of remote Aboriginal communities. By comparison, the SDAC is designed to be completed by people with disability and their carers, includes a much more comprehensive set of disability questions, and includes a smaller cohort of Aboriginal and Torres Strait Islander respondents. In terms of geographical reach, the SDAC does not cover remote Aboriginal communities.

Table 5.2.4.1 Comparison of methodologies used in the NATSISS and SDAC datasets

	NATSISS	SDAC
Date of latest survey data	2014-2015	2015
Survey approach	Self-reported quantitative sample survey	Self-reported quantitative sample survey
Designed to be completed by	Aboriginal and Torres Strait Islander people	People with disability and their carers
Question set used	The NATSISS uses a Short Disability Module that applies the same criteria as the SDAC to identify people with disability and determine their severity of restriction. However, it uses only a short question set and a series of prompt cards to establish the presence of effects of any long-term health conditions, limitations or restrictions, and then ascertains the extent to which these require the person to be assisted to carry out various core activities.	The SDAC contains over 140 questions designed to identify disability and underlying impairments causing disability. The SDAC includes a set of 39 questions that are designed to exclude people if their need for assistance is not the direct result of disability.
How Aboriginal and Torres Strait Islander disability is identified within the data collection	Disability questions are included within the survey and asked of people aged 15 years and over.	The survey contains an Aboriginal and Torres Strait Islander identifier.
Inclusion criteria for survey respondents	Aboriginal and Torres Strait Islander people living in private dwellings.	People with disability, all ages living in private households.
Geographical limitations	Some coverage of remote Aboriginal and Torres Strait Islander communities.	The SDAC does not include those living in very remote communities.

The NATSISS and the SDAC enable an intersectional analysis of disability prevalence and social outcomes within the Aboriginal and Torres Strait Islander disability population, and some comparisons to the social outcomes for Aboriginal and Torres Strait Islander people without disability, and social outcomes for people with disability who were not Aboriginal and Torres Strait Islander people. However, limits to the scope of the NATSISS and the SDAC meant it was not possible to compare social outcomes experienced by Aboriginal and Torres Strait Islander people with disability to the general Australian population. This necessitated use of data collected in 2014 GSS, which is a self-reported quantitative survey designed for people from the general Australian population. The GSS allows for self-identification of Aboriginal and Torres Strait Islander identity, and contains the same short form disability module that is included within the NATSISS. Including data from the GSS enabled a more comprehensive comparison across a select number of social indicators where data definitions were compatible with both the NATSISS and the SDAC.

The final data that were used for the analysis were the Aboriginal and Torres Strait Islander population estimates which are derived from the 2016 Census. Whilst the NATSISS and SDAC produce a prevalence rate for disability amongst the Aboriginal and Torres Strait Islander population, of themselves they do not produce a population estimate for the number of Aboriginal and Torres Strait Islander people with disability by levels of severity. As outlined in Chapters 4 and 6, an estimate of the number of Aboriginal and Torres Strait Islander people with disability is a vital number in developing and costing policy responses to social inequality through service and workforce strategies; yet previous research or government reports had not produced a population estimate. A formula created to produce a population estimate for the number of Aboriginal and Torres Strait Islander people with disability includes the post-enumerated population estimate of the Aboriginal and Torres Strait Islander population as a whole. This formula, used to estimate the number of Aboriginal and Torres Strait Islander people with disability is described in the analysis section below.

5.2.5 *Analysis*

There are four themes in the statistical analysis that were compiled to provide a breadth of understanding of the scope and nature of disability amongst the Aboriginal and Torres Strait Islander population. The four themes are:

- (i) Estimates of prevalence of disability amongst the Aboriginal and Torres Strait Islander population;
- (ii) A profile of disability amongst the Aboriginal and Torres Strait Islander population;
- (iii) An analysis across various datasets for indicators of social, health and wellbeing outcomes for Aboriginal and Torres Strait Islander people with disability by severity of disability, compared to other population groups comprising the general Australian population, the population of people with disability, and the population of Aboriginal and Torres Strait Islander people without disability; and
- (iv) A deeper analysis of the NATSISS for indicators of social, health and wellbeing outcomes for Aboriginal and Torres Strait Islander people with severe and profound disability compared to Aboriginal and Torres Strait Islander without disability.

The four themes of statistical analysis are now described in further detail.

(i) Estimating the prevalence of disability amongst the Aboriginal and Torres Strait Islander population

An estimate of disability amongst the Aboriginal and Torres Strait Islander population was generated using an expected value formula, which estimates the number of Aboriginal and Torres Strait Islander people with disability by multiplying the prevalence rates for disability generated by the NATSISS and the SDAC, and multiplying them by the Aboriginal and Torres Strait Islander population estimate. This formula is represented as follows:

$\text{Estimate of people with disability} = \text{Prevalence rate (a)} \times \text{Population}$

As the NATSISS and SDAC survey generated different prevalence rates for disability, this estimate was calculated twice, once using the NATSISS generated rate of disability prevalence, and another using the SDAC generated rate of prevalence.

An estimate of prevalence was generated for two levels of disability severity. It was first calculated for severe and profound disability, which was done by combining the field reporting 'severe' with 'profound' into a single field for 'severe and profound'. The purpose of combining the data field 'severe' with the data field for 'profound' disability into a single variable is that this estimate most closely reconciles with the definition of 'severe and profound disability' that is used to determine eligibility under the disability stream of the National Disability Insurance Scheme, and hence has direct policy relevance.

A second calculation was done for people with 'some disability', which combined all fields of reported functional limitation from mild to profound. Methodological differences between the NATSISS and the SDAC meant that the NATSISS included the presence of long-term health conditions within the reporting of disability, whereas the SDAC's use of a larger set of disability questions meant that long-term health conditions were able to be filtered out for reporting on the prevalence of Aboriginal and Torres Strait Islander people with some disability (ABS, 2019). The difference in how the NATSISS and the SDAC treatment of long term health conditions leads to stark differences in estimates of populations of Aboriginal and Torres Strait Islander people with some disability, which can only be reconciled through further research. In the meantime, this research presents both outcomes.

This analysis is presented in the results chapter in Section 6.2.

(ii) A profile of disability amongst the Aboriginal and Torres Strait Islander population

Using the NATSISS dataset, this section of the statistical analysis complements the population estimates with a section of descriptive statistics which profile the nature of disability amongst the Aboriginal and Torres Strait Islander population.

The descriptive statistics included in this section are:

- A ranking of the most common disability types grouped by the following categories: Physical; Sensory (sight, hearing, speech); Psychological;

Intellectual; Head injury, stroke or brain damage; and Disability type not specified.

- The number of disability types per person with severe and profound disability. The purpose of these descriptive statistics is to give an indication of the extent of co-occurring disability that Aboriginal and Torres Strait Islander people with disability experience.
- The prevalence rates of disability by gender, and by severity. The purpose of these descriptive statistics is to identify variation by gender.
- The prevalence rates of disability by remoteness (i.e. remote and non-remote regions of Australia), and by severity. The purpose of these descriptive statistics is to identify whether disability was more or less prevalent based on whether people lived in a remote part of Australia compared to urban and regional parts of Australia.
- Intersections of disability prevalence rates by gender and remoteness. This process cross-tabulates gender and remoteness, the two descriptive statistics referred to immediately above to inquire whether there is a possible intersectional effect that could be explored further.

This analysis is presented in the results chapter in Sections 6.3 to 6.5.

(iii) A comparative analysis of social, health and wellbeing outcomes for Aboriginal and Torres Strait Islander people compared to other population groups

This component of the statistical analysis used the NATSISS to compare a select number of social health and wellbeing indicators that Aboriginal and Torres Strait Islander people with disability experience compared to other population groups. The five population groups for which social outcomes were extracted are listed below. The population groups are listed in a cascading order reflective of an escalating intersectional effect: from the general Australian population, to sectional population groupings (people with disability; Aboriginal and Torres Strait Islander groups), to intersectional population groupings with and without a severity effect for disability (Aboriginal and Torres Strait Islander people with disability that is not severe or profound; Aboriginal and Torres Strait Islander people with severe and profound

disability). The purpose of organising the population groups as cascading in their intersectional effect was to test the validity of the conceptual model of intersectionality described in Chapter 3.

- General Australian population;
- People with disability (which may include Aboriginal and Torres Strait Islander people with disability within the data collection source);
- Aboriginal and Torres Strait Islander people without disability;
- Aboriginal or Torres Strait Islander people with disability that is not severe and profound;
- Aboriginal or Torres Strait Islander people with severe and profound disability.

As this analysis required comparing social health and wellbeing outcomes across different population groups, two datasets were required for the analysis, namely the NATSISS and the GSS. A number of indicators were used in a comparative analysis across the population groups. The indicators used in the comparative analyses were selected as representative across a range of social, health and wellbeing outcomes. Furthermore, the data were collected in the NATSISS and GSS in a form that could be reconciled for comparative analysis. There were five indicators that satisfied these requirements, which were:

- The proportion of the population group that had self-assessed their health as excellent or very good;
- The proportion of the population group that had experienced problems accessing health care services;
- The total who experienced one or more psychological stressors;
- Feelings of safety walking alone in local area after dark;
- Participation in the labour force.

This analysis is presented in the results chapter in Section 7.2.

(iv) Indicators of social, health and wellbeing outcomes for Aboriginal and Torres Strait Islander people with severe and profound disability compared to Aboriginal and Torres Strait Islander people without disability.

A fourth stream of analysis was conducted to provide greater depth of understanding on potential intersectional impacts that Aboriginal and Torres Strait Islander people with disability experienced compared other Aboriginal and Torres Strait Islander people. As this involved looking at comparative social, health and wellbeing for groups *within* the Aboriginal and Torres Strait Islander population, this analysis only required use of the NATSISS dataset. Using the single dataset in this analysis avoided the need for reconciliation with other datasets, and hence allowed comparison across a larger number of social, health and wellbeing variables in contrast to the analysis immediately above which involved multiple datasets.

The comparative indicators organised into the following thematic categories, which are reported in Chapters 7 and 8:

- (i) Inequality in accessible communities (reported in Section 7.3);
- (ii) Inequality in justice and personal safety (reported in Section 7.4);
- (iii) Inequality in access to education (reported in Section 7.5);
- (iv) Inequality in gaining employment (reported in Section 7.6);
- (v) Inequality in access to health and health services (reported in Section 7.7);
- (vi) Social exclusion and isolation (reported in Section 8.2);
- (vii) Exposure to trauma (reported in Section 8.5.1); and
- (viii) Mental health care outcomes (reported in Section 8.5.3).

In order to aid the translation of this research into Australian government policy, the first six thematic categories align with the priorities identified in the *Australian Government's Plan to Improve Outcomes for Aboriginal and Torres Strait Islander People with Disability* (Commonwealth of Australia - Department of Social Services, 2017). Further, additional thematic categories were established to differentiate somatic and mental health outcomes from issues relating to access.

The quantitative data on inequality experienced by Aboriginal and Torres Strait Islander people are presented concurrently with the qualitative testimonial data that were collected through interviews in a process described below in Part B of this Chapter.

5.2.6 *Limitations in the statistical data*

The NATSISS and the SDAC have limitations in the scope in their data collection methods that influence how the data relating to prevalence should be interpreted, particularly in reference to the estimating the prevalence rate of disability. The decision whether to use the Aboriginal and Torres Strait Islander-based NATSISS or the disability-based SDAC in estimating disability prevalence has been contested by various researchers. Some researchers located in a health paradigm assert that the SDAC must be used in establishing the prevalence of disability (Coleman et al, 2018), citing ambiguities in the inclusion of long-term health conditions in the broader definition of disability used in the NATSISS. Other researchers located in Aboriginal and Torres Strait Islander policy have argued that the sample size for the Indigenous population in the SDAC is too small to make reliable estimates (Biddle et al, 2014, p.35). As an intersectional study traversing both Aboriginal and Torres Strait Islander statistics and disability statistics, this research does not take a position either way on this point, and instead presents the best available data from both the NATSISS and the SDAC rather than favouring one dataset over the other. The strengths and limitations of each dataset are articulated in Table 5.2.4.1, and prevalence data from both the NATSISS and the SDAC are presented alongside each other in Table 6.2.1 and Table 6.2.2.

As a study focused on social inclusion and exclusion, this research is more concerned by the influence of under-reporting of disability by Aboriginal and Torres Strait Islander people. The first attribute is that the data collection processes for both datasets involve self-identification. In relation to Aboriginal and Torres Strait Islander disability this requires the respondent to first identify as being of Aboriginal and Torres Strait Islander person; and second, to identify as having functional impairment. Neither the NATSISS nor the SDAC undergo any form of post-enumeration adjustment to estimate the prevalence rates of disability. This is unlike a post-enumeration adjustment of the Aboriginal and Torres Strait Islander population data

from the Census. This process which determined there was an un-reporting by 22.9% of Aboriginal and Torres Strait Islander status in the 2016 Census, from 649,200 people who completed the Census form and identified as Aboriginal and/or Torres Strait Islander (ABS, 2017a), compared to the final post-enumeration population estimate of the Aboriginal and Torres Strait Islander population of 798,365 people (ABS, 2018).

The second limitation of the NATSISS and the SDAC is their geographic and demographic reach. As referenced in Table 5.2.4.1 above, the NATSISS survey is conducted in a limited number of remote Aboriginal and Torres Strait Islander communities, and the SDAC is not conducted in remote Aboriginal and Torres Strait Islander communities at all. Furthermore, the NATSISS and SDAC surveys are completed by people who live in 'private dwellings', which by the definition used by the Australian Bureau of Statistics excludes people who are homeless, are incarcerated or living in other institutional settings such as some group homes and in an out-of-home care environment.

These limitations are mainly an issue in respect to determining the prevalence of disability in Aboriginal and Torres Strait Islander communities, as they can relate to an under- or over-reporting on disability by the survey respondents. There is less of an issue when it comes to comparing social outcomes for Aboriginal and Torres Strait Islander people with disability to other population groups, as the raw social outcome data is converted to ratios which enable relativity analysis. There is insufficient research to determine the quantum of the effect under- or over-reporting has on estimating prevalence of disability amongst Aboriginal and Torres Strait Islander communities. However, given the relationship between the historical legacies of colonisation and trust in data and research as outlined in Chapter 1, and the exclusion from the datasets of people who homeless, incarcerated and living in institutional settings, it can be reasonably presumed that statistical analysis in this research sets a low watermark in estimating the prevalence of disability in Aboriginal and Torres Strait Islander communities.

The limitations of the statistical data and analysis reaffirmed the need for a mixed methods approach to the research. Running parallel to the quantitative data, a second set of methods were established for the collection and analysis of qualitative data to

provide depth of context for the statistical analysis. The method used in the collection and analysis of the qualitative data is the topic of the following section.

5.3 Data – Part B: Qualitative (testimonial data)

5.3.1 *Testimonial data collected through interviews*

A second aspect of the conceptual model of the narrative described in Section 4.4 is the testimony collected through interviews with Aboriginal and Torres Strait Islander people with disability. The testimonies of personal experiences of living with disability were collected to complement and contextualise the quantitative data referred to in Part A.

The inclusion of testimony affects the overarching aim of this research, which is to activate the participation Aboriginal and Torres Strait Islander people with disability in research and policy in a form that had not been realised through prior research. The study methods emanated from this aim through a participant recruitment strategy that was purposive and drew participants from networks where trust of the researcher and the host organisation had been established through a process of ‘community consent’.

The remaining chapter describes how the research methods evolved during the grounded approach to the study, responsive to the community’s principles outlined in Section 4.3, and informed by an understanding of the underlying traumatisation that the participant group have experienced as a population.

5.3.2 *Inclusion criteria*

Participants were recruited through non-randomised purposive sampling (Patton, 1990; Suri, 2011) and convenience sampling (Etikan et al, 2016). Elements of purposive sampling were incorporated into the recruitment of participants to reflect its power in selecting ‘information-rich’ participants to study in depth to learn about the central purpose of study (Patton, 1990, p.169), which in this study was a narrative of social isolation and exclusion. Elements of a convenience sampling were also required as the nature of the pre-existing social isolation of the participant group made randomised

selection of participants was impossible. Noting the limitations of non-randomised sampling, strategies were undertaken to ensure the validity and reliability of the qualitative data collected through the purposive and convenience sampling of participants, which are addressed further in Section 5.8.

Consistent with the underlying value of promoting inclusion of Aboriginal and Torres Strait Islander people with disability, the inclusion criteria for participation in the research interviews required participants to self-identify as:

- Criterion 1: an Aboriginal and/or Torres Strait Islander person; and
- Criterion 2: a person having direct lived experience of disability, either as a person with disability, or family member of a person with disability responsible for their care (e.g. a parent of a child with disability).

The self-identification process used in the qualitative research component of this study is compatible with the process of self-identification used by the Australian Bureau of Statistics on the datasets used in the quantitative components of the study. The inclusion of people with a ‘direct lived experience’ under criterion 2 was interpreted to include people with disability, and their immediate family member who acted in a principal caring capacity. This enabled the participation of people with disability who were non-verbal. For clarity, people who acted as carers or service providers in a professional capacity were not included in the study.

5.3.3 *‘Elders’ assent’ and ‘community consent’*

The recruitment of individual participants was precipitated by processes of ‘Elders’ assent’ and ‘community consent’. These processes involved meeting with acknowledged Elders within the First Peoples disability community (‘Elders’ assent’), and the Aboriginal and Torres Strait Islander communities in each of the designated research sites (‘community consent’). These processes ensured that the people from the research sites involved understood and endorsed the aims of the research and the methods used prior to the recruitment of individual participants. The processes of ‘Elders’ assent’ and ‘community consent’ used in this research extend upon minimum standards that have been established for ethical research in Aboriginal and Torres Strait Islander communities (AIATSIS, 2012; NHMRC, 2018) and serve two core purposes. The first purpose is to establish a relationship of trust with the researcher,

which in turn facilitates the participation of individuals within supportive communities. The second purpose is to provide surety to the researcher that they can speak to the issues with the permission and authority of the communities that were involved in the research as their ‘message stick’, a phrase that was described in Section 4.5.2.

(i) ‘Elders’ Assent’ – commencement of the fieldwork stage

As a first step in securing permission for the research by the community reflecting the participant group, an ‘Elders’ assent’ process was initiated as a mechanism for overarching oversight of the research conduct by acknowledged Elders and leaders of the First Peoples disability community. This was activated at the commencement of the project by a presentation of the research aims and methodology to the Elders on the Board of Directors of the First Peoples Disability Network, which is comprised in its entirety of Aboriginal and Torres Strait Islander people with disability. The Elders provided their assent to the research by a resolution of the Board, which reflected their permission for the research to commence the field-based research activities, which proceeded with site-based ‘community consent’. A copy of the letter of support for this research on behalf of the First Peoples Disability Network is attached to this thesis as Appendix A.

(ii) ‘Community consent’

As ‘community consent’ is a relational activity, the process of establishing consent was non-linear and was highly variable in the time taken to acquire consent in each site. Purposive sampling (Patton, 1990; Suri, 2011) and convenience sampling methods (Etikan, 2016) were used for the selection of research sites and individual participants. This was due to the exploratory nature of the research combined with the limited resources available relative to its scope and purpose. ‘Community consent’ started with the lead researcher’s existing community network, then expanded to First Peoples Disability Network’s established network, then, as the research built a good track record with community, expanded again into First Peoples Disability Network’s emerging networks. Within the convenience sampling approach, the research nonetheless aimed to obtain participation from a cross section of metropolitan, regional and remote areas. This was needed to enable some exploration of the comparative

experiences of Aboriginal and Torres Strait Islander people living in urban, regional and remote locations. This resulted in the following research sites providing their community consent

- **Deadly Deaf Mob (Commencing site):** The first cohort providing their ‘community consent’ to participate was the Deadly Deaf Mob, which is a self-named social networking group of Deaf Aboriginal people. Participation by the Deadly Deaf Mob in the research was initiated by one of the conveners of the Deadly Deaf Mob who had learned about the research, and then asked the lead researcher who is also a Deaf Aboriginal man whether the Deadly Deaf Mob could participate. As the request for participation was initiated by a representative of the participant cohort, ‘community consent’ was instantaneous, and this facilitated interviews with Deaf Aboriginal people, initially in Redfern (a metropolitan suburb of Sydney Australia), and later in Adelaide, South Australia. These interviews were conducted in Auslan. For clarity, no interviews involving Deadly Deaf Mob participants were conducted in sites outside of Redfern or Adelaide. To further reduce the risk of identifying participants, the results for the Deadly Deaf Mob are reported as a single discrete cohort, and not disaggregated by research site.
- **Community Consent – Disability community New South Wales, Australia:** ‘Community consent’ was then secured through members of the Aboriginal Disability Network (NSW), which is a state-based representative body for Aboriginal people in New South Wales that is affiliated with the First Peoples Disability Network. The researcher followed the community-based disability awareness, training and engagement activities within the New South Wales Aboriginal Disability network, which provided introductions to individual participants with a purposive, convenience sampling approach. This facilitated interviews in and around the Sydney metropolitan region, and at a number of other regional and remote locations in New South Wales, including Wagga Wagga, Grafton, Broken Hill, and Wilcannia.

- **Community consent - Barkly Shire, including Tennant Creek and Utopia, Northern Territory, Australia:** The researcher followed the community engagement activities of the First Peoples Disability Network into the Barkly Shire in the Northern Territory. This enabled access into a number of remote and very remote Aboriginal communities in Central Australia. Noting that the research timeline across the sites was a non-sequential, staggered process, the ‘community consent’ in the Barkly Shire was happening concurrently with interviews with participants in New South Wales.

During the course of the project, the research had attempted to obtain ‘community consent’ in additional sites in Northern Australia and regional South Australia. These were discontinued due to the resource constraints of both the project and the Aboriginal and Torres Strait Islander community organisations that were approached to facilitate access to research sites.

(iii) **‘Elders’ assent’ – conclusion of the fieldwork stage**

As an activity to conclude the individual interviews, one Elders’ Forum was conducted in Alice Springs, Northern Territory. The purpose of the Elders’ Forums were to present the preliminary findings for review and comment by groups of Elders, and obtain their permission on behalf of the First Peoples disability community to speak to the issues raised by the research in forums outside the community. These Elders’ groups had expanded since the commencement of the field work, and now comprised a more diverse geographical reach to incorporate Elders’ representatives from New South Wales, Northern Territory, South Australia, Queensland, Western Australia and the Torres Strait. Elders’ assent to speak to the research was explicitly with one Elder proclaiming during the Forum:

“We’ve got to have our voices heard through these people” (participant, Elders’ Forum, September 2017)

5.3.4 *Research sites and participant cohorts*

Based on the ‘community consent’ process described above, qualitative research interviews were conducted within the following sites and participant cohorts:

- (i) New South Wales – which was categorised into metropolitan, regional and remote areas;
- (ii) Central Northern Territory – this site was bounded by Alice Springs to the south and Tennant Creek to the north and included the Barkly Shore and Utopia homelands. This region was exclusively categorised as remote; and
- (iii) ‘Deadly Deaf Mob’ (Deaf Aboriginal people) – these interviews were conducted in Auslan, and conducted in New South Wales and South Australia.

5.3.5 *Participant profile*

Based on the inclusion criteria, 47 people with lived experience of disability participated in the qualitative interviews. The participants were interviewed over 41 interviews, as in some interviews a person with disability was accompanied by another participant who also met the inclusion criteria. This included three non-verbal people with disability who participated in interviews accompanied by a parent as their carer.

The participant profile reflected a balance across the metropolitan, regional and remote sites. There was also gender balance in the participant profile, with 25 female participants (53.2%) and 22 male participants (46.8%). The participant profile by gender and cohort is summarized in Table 5.3.5 below:

Table 5.3.5: Participant profile for qualitative research, by gender and cohort.

Total number of participants	47
Total number of interviews	41
Non-verbal participants (accompanied by parents as carers)	3
Average length of interview	31.01 minutes
Participants by gender:	
Female	25 (53.2%)
Male	22 (46.8%)
Participants by cohort:	
Deadly Deaf Mob (New South Wales and South Australia)	11
Metropolitan – NSW	11
Regional and remote - NSW	15
Remote - Northern Territory	10
TOTAL PARTICIPANTS	47
Elders' Forum	
Number of participants	11
Areas represented	NSW; Remote Northern Territory (Barkly Shire); Central Northern Territory (Alice Springs); Torres Strait Islands; Queensland; South Australia; North-west Australia.

5.3.6 Participant Consent Protocols

A participant information sheet and consent form was prepared to convey the aims and objectives of the research, and obtain the participant's written consent to participate in the research. Consistent with the participatory and emancipatory aims of the research, this was drafted from scratch in the presence of an Aboriginal person with disability who was representative of the participant group, and separately reviewed by another

Aboriginal person with disability. The drafting of the participant consent form considered feedback directly provided by the representatives of the participant group who said that they felt that forms that contained technical language was intimidating, and that they would be reluctant to sign them. They also provided feedback that they were encouraged in knowing the research was being led by an organisation from the Aboriginal and Torres Strait Islander community, rather than by a Government agency or University.

Based on this feedback, the participant information and consent were contained within a two-page (one single sheet, double sided) form, and included the First Peoples Disability Network's logo. To promote accountability of the research to the First Peoples disability community, it also contained the name and contact of the researchers; the Chair of First Peoples Disability Network, who is a respected Aboriginal Elder and person with disability; and the relevant Aboriginal Health Research Ethics Committee in each of the research jurisdictions as an independent avenue with whom concerns or questions about the research or its conduct could be raised.

The final participant information and consent form is attached to this thesis as Appendix B. The participant information and consent form was provided to prospective participants in advance of the interview to allow them time to read it and consider whether or not they wished to participate in the research. It was also read by the researcher immediately prior to the commencement of interviews to ensure that free and informed consent was obtained.

5.3.7 *Recruitment of participants – 'Rock up recruitment'*

To bridge the communication gap in which the language of research discourse was seen as alienating within community, the researcher coined the phrase 'rock up recruitment' to convey a flexible, non-threatening manner in which the researcher would 'rock up' to community, sit with the people, understand and then utilise the community communication structures to communicate the purposes and objectives of the research. The objective was to position the researcher as available within communities to take people's testimony, but not so obtrusive as to be seen as pressuring people to participate.

Emphasising the community-directed nature of the research, the researcher then utilised a relational recruitment approach, working within the Aboriginal community's informal communication processes, colloquially referred to as the 'Koori grapevine', to extend invitations to prospective participants. This facilitated referrals through word of mouth within the community; invitations to attend community gatherings and conferences; speaking on Koori Radio; and an invitation to sit with an Aboriginal men's group.

5.3.8 *Interview technique and protocol*

Given the marginalisation that Aboriginal and Torres Strait Islander people, the style and tone of the interviews were viewed as vital factors in determining the third aim of the research outlined in Chapter 1, which is to use a model of research that actively promotes participation of Aboriginal and Torres Strait Islander people with disability through the direct testimony of their lived experience. In this respect, the interviewing needed to be genuinely participatory in that it facilitated the testimony of participants without judgment or pre-supposition; and second, in that it was trauma aware and respectful to the safety of participants. This section addresses the interview technique aimed at facilitating the telling of the participant's story, and the following section will address the trauma informed response and safety protocols.

The interview protocol was designed to create a culturally safe space (Ramsden, 1990; Williams, 1999) in which Aboriginal and Torres Strait Islander people with disability could give their testimony on their terms and in their own time. The interview style and technique was consciously designed as a safe interviewing practice for research involving participants within populations that have experienced vulnerability and marginalisation. Taking a discrimination trauma aware approach reduced the risk of re-traumatisation of the participant potentiated by a structured or fixed interview approach. The interviews in this research were designed and conducted as non-invasive to the participant and deliberately non-prescriptive in anticipating how much time that an interview would take. This approach reinforced that their participation was voluntary, and the participants were able to recount as much or as little of their testimony as they chose.

Consistent with the trauma aware (Pittaway et al , 2010) and grounded approach for the research, an unstructured interview technique was utilised to enable participants to tell their story on their terms and at their own pace. As opposed to questions, five discussion prompts were woven into the interview to facilitate the telling of testimony. It commenced by asking a general question: “What is your story?”. This open-ended question was designed to situate the participant at the centre of the interview from the outset, rather than the researcher. The interview protocol then proceeded to prompt discussion of barriers, strengths and sources of personal support. It then concluded with a question around what mattered to the participant in regard to their future. In total, there were five discussion prompts that were used across all interviews:

1. What is your story?
2. What barriers and obstacles have you faced in getting the help you need?
3. Who do you turn to when you need help?
4. What are some of the good things you have been able to do? What keeps you strong?
5. What matters to you regarding your future?

Notably, the discussion prompts did not contain any reference to ‘disability’. Other than introducing the researcher as being from the First Peoples Disability Network, which set the general domain for discussion, references to ‘disability’ were otherwise avoided unless introduced into the discussion by the participant. This was consistent with one of the aims of the study that was to understand how Aboriginal and Torres Strait Islander people with disability intuitively identify with their disability.

5.3.9 *Safety protocols for trauma aware interviewing*

The degree of vulnerability experienced by the participant population necessitated protocols to be developed for trauma aware interviewing to assure the safety of both the participant and researcher conducting the interviews. Safety protocols (Attachment C) were developed by the researcher in consultation with community engagement staff at the First Peoples Disability Network which outlined the preparatory steps to reduce the risk of re-traumatisation of the participant. This included making sure a separate support person was available at all times during the interview, offering the participant a choice of someone that they would be comfortable with, and allowing the participant

to select the location and timing for the interview. These protocols prescribed stopping the interview if the safety of the participant was of concern, with an offer to resume the interview after a break or cease the interview completely. A decision to stop an interview happened with two participants, both of whom resumed after a short break.

5.3.10 *Data management*

Subject to participant consent, the interviews were recorded in audio format on a portable voice recorder. There were three interviews conducted in one remote Aboriginal community where the researcher did not seek to record the interviews, based on the advice of an Aboriginal community member who had said that recording the interviews in that particular instance may be taken as invasive and culturally inappropriate. In these three interviews, hand written notes were taken by an Aboriginal note-taker, who sat in on the interviews with the permission of the participants. In the remaining 38 interviews, permission to record the interviews was sought by the researcher and provided in all cases by the participants.

For the interviews with the Deadly Deaf Mob cohort that were conducted in Auslan, the interviews were recorded in video as well as audio format. This acted as a precaution in event that video images of the testimony provided in sign language would be needed to confirm the audio recordings during the transcription stage. As the transcriptions of audio recordings of the Auslan interviews were adequate, the video recordings were proved to be unnecessary and destroyed.

On completion of the interviews, the audio recordings were transcribed verbatim. The researcher then went through the raw transcripts to remove any attributes that might identify participants. During this process, peoples' names were converted to a gender identifier, place names were converted to a geographical identifier (metropolitan; regional; remote); and specific organisational or institutional names were converted to a higher order category (for example, an identified school name would be converted to 'Public School' or 'Private School'). The exception to the de-identification of attributes that were referenced by the participant during the interview was the retention of references to Aboriginal nations (for example, 'Worimi', or 'Wiradjuri') where the person lived or was born, as these names were asserted as a source of pride in the participant's identity and could not of themselves be used to identify any individual.

Once the raw interview transcripts were de-identified, the de-identified text was stored on a secure server at First Peoples Disability Network and imported into NVivo software for analysis of qualitative data.

5.3.11 *Analysis*

Once the de-identified testimonial data was imported into Nvivo software, it was subjected to a layered, iterative analysis. In the first iteration of the qualitative data analysis, a categorical screening of all testimonial was undertaken to determine the key theses and issues that were portrayed by the testimony. This screening categorised the issues within testimony into four overarching themes which were aligned to the research questions. The four core categories were:

- (i) Experiences that contextualised the prevalence, nature and self-identification of disability by Aboriginal and Torres Strait Islander people;
- (ii) Social inequality and barriers to accessing systemic supports and services;
- (iii) Exposures to discrimination and inequality and their impact upon mental health and trauma; and
- (iv) Cultural influences upon social participation and inclusion in community.

Once the core themes were established in the first iteration, a second iteration involved a deeper thematic analysis. This second iterative analysis provided a more thorough dissection of the core themes, as texts relating to a particular theme were collated from all texts for an analysis of key messages and issues. This analysis provided a more detailed description on the core themes identified in the first iteration, including on the types and nature of discrimination that were described in the testimony; issues relating to barriers in accessing services were organised into key policy domains. The testimonial data organised into these categories and themes are co-presented with the statistical data in the results section of this thesis from Chapter 6 to Chapter 9.

The Nvivo software also provided the capacity for detailed key word searching. This was particularly beneficial as it enabled key themes that were identified in the analysis to be illustrated using the exact words and context extracted from the participants' testimony.

5.3.12 *Creation of ‘yarning pieces’*

During the writing up of the analysis of the testimonial data, it became apparent that a categorical and thematic analytical approach alone could not fully convey a comprehensive narrative of Aboriginal and Torres Strait Islander peoples’ experiences of living with disability. One particularly obvious limitation in organising the data along thematic lines is the loss of the multi-faceted experience of disability, or how many issues and factors can combine and interact within a single person’s testimony. To counter this limitation, a number of vignettes were constructed from the testimonies and the researcher’s interview notes to illustrate the multi-faceted nature of disability and social inclusion for Aboriginal and Torres Strait Islander peoples. Drawing upon Aboriginal concepts of ‘yarning’, these vignettes were prepared and written as ‘yarning pieces’, reflecting the interview as a conversation between the participant and the researcher. These ‘yarning pieces’ complement the statistical data and testimony to become a third stream in the conceptual model of the narrative that was described in Section 4.4.

5.4 Research ethics review

The research was reviewed for ethics compliance and approved by four separate research ethics committees. As the research affected Aboriginal and Torres Strait Islander people, approval was required from the Aboriginal Health Research Ethics Committees in each of the three regional jurisdictions where the research was conducted. Once approval was obtained from each of the jurisdictional Aboriginal Health Research Committees, approval for research ethics was ratified by Human Research Ethics Committee at the University of Technology Sydney.

The ethics review process, required as a precursor to commencing the fieldwork, was variable in each of the jurisdictions where there are research sites. The first stage of the Aboriginal ethics review process is obtaining community consent. The community consent process, which is described in Section 5.3.3 above, was highly variable depending on the research site. In some cases, such as with the Deadly Deaf Mob, community consent was instantaneous; whereas in other areas, such as Central

Australia, it took many visits over a year to build trust before community consent was obtained.

Another issue affecting the progress of ethics approval was negotiating the requirements of the jurisdictional Aboriginal Health Research Ethics Committees. Compared to Aboriginal and Torres Strait Islander Health research, the quantum of disability focused research involving Aboriginal and Torres Strait Islander people is relatively sparse. Whilst each of the Aboriginal Health Research Committees strongly supported the community-directed approach, the ethical review processes were structured to be conducted through a health and medical focus, as their name suggests, and their previous exposure to reviewing disability research was not high. This led to occasional incompatibilities between the recommendations of the Ethics Committees and the principles of inclusion that underpinned this research. In one jurisdiction, an Aboriginal Health Research Ethics Committee had requested additional consent protocols to determine the capacity of people with disability to consent to participate in the interviews. As this requirement created an unnecessary additional barrier to the participation of people who had historically been subjected to exclusion from participating in research, it was deemed incompatible with the third value-based principle of the research which, as stated in Section 4.3, is that the research is to be inclusive of all people who wish to participate, subject only to their self-identification as a member of the First Peoples disability community. This incompatibility necessitated four months of direct negotiation with the relevant Ethics Committee before the unique circumstances of inclusive disability research were accepted, along with the level of experience of the researcher and host organisation within the disability community, enabling ethics approval to be granted.

The process of ethics approval from each of the relevant Human and Health Research Ethics Committees is detailed below:

- **New South Wales Aboriginal Health and Medical Research Council (Approval No: 1157/16):** Ethics approval for research in New South Wales was prioritised. As this is the domicile state of the researcher and host organisation's head office, this site is where the community consent process was furthest advanced. The ethics review process commenced in January 2016

with approval granted on 6 April 2016, with annual renewal over the duration of the project.

- **Central Northern Territory Aboriginal Research Ethics Committee**
(Approval No. HREC-16-435): The ethics proposal was submitted in August 2016 for research in the Barkly Shire and an Elders' Forum in Alice Springs. Provisional approval was provided on 10 November 2016 and following the provision of further information, final approval was granted on 19 April 2017. This approval also included Alice Springs as a contingent site for the Elder Forum.
- **South Australian Aboriginal Health Research Ethics Committee**
(Approval No: 04-16-693): An original ethics proposal was submitted in September 2016 for a second round of interviews involving the Deadly Deaf Mob, and one site in remote South Australia. However, on the basis of initial feedback, the Ethics Committee advised that the inclusion of a remote South Australian site was beyond the scope of what the research could achieve with the available resources. This advice was accepted, and the submission was refined to include interviews with Deadly Deaf Mob only. After some further negotiations regarding the study protocols, approval was granted on 8 June 2017.
- **The Human Research Ethics Committee at the University of Technology, Sydney** formally ratified the ethics approvals from the three Aboriginal Health Research Ethics Committees on 6 July 2017 (Approval No: ETH16-0966).

5.5 Community and technical review processes

In addition to the formal ethics review processes, the research also underwent separate informal community and technical review processes. These processes were built into the research governance, principally to ensure that the research was foremost accountable to the First Peoples disability community and culturally compatible to their values. The additional purpose of these processes was to establish validity and credibility of the research within a contested policy arena that complemented other

measures that were taken to address limitations of the research. The full suite of measures taken to ensure validity and credibility of the research is comprehensively described in Section 5.8.

These processes were implemented in the research by submitting preliminary results of the research to representatives from the First Peoples disability community, including the Board of Directors at First Peoples Disability Network. This community review process served three functions: first, to ensure that the language used in the research was culturally compatible; second, to ensure that the presentation of testimony could not be used to inadvertently identify any individual participant; and third, to critique whether an interpretation of the research could be used to the detriment to the participant group or the First Peoples disability community as a whole population. The initial step in the community review process was to ensure that the participants could be not inadvertently identified when presenting the research to the broader community. This involved the researcher manually removing all identifying markers from the participants' raw testimony. The researcher undertook a secondary review to ensure no participant could be identified once the thematic analysis was completed. Prior to its presentation at community forums, the researcher referred the outcomes of his review to a small group of Executive Staff within First Peoples Disability Network, all of whom were subject to confidentiality provisions, for an independent check. Once this group reviewed the analysis for cultural compatibility and securing the participants' privacy, the research was presentable as preliminary results to the broader First Peoples disability community in a form that facilitated their review and feedback. The research was then presented at various community forums during the course of the research, as listed in the Schedule of Research Impact in the preface of this thesis.

In addition to the community review, the statistical data underwent a technical review by representatives from the Australian Bureau of Statistics who acted as technical advisors in the co-production of statistical data. The statistical data were reviewed separately by the Centre of Excellence for Aboriginal and Torres Strait Islander Statistics which was responsible for the production of the NATSISS survey, and the Department of Disability and Carer Statistics which was responsible for the production of the SDAC. The technical advice provided by the Australian Bureau of Statistics was strictly limited to the technical accuracy of the extraction and presentation of statistical

data, and excluded advice and commentary in relation to the analysis of the statistical data.

As a final process of review, the research was reviewed by an Academic Advisory Panel which had been established by the researcher on behalf of the First Peoples Disability Network. The Academic Advisory Panel was established as a formal structure to invert traditional power relationships between the researcher and the researched (Hanley, 2005), from one where the community act as advisors to institutional-based researchers, and into a power relationship in which academic researchers provide their expertise to support community-based research. The Academic Advisory Panel comprised the researcher's thesis supervisory team, plus one Aboriginal researcher and two disability researchers. The Academic Advisory Panel operated to provide strategic guidance on positioning the research within government policy, as well as general advice on building the grounded community-based approach into a rigorous research methodology. As the Academic Advisory Panel acted in an advisory capacity only, all accountability for the research quality and findings resides solely with the researcher.

5.6 Reporting

5.6.1 *Concurrent reporting of qualitative and quantitative analysis by themes*

In applying a mixed methods approach (Leech and Onwuegbuzie; 2008; Creswell and Plano Clark, 2011; Bowers et al, 2013; Shorten and Smith, 2017) to reporting, the statistical data is co-presented with the testimonial data. The results are presented according to the four core categories identified in the initial analysis of the statistical and testimonial data. The four results chapters that follow this chapter are:

- Prevalence and profile of disability amongst the Aboriginal and Torres Strait Islander population (Chapter 6);
- Social inequality (Chapter 7) which also contains a deeper thematic analysis of inequality and access for the discrete policy domains of accessible community;

justice and personal safety; employment; and access to somatic and mental health services;

- Social isolation, discrimination and trauma (Chapter 8); and
- Cultural and community participation by Aboriginal and Torres Strait Islander people with disability (Chapter 9).

Each chapter initially presents the disaggregated statistical data specific to the Aboriginal and Torres Strait Islander population with disability. This is to convey the population-wide scope of the issue that is being addressed within that section of analysis. The qualitative data is then co-presented, using verbatim quotes from the participants' testimony to illustrate a thematic issue using the words and context provided by the participants. This thematically organised analysis is periodically punctuated with 'yarning pieces', which are the vignettes extracted from the testimony as a reminder to how many themes and issues that are discussed as discrete issues can come together within a single person's whole of life experience.

Embodying the principle of elevating and promoting the voices of Aboriginal and Torres Strait Islander people with disability, great care was exercised to preserve the participants' testimony in the exact manner as narrated by them. To avoid inadvertently altering the message and tone of the participants' testimony, the researcher refrained from editing the transcribed text of the interviews by paraphrasing, changing words or editing the syntax and grammar, other than for the removal of pauses and consecutively repeated words. The effect of this technique is to centralise the lived experience of Aboriginal and Torres Strait Islander people with disability when using testimony to illustrate concepts, undertake thematic analysis, and in the 'yarning pieces'.

The researcher then synthesised the quantitative data and the qualitative data with the conceptual framework presented in Chapter 3 to present a coherent narrative of inclusion and disability amongst Aboriginal and Torres Strait Islander people that is theoretically, methodologically, empirically and culturally attuned. Drawing from the researcher's publication *Culture is Inclusion*,

“The synergies between testimony, data and a culturally grounded analytic have taken the research from an exercise in statistical analysis to an immersive process of ‘data whispering’. The data speaks a story, has patterns and flows, much like dots on a painting speak to an artist, the topography of the landscape speaks to a tracker, or stars to a night-time navigator. Together with the spoken word, the statistics and the stories have fused to deliver a dynamic narrative of disability in Aboriginal and Torres Strait Islander communities.” (Avery, 2018, p 29).

5.6.2 *‘Real-time’ research translation*

Once the research commenced, it was soon evident that members of the participant group were experiencing undue suffering through their exposure to discrimination and social inequality. The gravity of their suffering witnessed first-hand by the researcher, and its impact upon the participant group’s social health and wellbeing, gave rise to a duty of care to disclose the findings in the public domain as they came to light. There is an accompanying ethical principle of ‘reciprocity’ in all research that has a particular significance in Aboriginal and Torres Strait Islander research (AIATSIS, 2012), that compels a researcher to give back to the Aboriginal and Torres Strait Islander communities who were involved in the research. The principle of reciprocity was particularly significant in this research, as it provided concepts and data to a marginalised community bereft of research to enable it to self-advocate for social reform. Being positioned within the community, the researcher felt these ethical obligations acutely. This sense of duty to the community led to a ‘real time’ research translation strategy, in which the research findings were progressively translated through advocacy and public policy engagements in ‘real time’, rather than waiting for the project to be concluded in its entirety. The real time research translation was effected through a number of formal policy engagements involving Government agencies, expert witness appearances at Government Inquiries and Royal Commissions, statements to United Nations Human Rights forums, and presentations at academic and community conferences. The list of these engagements is included in the Statement of Research Impact in the preface of this thesis.

In respect to published works, three original works by the researcher have contributed materially to the content of this thesis. The first publication is ‘Intersectional

Dimensions on the Right to Health for Indigenous Peoples – A Disability Perspective’ (Avery, 2016a). This was prepared for and cited by the United Nations Expert Mechanism on the Rights of Indigenous Peoples (EMRIP) in their study *Right to Health and Indigenous Peoples with a focus on Children and Youth* (United Nations Human Rights Council, 2016, p. 18). This publication introduced concepts on the intersectional impact of being an Indigenous person and having disability upon health and wellbeing that is expanded upon in Chapter 3 of this thesis.

The second publication is ‘The life trajectory for an Aboriginal and Torres Strait Islander person with disability’ (Avery, 2016b). This publication described a conceptual approach to understanding how the detrimental social and health effects of ‘intersectional inequality’ accumulate over the course of the life of an Aboriginal and Torres Strait Islander person with disability, and places them upon a ‘matriculation pathway to prison’. This conceptual model is described in Chapter 3 of this thesis, and revisited in relation to the research findings in Sections 7.4 and 10.3. This publication, published in manuscript format, has become a community resource for people working with young Aboriginal and Torres Strait Islander people interacting with the justice system. It further initiated a summons for the researcher to provide expert testimony on issues affecting young Aboriginal people with disability coming into contact with the justice system at the *Royal Commission into the Detention and Protection of Children in the Northern Territory* (2017).

The third publication is a research book *Culture is Inclusion: A Narrative of Aboriginal and Torres Strait Islander Peoples with Disability* (Avery, 2018), that has become a cornerstone publication from this research. This book was motivated by the principal aim of the research to give voice to Aboriginal and Torres Strait Islander people with disability by giving back to their community a resource that they can own and use in their self-advocacy for social change. In terms of its content, the book contains a precis of the methods which are described in more depth in this chapter, and collation of the research findings that are presented in the following chapters. Beyond a presentation of the research methods and findings, *Culture is Inclusion* seeks to apply the theories and learnings on power relativities and the influence of discourse addressed in Section 2.4, by generating a disruptive discourse that reclaims a focus on inclusion for people with disability based on Indigenous values and culture. Whilst its primary obligation was giving back to the First Peoples disability community, it has

engaged a broad range of stakeholders beyond the Aboriginal and Torres Strait Islander and disability sectors. The infusion of Aboriginal art and high resolution graphic imagery into the text and testimony makes *Culture is Inclusion* an appealing, if sometimes confronting, read for anyone who has an interest in how social justice is applied within Australian society.

5.7 Addressing criticisms of an emancipatory and participatory research approach

Before moving to how the limitations of the study were addressed, this section addresses criticisms of emancipatory and participatory methodologies. A common criticism of emancipatory and participatory research is that it lacks objectivity in contrast to positivist research approaches. This is referenced in the researcher's positionality statement in Chapter 2, when as a social policy researcher embedded in a non-government community organisation, he would encounter comments such as "you would say that" from those seeking to dismiss the research as invalid. Central to this criticism is that the politics of the disability rights movement become inseparable from the processes of research production, as argued most thoroughly in Danieli and Woodhams' critique of emancipatory research methodologies in the disability movement (Danieli & Woodhams, 2005). They argue that the pressures on a disability researcher to conform to a pre-determined assumption of a social model of disability coerce the research 'subject' to conform to the agenda of researcher, rather than authentically representing the views of the people with disability. They state: "Under the guise of objectivity and value neutrality, the ontological and epistemological assumptions of previous research on disability perpetuated a dominant understanding of disability which maintained the oppression of disabled people" (Danieli & Woodhams, 2005, p.282). They then argue there is an irony in that instead of emancipatory research becoming a means of legitimising the views of previously silenced disabled people, it can potentially become a means of silencing those whose views do not conform to those of the 'expert' researcher. (Danieli & Woodhams, 2005, p288).

In responding to these criticisms, there are no pretensions on the value neutrality of this study. The aim of this study is clearly stated as promoting the voices of Aboriginal

and Torres Strait Islander people with disability in research and policy. The community-based values of research are transparently articulated as the foundation of the research and have been carried through all stages of the research. It was principally motivated as a reaction to the institutionalisation of positivist methodologies in disability research that had silenced Aboriginal and Torres Strait Islander people with disability. The observations that came from within the First Peoples disability community at the commencement of this study were consistent with those of noted disability scholar Mike Oliver, when he wrote:

“Neither positivist nor interpretive paradigms are immune from the characterisation of research as alienation, and hence it is suggested that the only way to produce unalienated research is to change the social relations of research production. This change will require the development of an emancipatory research paradigm.” (Oliver, 1992, at p 101).

Stone and Priestley (1996) have proposed a set of principles against which the authenticity of emancipatory research can be judged (Stone and Priestley, 1996). Included within these principles are: the devolution of control over research production to ensure full accountability to disabled people and their organisations; the ability to give voice to the personal while endeavouring to collectivise the commonality of disabling experiences and barriers; and the willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people (Stone and Priestley, 1996, p 706). This study has met all these markers of authentic emancipatory and participatory research. Woodward and Hetley (2007) state that for ‘de-elitization’ of research to occur, researchers must “leave the laboratory to work with an oppressed or exploited community to identify a problem” (Woodward and Hetley, 2007, p103). Rather than seeing the researcher’s ‘insider’ positionality as a limitation of this study, having a deaf Aboriginal researcher doing research on Aboriginal and Torres Strait Islander disability located within an Indigenous Disabled Peoples Organisation represents as a pure a model of emancipatory disability research as can be conceived.

Nonetheless, this research can ultimately only speak to the testimony from the people who have participated in the study. Accordingly, it has been carefully positioned to present ‘a narrative’ of Aboriginal and Torres Strait Islander people with disability,

rather than ‘*the* narrative’ of Aboriginal and Torres Strait Islander people with disability. This is in recognition that there are many untold stories that this research could not capture. This research did not go into institutional care, such as prisons and out of home care, where many Aboriginal and Torres Strait Islander people are known to live. It did not directly access the voices of young Aboriginal and Torres Strait Islander people and children, although it did obtain testimony from parents of children with disability. It did not reach deep into people who were homeless, although there were references to homelessness in the testimony. These are the narratives of the even harder to reach population groups. That these stories were out of scope of this study is its major limitation.

5.8 Securing the validity of the research in response to limitations

5.8.1 *Limitations of non-randomised sampling*

As mentioned in Section 5.3, the scope of the study and the profile of a participant group who has experienced social isolation made randomised recruitment of participants impossible. Instead of a randomised approach to recruiting participants, the study utilised elements of purposive sampling (Patton, 1990; Suri, 2011) and convenience sampling (Etikan et al, 2016). As the purpose of the recruitment strategy was to generate personal testimony from a marginalised group for a narrative review, the risk to data quality through the recruitment methods used is low. Nonetheless, both purposive and convenience sampling carry a limitation of perceived bias, principally through the risk of self-selection by the participants. The validity of the research was secured through a number of strategies that included: reflexivity (Finlay, 2002); triangulation of various data types and sources (Guion et al, 2011); identification of disconfirming evidence; and academic, technical, community and peer review processes.

5.8.2 *Reflexivity*

Reflexivity refers to a systematic process of reflecting upon the context of the research as it affects the researcher (Finlay, 2002), including how their motives, values, beliefs, and experiences affect how the research is done and is presented. In this study, the researcher has been transparent in his motives in conducting this research and the social justice values and beliefs that have underpinned it. The notion of reflexivity, central to exercising Indigenous Standpoint Theory (Nakata, 1998, 2007; Rigney, 2000; Foley, 2003), and the researcher's statement of positionality in Chapter 2 that recurs throughout this thesis present this standpoint as a strength of the study rather than a position that requires defending.

5.8.3 *Poly-angulation of various data types and sources*

Poly-angulation, also referred to as 'triangulation' (Guion et al, 2011), was used as a strategy to cross-validate the analysis of the statistical data (quantitative data) and the testimony (qualitative data). This is reflected in the choice of a mixed methods approach (Leech and Onwuegbuzie; 2008; Creswell and Plano Clark, 2011; Bowers et al, 2013; Shorten and Smith, 2017) to data collection and presentation of the research findings.

The data collection involved multiple cross-validations, both within the type of data, and across the qualitative data and qualitative data (hence the choice of the term 'poly-angulation' in preference to 'triangulation'). The statistical data that was used was sourced from the Australian Government's official data collection agency. The statistical data was collected using a process that was separated from the process of collecting qualitative data undertaken by the researcher. There was also poly-angulation of the statistical data sources used for the quantitative analysis, namely a comparison of the NATSISS and the SDAC datasets, where the data collection methodologies were sufficiently aligned to allow this comparison. The description of the statistical data, their scope and limitations are presented in Section 5.2.6 above.

The statistical data and testimony are co-presented in the findings. In this way, the two data types cross-validate each other. The statistical data provides scoping of the

research problem that can be empirically measured, and the testimony provides an empirical context that explains it.

5.8.4 *Identifying disconfirming evidence*

The researcher made explicit attempts to identify and present evidences that might disconfirm theories or presumptions on the presence of social inequality and cultural inclusion that were the focus the study. There was large degree of convergence between and within the quantitative and qualitative data, and there were no aspects of the findings that could be regarded as contradictory that required reconciliation.

Nonetheless, there were a small number of examples where the evidence might be construed as disconfirming. These examples took the form of omissions from the testimony on issues where some narrative of them might be expected from the statistical result. This was evident in a general absence of testimony on the experiences of Aboriginal and Torres Strait Islander people with disability who have experienced imprisonment, and to a lesser degree testimony on the implementation of the National Disability Insurance Scheme. The finding on these issues are qualified appropriately and are identified as emerging areas for further research.

5.8.5 *Academic, technical, community, and peer review processes*

This study was conducted as doctoral research program, commencing at the University of New South Wales and concluding at the University of Technology Sydney. During this time, the researcher received ongoing review and guidance from an academic supervisory team and was subject to routine procedures of academic progress and review.

In addition to the formal academic procedures established to review the study as a doctoral program, the researcher initiated a multi-layered review process to secure the validity of the research within a policy and community environment. As the technical review process, the research forwarded the statistical methods and analysis to two specialist units at the Australian Bureau of Statistics. The two units were the National Centre of Excellence for Aboriginal and Torres Strait Islander Statistics who are data custodians of the NATSISS, and the Disability, Ageing, Carers and Mental Health

Section who are the data custodians of the SDAC. This review was to ensure that statistical data had been correctly extracted, presented and described. The methods and findings have also been formally reviewed by a group of government disability policy officers representing the Research and Data Working Group who administers the National Disability Research Development Scheme and who provided partial funding support to the First Peoples Disability Network for this research.

The research was also subjected to researcher ongoing community review. At the highest level of research accountability, this research reported into the Board of Directors at the First Peoples Disability Network, who are comprised entirely of Aboriginal and Torres Strait Islander people with disability. An academic perspective to community review was provided by an Academic Advisory Panel to the First Peoples Disability Network that comprised the researcher's supervisory team plus three additional research academics, one of whom is Aboriginal and two are from disability research. The Academic Advisory Panel operated separately from the academic supervision of the doctoral program. In addition to the formal engagements with the Board and Academic Advisory Panel of the First Peoples Disability Network, the research was progressively submitted to community review via a number of regular community and stakeholder engagements, as described in Section 5.5 and listed in the Statement of Research.

5.9 Concluding comments on research methods

This chapter has outlined how the created research methodology gave effect to a community-directed research epistemology. Whilst the research methods in this chapter have been structured in a way to aid their readability, the application of an uncompromising grounded approach meant that in practice, the sequence of events was far less linear and structured. This was particularly so as the research moved between the participant groups and their communities to ensure that they were participating all the way through, and that their assent was maintained.

As an outcome, this research has produced a research methodology that has taken the concepts of emancipatory research (Freire, 1970) to a vulnerable and marginalised community and operationalised them in their purest possible form. In doing so, this chapter and the preceding chapter presents a philosophy and method of research that

actively promotes participation of Aboriginal and Torres Strait Islander people with disability, using community processes to facilitate participation in a way that institutional approaches to research are unable to attain.

The thesis behind the thesis is how the First Peoples disability community and other vulnerable groups have warmly responded to an ethos in research that focusses on inclusion and participation. This is most notable within the response to *Culture is Inclusion*, the book which embodies the character of inclusive research. Since its release in July 2018, the reaction to *Culture is Inclusion* has been broad and abundant, with people from a diversity of backgrounds conveying an emotional connection to its tone, text and imagery. This response has invited a reimagining of what research impact means when a community that has been historically marginalised is provided a platform through authentic emancipatory and participatory research. This reimagining of research impact takes place in the discussion section in Chapter 10.

This thesis now moves from a description of the research methods used to a presentation of the findings that were generated by applying a grounded and participatory approach. These findings are presented over four chapters, aligned to each of the core issues that were identified in the categorical analysis described earlier in this chapter. The initial chapter on findings reverts to address the first question of this research with a presentation of statistical data and testimony relating to the prevalence and nature of disability.

6. RESULTS: Prevalence and profile of disability amongst the Aboriginal and Torres Strait Islander population

6.1 Introduction to the Results Chapters

This is the first of four chapters that address the results of the research conducted for this thesis. The quantitative and qualitative data presented in these chapters are derived from the mixed methods approach (Leech and Onwuegbuzie; 2008; Creswell and Plano Clark, 2011; Bowers et al, 2013; Shorten and Smith, 2017) outlined in Chapter 5. Quantitative and qualitative data are presented concurrently according to themes that are aligned to the four research questions outlined in Chapter 1. The results apply the conceptual model of ‘narrative’ that is presented in Chapter 4 by concurrently presenting statistical data with personal testimony within a thematic issue. This mixed methods approach to presenting the results enables a concurrent analysis of the scope of the issue that can be quantified as well as its qualitative impact. When interspersed with ‘yarning pieces’, the co-presentation of statistical data and testimony provides a cohesive narrative on the experiences of Aboriginal and Torres Strait Islander people with disability.

The following four chapters present the results from the research. The four chapters are separated into the following themes:

- Chapter 6 presents results on the prevalence and profile of disability amongst the Aboriginal and Torres Strait Islander population. These results directly address the first question of the research.
- Chapter 7 presents the results on social inequality experienced by Aboriginal and Torres Strait Islander people with disability compared to other population groups. These results provide the empirical evidence in support of the theoretical model of social inequality that was conceptualised in Chapter 3 in addressing the second question of the research.

- Chapter 8 details the experiences of Aboriginal and Torres Strait Islander people with disability to various forms of discrimination. These raw accounts of racism, ableism, and an intersectional form of discrimination provide a grounded understanding of underlying trauma when designing a participatory approach to research involving vulnerable populations, as captured by the third research question.
- Chapter 9 changes the tone of the results from a focus on inequality to a focus on equality and inclusion, specifically towards parity in the participation in community and cultural events by Aboriginal and Torres Strait Islander people with disability. The equal participation by Aboriginal and Torres Strait Islander people with disability in community and cultural activities is the sole categorical exception to their experience of social inequality and exclusion found elsewhere in the data. This finding is the foundation of a ‘cultural model of inclusion’ that is derived from Indigenous cultural beliefs and values, and that addresses the fourth question of the research.

6.2 Prevalence of disability amongst the Aboriginal and Torres Strait Islander population

The remainder of this chapter is devoted to the prevalence and nature of disability amongst the Aboriginal and Torres Strait Islander population. This was determined as a priority at the start of the research, on the commencing presumption that there was a general absence of data that could be used to support decision-making in policy. As the research progressed, it became clearer that data was available; it was just dispersed across multiple datasets and not configured to allow a disaggregated analysis of data specific to the population of Aboriginal and Torres Strait Islander people with disability.

As noted in the methods Section 52.4, there are two core datasets that are used to determine prevalence estimates of disability amongst the Aboriginal and Torres Strait Islander population. These are the National Aboriginal and Torres Strait Islander Social Survey (NATSISS), and the Survey of Disability Ageing and Carers (SDAC). Data from these datasets are first used to estimate the prevalence of disability and its

severity, and to produce a select number of descriptive statistics on the profile and nature of disability. Testimony is also included to contextualise the interpretation of the statistical data and its limitations, with a focus on the factors that might explain non-disclosure or an under-reporting of the prevalence of disability.

6.2.1 *Estimates on the number of Aboriginal and Torres Strait Islander people with disability*

Comparative estimates on the percentage of the Aboriginal and Torres Strait Islander people who self-report as having some disability from the NATSISS and SDAC datasets, referred to as the prevalence rate, is reported in Table 6.2.1 below:

Table 6.2.1: Estimates of the prevalence rate of disability amongst the Aboriginal and Torres Strait Islander population.

	NATSISS	SDAC
Percentage of Aboriginal and Torres Strait Islander population reporting as living with disability and/or long-term health condition	45%	
Percentage of Aboriginal and Torres Strait Islander population reporting as having some disability (without including long-term health conditions)		23.9%

Source: NATSISS (ABS, 2016a) and SDAC (ABS, 2016b)

Differences emerge between the NATSISS and SDAC in estimating the prevalence of some disability amongst Aboriginal and Torres Strait Islander people. Using the NATSISS data, 45% of Aboriginal and Torres Strait Islander people report living with a disability or long-term health condition, which compares to 23% of Aboriginal and Torres Strait Islander people reporting as living with a disability in the SDAC. The principal methodological difference contributing to the different prevalence measures between the two surveys is the recording of ‘long-term health conditions’ in the NATSISS, but not in the SDAC.

However, the differences in the scope of statistical data collected do not in themselves explain the discrepancy between the two surveys, and there is still an amount of

unexplained difference. Possible factors in the discrepancy between the NATSISS and the SDAC may include differences in how the questions are framed and interpreted by Aboriginal or Torres Strait Islander people in respect to the cultural and systemic factors; and the level of involvement that Aboriginal and Torres Strait Islander people have had in formulating the question and in collecting the data.

6.2.2 *Estimates on the prevalence of severe and profound disability amongst Aboriginal and Torres Strait Islander people*

Disability prevalence data can be further disaggregated for Aboriginal and Torres Strait Islander people with disability by severity of disability. The significance of these statistics is that the data definitions of severe and profound disability used by the Australian Bureau of Statistics align closely, but not exactly, to the eligibility criteria under which people with disability can access a personalised disability support package under the National Disability Insurance Scheme. The National Disability Insurance Scheme provides support packages to people with a severe and profound disability that meet the Scheme's disability requirements (*National Disability Insurance Scheme Act*, 2013, Section 24) including, but not limited to:

- (i) having a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments, or to one or more impairments attributable to a psychiatric condition (*National Disability Insurance Scheme Act*, 2013, Section 24(1)(a)); and
- (ii) is, or is likely to be, permanent (*National Disability Insurance Scheme Act*, 2013, Section 24(1)(b)); and
- (iii) results in a substantially reduced functional capacity and/or psychosocial functioning in undertaking on or more of the following areas: communication; social interaction; learning; mobility; self-care; or self-management (*National Disability Insurance Scheme Act*, 2013, Section 24(1)(c)).

Whilst the NDIS eligibility criteria does not expressly reference 'severe and profound' in relation to the disability requirements for accessing a support package, estimates of

Aboriginal and Torres Strait Islander people with severe and profound disability using the Australian Bureau of Statistics datasets serve as an independent population-based measure from which to model access to the National Disability Insurance Scheme by Aboriginal and Torres Strait Islander people. Further, as a ‘generative number’ in discourse, it is also consequential in generating deeper strategic policy discussion on the workforce and support systems that are required to meet the demand for disability supports by Aboriginal and Torres Strait Islander people.

Table 6.2.2 below reports the prevalence rate of severe and profound disability measured as a percentage of the Aboriginal and Torres Strait Islander population, and a relative ratio compared to the general Australian population. An estimate of the number of Aboriginal and Torres Strait Islander people with disability is also reported using the expected value formula defined in Section 5.2.5.

Table 6.2.2 Estimates of the prevalence rate of severe and profound disability amongst the Aboriginal and Torres Strait Islander population, relative ratios to the entire Australian population, and population estimates.

	NATSISS	SDAC
Percentage of Aboriginal and Torres Strait Islander population reporting as living with severe or profound disability	7.7%	7.3%
Ratio of severe and profound disability in the Aboriginal and Torres Strait Islander population compared to the Australian population	2.1 times	1.8 times
Estimated number of Aboriginal and Torres Strait Islander people reporting as having severe and profound disability	61,474	58,280

Source: NATSISS (ABS, 2016a) and SDAC (ABS, 2016b)

There is greater convergence between the NATSISS and the SDAC on the estimated rate of severe and profound disability amongst the Aboriginal and Torres Strait Islander population. The NATSISS found that 7.7% of Aboriginal and Torres Strait Islander people reported having severe and profound disability. This result compares to a prevalence rate of severe and profound disability of 7.3% of the Aboriginal and

Torres Strait Islander population using SDAC data. Using age-adjusted comparators, the SDAC and the NATSISS respectively estimate that the prevalence of disability is between 1.8 and 2.1 times the prevalence rate of severe and profound disability in the non-Indigenous Australian population. These relativities in the prevalence of disability for the Aboriginal and Torres Strait Islander population and non-Indigenous population have been age adjusted by the ABS to consider differences in the age composition of the two populations. This is illustrated by the material differences in the life expectancy between Aboriginal and Torres Strait Islander people and the rest of the Australian populations, with Aboriginal and Torres Strait Islander males experiencing 10.6 years shorter life expectancy compared to other Australian men, and Aboriginal and Torres Strait Islander women experiencing 9.5 years shorter life expectancy compared to other Australian women (ABS, 2013). The significance of this is that not only is disability more prevalent amongst Aboriginal and Torres Strait Islander people, the burden of disability is compressed into a shorter life.

The estimated Aboriginal and Torres Strait Islander population as at 30 June 2016 using 2016 Census data is 798,365 people (ABS, 2018). Based on this as an Aboriginal and Torres Strait Islander population estimate, the best available estimate of Aboriginal and Torres Strait Islander people with severe and profound disability is 61,474 people using the prevalence rate derived from the NATSISS, and 58,280 using the prevalence rate derived from the SDAC.

6.3 Profile of disability by disability type

Table 6.3 highlights the prevalence of disability by disability types that have been self-reported by Aboriginal and Torres Strait Islander people with severe and profound disability in the NATSISS dataset. Restating the limitations of the survey methods, these data present an indicative profile of disability by type in Aboriginal and Torres Strait Islander communities. Another indicator in the profile of disability amongst the Aboriginal and Torres Strait Islander population is the incidence of co-occurring disability, or the extent to which people are living with more than one disability type.

Table 6.3: Incidence of disability by type, and rate of co-occurring disability amongst Aboriginal and Torres Strait Islander people with severe and profound disability.

Disability type (Severe and profound disability)	Numbers (Australia)	% of Aboriginal and Torres Strait Islander population
Physical	27,800	6.2%
Sensory (sight, hearing, speech)	16,100	3.6%
Psychological	11,300	2.5%
Intellectual	11,200	2.5%
Head injury, stroke or brain damage	3,400	0.8%
Disability type not specified	16,200	3.6%
Number of disability types per person with severe and profound disability	2.5	

Source: NATSISS (ABS, 2016a). Note that the number of Aboriginal and Torres Strait Islander people with disability by type that is shown in column 2 reports estimates from the NATSISS. This method of estimation does not correlate exactly to the estimated incidence of disability by type when the estimated Aboriginal and Torres Strait Islander population from the Census is used as the denominator.

The most common category of disability reported by Aboriginal and Torres Strait Islander people is physical disability, which includes mobility impairments, experienced by 6.2% of the Aboriginal and Torres Strait Islander population. The second most commonly reported disability category was sensory impairment, reported by 3.6 % of the Aboriginal and Torres Strait Islander population. The sensory category of disability includes sight, hearing and speech impairments. Third on the list of most prevalent disability categories for people with severe and profound disability is psychological disability, reported by 2.5% of the Aboriginal and Torres Strait Islander population. The reported prevalence of severe and profound psychological disability equates to approximately one in three of all Aboriginal and Torres Strait Islander people with severe and profound disability. The effects of trauma that are generated through multiple exposures to social isolation that accumulate over the life of a person who is both Aboriginal and/or Torres Strait Islander and has disability are explored further in Chapter 8.

There are two notable issues that arise for a statistical profile of severe and profound disability amongst the Aboriginal and Torres Strait Islander population. The first is the extent of disability that is not specified by type; and the second is the extent to which people have co-occurring disability types. Both of these issues are discussed below.

6.4 Unspecified disability and access to disability diagnoses

In addition to specific disability categories, 3.6% of the Aboriginal and Torres Strait Islander population have been included in the category ‘other not specified’. To place the size of the ‘other not specified’ category in context, it is equal to second highest category of severe and profound disability by type. This relatively high rate of unspecified disability within the mix of disability types alludes to an issue whereby Aboriginal and Torres Strait Islander people can have difficulty in obtaining a diagnosis for their disability. This issue is uncovered through the personal testimony, which is co-presented here to aid the interpretation of this statistical data. The testimony from the research showed that people with disability are not clear on the role that having a specific diagnosis has in being able to accessing supports for disability. The distinction between ‘disability’ and ‘diagnosis’ within the communications and practices of disability services providers is not clear to Aboriginal and Torres Strait Islander people. Having a diagnosis for a disability is understood to be vital in driving the systems of support for a disability, and further, there is a concern if people with disability are in need of support and don’t have a diagnosis, they will fall through the cracks. This concern is expressed by a support person who attended an interview with one of the participants who did not have a diagnosis for her disability:

“The doctor hasn’t given her a diagnosis....They’re not even doing the tests. So, I wouldn’t know how to, myself, to get the help. You know, to get [her] diagnosed without costing a lot of money.” (Interview 11, metropolitan cohort).

Accessing a diagnosis is further complicated by living in a remote community, as pointed out by one of the participants, a mother speaking about her long battle to obtain a diagnosis for her daughter who is non-verbal, uses a wheelchair, and has profound disability:

[PARTICIPANT]: *“We was going to [the city, from a remote community] but I had to change because we was down there for about four years, travelling down there, and we been down there and they couldn’t tell me what she was diagnosed with. And so, all that time we were back and forward they couldn’t find right genes for her. And, so when we went to [a hospital in a different city] and then we made a big change. So, there was a bit of trouble getting a diagnosis in the start. They just didn’t know or they had it wrong. Well, she got all the tests done that many times in [the first city] and every time we go back they couldn’t find anything. And, they switching her, like, changing medication and so went to [the second city] and then she had scan done on her brain and changed her medication and slowed her seizures right down.*

[RESEARCHER]: *So, you’ve got a diagnosis now. Is that right?*

[PARTICIPANT]: *Yeah. But, I don’t know what [it is] - but I leave it all up to Doctor.”* (Interview 19, remote cohort).

6.4.1 *The incidence of co-occurring disability types*

For the purposes of this research, ‘co-occurring disability types’ refers to when a person with disability experiences more than one disability type. In other words, a person with a disability affecting their mobility may also have a sensory disability such as hearing or vision impairment, and/or have a cognitive disability, and/or a psychological disability. The concomitance of intellectual disability with mental illness is one form of co-occurring disability that has been noted in a number of studies (White et al, 2005; Morgan et al 2008; Dias et al 2013).

Amongst Aboriginal and Torres Strait Islander people with severe and profound disability, the rate of co-occurrence of disability types is on average 2.5 disability types per person with disability, as shown in Table 6.3. This means that every person experiencing one disability type will most likely have at least an additional one or two other disability types.

The co-occurrence of disability types is an important consideration in ensuring that support for people experiencing multiple disability types is adequate. If the focus of support is exclusively based upon a primary presenting disability, there is a risk that it may ‘overshadow’ the presence of a co-occurring disability types. This is a variant of ‘diagnostic overshadowing’, a term in used to describe an under-diagnosis of health needs because symptoms are attributed to a person’s disability rather than a serious illness (Jones et al, 2008; Mason and Scior, 2004; Katteri and Bywood P, 2011). ‘Diagnostic overshadowing’ is discussed further in reference to accessing health care in Section 7.7.2. In this extension to the concept of ‘over-shadowing’, the comprehensive needs of people with disability are under-diagnosed because a focus on one disability obscures the support requirements for other disabilities. Given the issues that Aboriginal and Torres Strait Islander people face in accessing even a primary disability diagnosis, there is a risk that co-occurring disability types will remain invisible in assessment of their need. As such, ‘overshadowing’ warrants further focussed exploration beyond what could be achieved through this research, with particular attention to the practices of assessing needs by disability specialists and service providers.

6.5 Disaggregating Aboriginal and Torres Strait Islander disability data by gender, remoteness, and their intersection

Whilst the principal objective of this research was to disaggregate statistical data for the population of Aboriginal and Torres Strait Islander people with disability, there is capacity for further disaggregation of statistical data by additional demographic attributes for deeper more nuanced analysis. As an example of the capacity for further disaggregation, this section disaggregates the Aboriginal and Torres Strait Islander disability data first by severity, gender and remoteness (Table 6.5.1), and then by intersecting gender and remoteness (Table 6.5.2).

The following table 6.5.1 reports data on the prevalence of disability by three disaggregated attributes. The first disaggregation is by severity of disability, separating statistical data for people with some disability or long-term health condition, and people with severe and profound disability. The second disaggregation separates statistical data by gender. The third disaggregation separates non-remote (metropolitan

and regional) areas, and remote areas of Australia. These three disaggregations are consolidated into Table 6.5.1 below:

Table 6.5.1: Percentage of the total Aboriginal and Torres Strait Islander population with disability, by severity, gender and remoteness.

By Gender		By Remoteness		TOTAL
Female	Male	Non-remote	Remote	
<i>Living with disability or restrictive long term health condition:</i>				
47.0%	42.9%	45.4%	44.0%	45.1%
<i>Severe or profound disability:</i>				
8.4%	7.1%	7.8%	7.5%	7.7%

Source: NATSISS (ABS, 2016a)

The prevalence of disability is higher among Aboriginal and Torres Strait Islander women (47.0% reporting living with disability, with 8.4% experiencing severe and profound disability) than Aboriginal and Torres Strait Islander men (42.9% reporting living with disability, and 7.1% experiencing severe and profound disability).

There are also differences in the reported prevalence by remoteness. 45.4% of all Aboriginal and Torres Strait Islander people living in non-remote areas (metropolitan and regional) reporting having some disability, and 7.8% report having severe and profound disability. The prevalence of disability in remote areas is slightly lower, with the prevalence of some disability 44.0% and severe and profound disability 7.5% among Aboriginal and Torres Strait Islander people living in remote locations.

An interesting observation is the relative prevalence when looking at the combined effect of gender and remoteness. The intersectional effect of gender and remoteness can be explored by an additional iteration of disaggregation. This statistical data is prioritised for Aboriginal and Torres Strait Islander people with severe and profound disability in Table 6.5.2 below:

Table 6.5.2: Percentage of the total Aboriginal and Torres Strait Islander population with disability severe and profound disability – Intersecting gender and remoteness

	Remote	Non-remote
Female	6.1 %	8.9 %
Male	9.2%	6.4%

Source: NATSISS (ABS, 2016a)

Among Aboriginal and Torres Strait Islander women living in remote communities, the reported prevalence of severe and profound disability is 6.1%. The reported prevalence for Aboriginal and Torres Strait Islander men is 9.2%, or 1.5 times the prevalence rate amongst women. However, when looking at the same statistics for non-remote areas, the result is the reversed. The reported prevalence of severe and profound disability among Aboriginal and Torres Strait Islander men living in non-remote areas is 6.4% of that population cohort, where the reported prevalence for Aboriginal and Torres Strait Islander women in non-remote areas is 8.9%, or 1.4 times the prevalence rate amongst men in non-remote areas. The potential significance of these results as they relate to the burden placed upon Aboriginal and Torres Strait Islander women to support people with disability in remote communities is considered in Chapter 10.

6.6 Concluding comments on statistical data on prevalence and profile of disability

Establishing baseline data on the prevalence and profile of disability in Aboriginal and Torres Strait Islander communities is the foundation step in supporting policy, decision-making and workforce development strategies that meet the demand for disability supports by Aboriginal and Torres Strait Islander people. The implementation of disability support policies that are built upon market-based assumptions logically requires rigour in scoping the size of the market. No government agency or research had previously undertaken a statistically-based scoping of the size of the Aboriginal and Torres Strait Islander disability market, which is why this objective was prioritised as the first research question. The statistical data on prevalence and profile of disability in the Aboriginal and Torres Strait Islander

population presented in this chapter, complemented by illustrative quotes from the testimony acting as an interpretive guide, is a core contribution of this research.

In addition to establishing a baseline prevalence and profile of disability amongst the Aboriginal and Torres Strait Islander population, the methods and processes used in disaggregating the statistical data open up potential for future development in data and research. One example of a future research possibility that is spawned from this research relates to Aboriginal and Torres Strait Islander women bearing the burden of providing informal disability supports in remote communities, as referenced in the above section and discussed further in Section 10.6.6. It also has broader potential beyond this research, and it sets a tested method for intersectional analysis that can be transported into research involving other vulnerable groups in society.

Having presented the results that address the first research question, the next chapter moves to the second research question, which is a presentation of statistical data and testimony on the social inequality experienced by Aboriginal and Torres Strait Islander people with disability across a range of social policy areas.

7. RESULTS: Social inequality

7.1 Introduction to the Chapter

This chapter presents the findings that address the second research question in relation to the social inequality experienced by Aboriginal and Torres Strait Islander people with disability. This chapter focusses on social inequality that occurs within policy areas that directly relate to the provision of systemic support. Due to the distinctly different quality of the participants' experience of social exclusion, inclusion, discrimination and trauma, the findings relevant to these issues are separated from social inequality in accessing systems of support, and will be covered in a dedicated chapter that follows.

The statistical data on social inequality is presented across a range of social policy areas. In the first section of this chapter, the statistical data is drawn from the NATSISS, SDAC and General Social Survey across a select range of social, health and wellbeing indicators to reveal a pattern of 'intersectional inequality' that is greater for Aboriginal and Torres Strait Islander people with disability compared to other population groups, including the Aboriginal and Torres Strait Islander people without disability, and people with disability who are not Aboriginal or Torres Strait Islander.

The analysis then uses the NATSISS data to further explore social inequality that Aboriginal and Torres Strait Islander people with severe and profound disability experience compared to other Aboriginal and Torres Strait Islander people without disability, across an extended range of social health and wellbeing indicators. The pattern in the data showing 'intersectional inequality' was repeated across every indicator of social health and wellbeing that was analysed, with one categorical exception.

The sole exception to the data showing 'intersectional inequality' was found in data on participation in cultural and community events, which showed a parity in participation by Aboriginal and Torres Strait Islander people with disability with other people. Given the significance of this finding of parity in the cultural participation by

Aboriginal and Torres Strait Islander people with disability, these results have been separated from this chapter and presented in a dedicated Chapter 9.

In this chapter the personal testimony of the personal experiences of social inequality take a prominent role. Whilst the statistical data shows inequality in social outcomes that can be measured, the testimony reveals an underlying social injustice that is fuelled by prejudice, institutionalised discrimination, and the subconscious indifference of support systems and those with the decision-making power in operating them. The testimony from Aboriginal and Torres Strait Islander people with disability reveals that they can encounter racism, ableism and ‘intersectional discrimination’ across every aspect of their social engagement. This chapter focuses on the systemic forces that are factors in their social isolation, which should be read alongside the evidence of personal exposures to discrimination that are covered in the following chapter.

7.2 Patterns in the data – ‘intersectional inequality’

This section compares selected social, health and wellbeing outcomes from Aboriginal and Torres Strait Islander people with disability against other population groups. The data is sourced from the NATSISS and the General Social Survey. The NATSISS produces population-wide data on social, health and wellbeing outcomes for Aboriginal and Torres Strait Islander people, which can be disaggregated by disability status. To enable a comparison with the social, health and wellbeing of other Australians, selected indicators are compared to responses in the General Social Survey, which is a sample survey of the entire Australian population.

In Table 7.2 below, there are five population sub-groups where the selected social, health and wellbeing indicators are compared. The sub-groups are categorised to enable an analysis of the effect of intersectionality on social, health and wellbeing outcomes. This is achieved by progressively disaggregating the whole of population data (Group i); first by disaggregating by disability status (Group ii) *or* Aboriginal and Torres Strait Islander without disability status (Group iii); then by intersecting disability with Aboriginal and Torres Strait Islander status for people without severe and profound disability (Group iv) and with severe and profound disability (Group v). This is to demonstrate an escalation in social inequality as additional dimensions of

marginalisation are introduced into the analysis, starting with people without disability and progressing step-wise to conclude at Aboriginal and Torres Strait Islander people with severe and profound disability. The five population groups in cascading order are:

- Group (i): The general population that does not have disability³;
- Group (ii): People with disability; (which may include Aboriginal and Torres Strait Islander people with disability within the data collection source);
- Group (iii): Aboriginal and Torres Strait Islander people who do not have disability;
- Group (iv): People who are both Aboriginal or Torres Strait Islander and living with disability that is *not* severe and profound; and
- Group (v): People who are both Aboriginal or Torres Strait Islander and living with severe and profound disability.

There were five indicators where social, health and wellbeing outcomes in the General Social Survey and the NATSISS aligned and could be compared across the five population groups using this process of disaggregation. These indicators were:

- Indicator 1: Self-assessed health as excellent/very good;
- Indicator 2: Had problems accessing health care services;
- Indicator 3: Experienced one or more stressors;
- Indicator 4: Feelings of safety walking alone in local area after dark; and
- Indicator 5: Participation in the labour force.

³ Due to the configuration of the data this sub-group may include Aboriginal and Torres Strait Islander people without disability within the data collection source. As Aboriginal and Torres Strait Islander people constitute less than 3%, of the total respondents to the General Social Survey, it is not materially significant to affect the statistical outcomes for general population without disability.

Table 7.2: Percentage of population experiencing selected social, health and economic outcomes, by population group.

INDICATOR	Percentage of population experiencing outcome				
	Group (i): General population without disability	Group (ii): People living with disability	Group (iii): Aboriginal and Torres Strait Islander people without disability	Group (iv): Aboriginal and Torres Strait Islander people living with disability that is not severe and profound	Group (v): Aboriginal and Torres Strait Islander people living with severe and profound disability
Self-assessed health as excellent/very good	69.0%	32.0%	53.4%	22.9%	13.9%
Had problems accessing health care services	2.8%	11.4%	11.3%	19.5%	27.0%
Experienced one or more stressors	59.2%	69.8%	62.6%	75.3%	82.7%
Feelings of safety walking alone in local area after dark	55.9%	43.9%	58.6%	47.5%	37.5%
Participation in the labour force	83.0%	53.0%	68.1%	51.8%	31.1%

Source: The GSS (ABS, 2014) is used as the data source for the general population (group i) and people with disability (group ii). The NATSISS (ABS, 2016a) is used as the data source for: (iii) Aboriginal and Torres Strait Islander people with no disability (group iii), Aboriginal and Torres Strait Islander people living with disability (group iv), and Aboriginal and Torres Strait Islander people and with severe and profound disability (group v).

There is a pattern in the data that illustrates ‘intersectional inequality’ across all of the indicators. This is demonstrated by an escalation of social inequality as intersecting dimensions are added to the categorisation of the sub-groups:

- (i) As discrete population sub-groups, Aboriginal and Torres Strait Islander people, and people with disability, experience greater inequality in their social and health outcomes compared to the general population of Australians living without disability.
- (ii) When the Aboriginal and Torres Strait Islander group is intersected with the people with disability group, the resultant subgroup of Aboriginal and Torres Strait Islander people with disability that is *not* severe and profound are shown to experience greater inequality in their social, health and wellbeing outcomes when compared to both Aboriginal and Torres Strait Islander people without disability, and people with disability who are not Aboriginal and Torres Strait Islander.
- (iii) When severity of disability is then added as an intersectional dimension in the categorisation of the subgroups, the resultant sub-group, Aboriginal and Torres Strait Islander people *with* severe and profound disability, experience greater inequality in social, health and economic outcomes than Aboriginal and Torres Strait Islander people with disability that is *not* severe and profound.

Three types of social inequality have been created for this study to explain the effect of intersectionality in the comparative analysis of social health and wellbeing outcomes across the five population groups. The three types of social inequality that have been created in this analysis are developed from the concepts of intersectionality and ‘intersectional discrimination’ that were introduced in Chapter 2. They are:

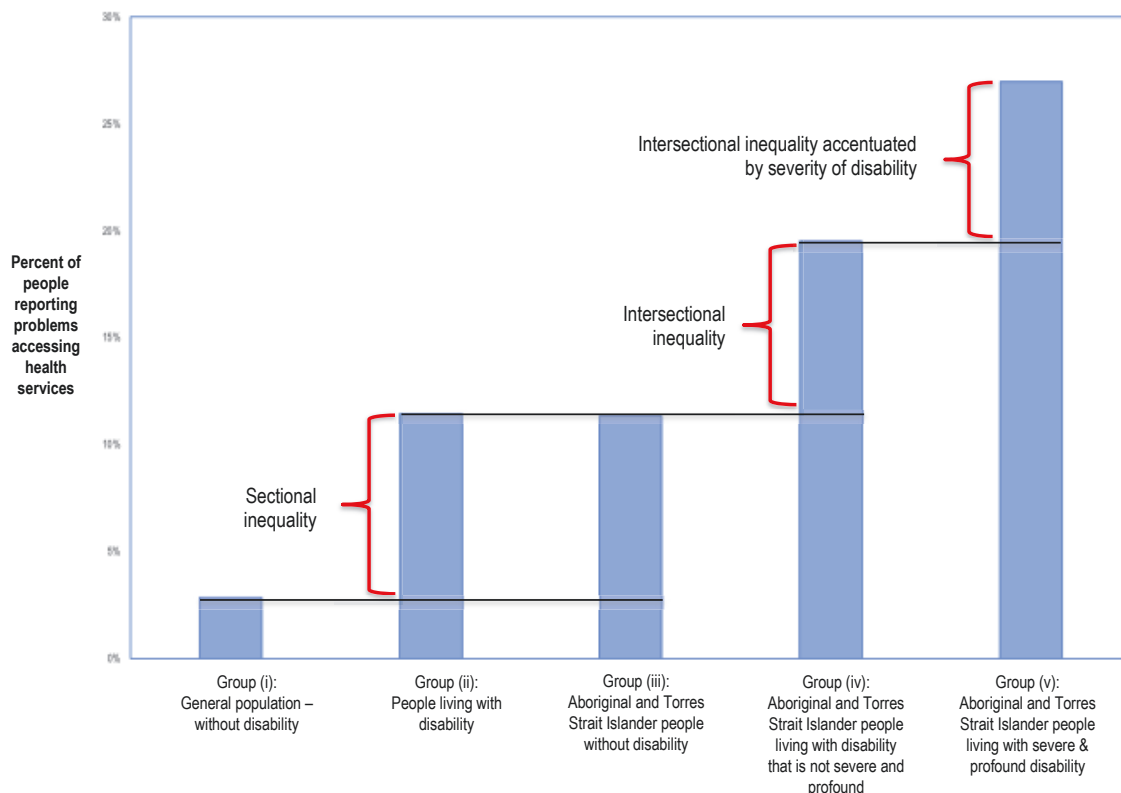
‘Sectional inequality’: This is inequality that affects the *one* marginalised group as a discrete population, i.e. the population of people living with disability (group ii), and Aboriginal and Torres Strait Islander people without disability (group iii). This is referred to as ‘sectional inequality’ to provide a point of contrast to ‘intersectional inequality’.

‘Intersectional inequality’: This is the compounding of inequality that affects those people who are members of two marginalised groups, i.e. people who are Aboriginal and Torres Strait Islander *and* live with disability (group iv).

‘Intersectional inequality’ accentuated by severity of disability: Separating populations who report having any disability (group iv) and people reporting severe and profound disability (group v) recognises that disability exists on a spectrum, and hence highlights how the severity of disability can further accentuate ‘intersectional inequality’.

The clearest example of ‘intersectional inequality’ presented in Table 7.2 relates to problems demonstrated in the outcome measure for accessing health services. The question asked by this indicator is ‘do you have problems accessing health care services?’. The responses relating to each of the five population groupings is represented diagrammatically in Diagram 7.2 below. Moving from left to right in this diagram, the far left column are outcomes for the general population; the next two columns are outcomes for population of people with disability and the Aboriginal and Torres Strait Islander populations respectively; and the next column shows outcomes for Aboriginal and Torres Strait Islander people with disability that is not severe and profound as an intersecting subgroup; and the final column on the far right shows outcomes for Aboriginal and Torres Strait Islander people with disability that is severe and profound. The escalating social inequality for this outcome indicator using the descriptors of ‘sectional inequality’, ‘intersectional inequality’, and ‘intersectional inequality accentuated by severity of disability’ is annotated in the diagram.

Diagram 7.2: Sectional inequality, ‘intersectional inequality’, and ‘intersectional inequality’ accentuated by severity of disability in accessing health care services.



Data sources: GSS (ABS, 2014), NATSISS (ABS, 2016a)

The data demonstrates that there is an intersectional effect to the social inequality that is experienced by Aboriginal and Torres Strait Islander people with disability when compared to other population groups, including Aboriginal and Torres Strait Islander people without disability, and people with disability, as discrete population groups. In addressing the second aim of this research, this result adds empirical weight to the theory of intersectionality and cascading disempowerment presented in earlier chapters.

The remainder of the chapter is a deeper exploration of social inequality that exists *within* the Aboriginal and Torres Strait Islander population. These findings will demonstrate that the finding of ‘intersectional inequality’ experienced by Aboriginal and Torres Strait Islander people with disability holds across a larger set of social indicators. These sections will introduce the participants’ testimony and yarning pieces to provide a human context to the statistical representation of social inequality.

The following sections use the NATSISS as the exclusive source for statistical data that allows this deeper analysis. The social, health and wellbeing indicators are organised according to the following social policy themes:

- (i) Inequality in accessible communities, including housing, the provision of fit for purpose disability aids, and transport;
- (ii) Inequality in justice and personal safety;
- (iii) Inequality in access to education;
- (iv) Inequality in gaining employment;
- (v) Inequality in access to health services; and
- (vi) Emerging issues of inequality in accessing the National Disability Insurance Scheme.

To aid cohesive reading, there is some interpretation on the findings and their implications for the relevant policy domain under each section. Later, in chapter 10, the patterns in the data and implications across all policy domains will be brought together with findings presented in other chapters for a broader discussion of the core findings and implications of the research program as a whole.

7.3 Inequality in accessible communities

A consistent and critical issue raised by participants included the barriers that Aboriginal and Torres Strait Islander people face to mobility in their communities due to limitations of the physical environment in which they lived. Beyond the functional requirement of being able to get from point A to point B, mobility was conveyed as central to independence, and barriers to their mobility that required them to rely on others to get around eroded their sense of self-worth. Issues around personal mobility were condensed into three main topics: first, housing that is inaccessible for people with disability; second, disability support aids that are not fit for purpose within the environment in which they are used; and third, a lack of access to disability accessible transport. Specific issues within each of these topics are presented below.

As a note on the statistical data, neither the NATSISS or the SDAC collect statistical data on access to public infrastructure or the physical environment that Aboriginal and Torres Strait Islander people with disability are living in. As an example, the SDAC includes a question of the respondent “Can you walk up and down stairs without a handrail?” (ABS, 2016c, p.139). However, the survey does not record deficits in the physical environment to provide insights into why the stairs are there in the first place. The exclusive focus on the person within these survey instruments unconnected to the environment limits the analytical capacity that can be obtained from the statistical data.

7.3.1 *Disability accessible housing*

Accessible housing was raised as a major issue for participants in the interviews, with 10 of the 47 participants referencing it as an issue. There was a broad range of topics raised within the theme of inaccessible housing: from disability access, to housing affordability and experiences in and access to social housing. Housing that was not accessible for people with disability was particularly evident in remote areas, emerging in the testimony and visually apparent during fieldwork. One participant described their difficulty in getting accessible housing or modifications for disabled people, suggesting that providers of remote housing viewed disability access as an afterthought, or possibly a wilful oversight:

“It’s disgusting how the working party, how our housing company is treating these disability people in their homes. You’ve got her son can’t get no help, you’ve got another man who –, he’s got to walk up steps and he’s nervous because there’s no rail for him to get into his house, there’s no rails for him to hang onto in the bathroom.” (Interview 16, remote cohort).

The picture below⁴ illustrates the issues of disability accessible housing in remote communities. Taken in a very remote community, this picture shows the entrance to a house which had recently been built as part of a remote housing project. The occupants said that they had been on a waiting list for seven years before the house was built, and were not consulted during its construction. What is shown below is a steel ledge,

⁴ This picture was taken with the express permission from the community.

approximately five centimetres high, at the main entrance to the house. The occupants said that when people with disability visit, they have to lift them over the ledge so they can come into the house.



Another of the participants who uses a wheelchair said that she was living in an apartment with standard height shelves that she could not reach. There was also a raised ledge at the entrance which made it difficult for her to enter. The participant said that she had been asking for some time for modifications to her home within the National Disability Insurance Scheme but had not heard back from them about her requirement for accessible housing.

The most acute form of inaccessible housing that emerged was the increased likelihood that Aboriginal and Torres Strait Islander people with disability will experience homelessness. The statistical data from the NATSISS shows an intersectional effect, whereby Aboriginal and Torres Strait Islander people with severe and profound disability as a marginalised subgroup within a marginalised group have reported experiencing homelessness (41% of respondents) at a rate 1.9 times that of Aboriginal and Torres Strait Islander people without disability (22% of respondents).

A number of participants spoke of experiencing homelessness or a direct threat of homelessness, although they did not necessary describe it directly in those terms. One

participant, a deaf Aboriginal woman, spoke of difficulties in finding housing when she moved to a city area to better access other services:

“In [other cities], there’s lots of Aboriginal organisations whereas in [the city I live in] the access is limited. When I came here, I couldn’t get a house here, because here the [Housing organisation] have merged with – like, single mothers or abused mothers, deaf, disability, it’s all in one. So, there’s a ten-year waiting list to get a home. I had nowhere to stay. So, [my female friend] she’s bought her home, so luckily she allowed me to stay with her, and she doesn’t mind me living with her until I can get a home.” (Interview 35, Deadly Deaf Mob cohort).

Another participant from a remote area described his current living situation as ‘living rough’ in a town camp, unable to secure any form of housing:

“We tried [talking with someone about getting housing]. We tried. Nothing happened. It’s just overcrowding what existing houses are there. There was some houses bought, [a person from the Government] bought those houses, didn’t they? But, they never connected them up. They’re just sitting there in a paddock.” (Interview 25, remote cohort)

The participant also addressed the psychosocial dimension of living in a place you can call your own. This was evident in the way that the participants preferenced the word ‘home’ over ‘housing’. When one person who said that they were ‘living rough’ was asked what having a house would mean to him, he replied:

“I want to go home. That’s all.” (Interview 25, remote cohort).

7.3.2 *Disability aids that are not suitable in the environment*

A second issue that participants described as a significant barrier to their independent living was the provision of disability aids that were not suitable within the physical environment in which they were being used.

One consistent observation over the course of the research were wheelchairs that were not suitable for use in remote Aboriginal communities. The following photograph taken in a remote community⁵ is emblematic of this problem. It shows a ‘standard issue’ foldable, light and portable wheelchair that is designed for use in an urban environment where there are footpaths. The same wheelchair ceases to be suitable when used a different physical environment, in this case a remote environment where there is extreme heat and no footpaths. In this photo, rubber wheels have melted off due to heat and dirt, making it completely unusable in the environment where it had been assigned.



The photo above was not an isolated observation of a broken and unusable wheelchair. One of the participants had travelled to the Elders’ Forum with a manual wheelchair. It

⁵ This picture was taken with the express permission of the community.

had broken at the seat support which made it rub against the wheel, requiring such physical exertion to make the wheelchair function that people had to take turns to push her. At another remote site, one participant said she lived in a house that had an unsealed road. Whilst only a few streets from the Town Centre, she reported rarely going into town or too far from home as she was concerned that that if the wheelchair broke down, she would be stranded without any means of transport at all (Interview 37, remote cohort).

Indeed, it was rare for the researcher to see a fully functioning wheelchair in any remote communities visited. In one remote community, a ‘graveyard’ of discarded wheelchairs was the only outwardly visible sign of people with mobility impairment living in that community. Discarded broken wheelchairs coupled with a lack of fit for purpose disability support structures such as ramps testified that for people living in remote communities who rely on wheelchairs, the lack of suitable and well maintained chairs leaves them isolated within their own homes.

7.3.3 *Transport*

A third core barrier to mobility and independence consistently raised by participants was a lack of accessible transport. In addition to the functional barriers to personal mobility and independence, inaccessible transport triggered secondary access barriers, such as in getting to school, getting to a job interview, or getting to medical appointments. As one participant described:

“Transport is another failure because there’s no transport to get to hospital and appointments, because if you go to your local doctor and you get a referral to go to the Women’s and Children’s [hospital]. I had my grandson, nobody could transport me, so I had to get up at four o’clock in the morning, catch a bus to Women’s and Children’s to have an MRI, you know.” (Participant, Elders Forum).

Another participant living in a remote site said that transport was a major problem for wheelchair users, and that there was only one disability accessible taxi in the region where she lived:

“Well, there isn’t much transport here. There’s only one taxi. And, it’s only going till like, morning, till six o’clock in the afternoon. Which, isn’t really right at all. You know? Like, other people that walk everywhere or push themselves, yeah.” (Interview 33, remote cohort).

When asked how she gets around, she captured a lifetime’s experience in three words:

“I push everywhere.” (Interview 33, remote cohort).

Much like housing, transport has both a functional dimension and a psychosocial dimension. Whilst there is a practical requirement for people with disability to get from point A to point B, the ability to do so without being made to feel a burden is a vital aspect of a person with disability’s sense of independence. This is where promoting and providing inclusive transport can be as significant as the logistical aspects of transport, and the testimony of one participant pointed to Australian airlines as poor performers in this regard:

“So, with some of the barriers that I’ve met would be with just, say, one to tick off would be transport and a couple of years ago I flew with [an airline]. And, they – their whole disability policy, which my wife went through to make sure that we knew what steps were in place. Then we went through the whole system of going to the airport... that was blown out of the water. Nothing was in place. There was no transfer equipment. The people didn’t know how to use it properly.

“They took apart my chair completely when it hadn’t ever been taken apart before, and when I got to [the city] I had to put the whole thing back together. And, just the whole experience with the crew on board was negative and – and especially then when we come back to [the city] and had a really rude altercation with one of the [airline] staff because we couldn’t find my wheelchair and the lady was going off at my wife, which brought her to tears. And, we ended up eventually finding my wheelchair that was, not in pieces, but it wasn’t right. So, we had to sort of put it back together.” (Interview 8, metropolitan cohort).

Taken together, inaccessible housing, unsuitable disability aids and inaccessible transport highlight the role that public infrastructure has upon a person's social, health and wellbeing status. Simply put, people with disability can't go to school, can't go to work, and can't access health care if they can't get there. As the following sections will move on to address inequality as expressed by person-centred outcomes in justice, education, employment and health, the findings in this section are a reminder of the role that structure has as an underlying co-occurring factor in social inequality. The implications for Australian social policy that adequate public infrastructure is essential in enabling personal agency are discussed in greater depth in Chapter 10.

7.4 Inequality in justice and personal safety

7.4.1 *Exposure to threatened or actual violence*

The most distressing aspect of social inequality as reported by the participants was their testimonies on their exposures to violence or threats to their personal safety. The gravity of the incidents reported, as well as the regularity by which they came up in the testimonies revealed a depth of underlying trauma in the lives of Aboriginal and Torres Strait Islander people.

Exposure to violence, sometimes occasioning a violent death, by themselves, a close family member or friend, was reported in 22% of all participant interviews (9 of the 41 interviews). The nature of violent and traumatic incidents that participants provided testimony on included: references to close family members who had been murdered or "lost" (Interviews 13; 16 and 18); women speaking to their difficulties in accessing respite services to escape gender-based violence (Interview 35); being subjected to a violent attack with a weapon (Interview 23); deaths by suicide (Interviews 5 and 41); a young child dying due to medical neglect (Interview 18); and an extensive and detailed account of sexual assault and being exploited by a human trafficking ring (Interview

12).⁶ There is a clear gender bias in the reporting of violence and traumatic incidents, at least in respect to the person providing the testimony, as 7 of the 9 accounts were made by women.

At this point it is worth remembering that participants were not directly asked whether they had been exposed to violence. These incidents were voluntarily disclosed by the participants in response to a general invitation to share their life story.

The statistical data collected by the NATSISS does not allow for comparison with groups outside the Aboriginal and Torres Strait Islander population, but it does confirm that disability has an intersectional effect on social inequality within the Aboriginal and Torres Strait Islander population. The data shows that Aboriginal and Torres Strait Islander people with severe and profound disability are approximately twice as likely as Aboriginal and Torres Strait Islander people without disability to have been either threatened with or exposed to violence within the past year. The comparative personal safety indicators are presented in Table 7.4.1 below:

Table 7.4.1: Personal safety indicators Aboriginal and Torres Strait Islander people – by disability status

INDICATOR	Aboriginal and Torres Strait Islander people		
	With severe and profound disability	Without disability	Rate (x times likely)
Experienced threatened violence in past year	25%	14%	1.8
Experienced physical violence in past year	19%	11%	1.7
Felt safe at home	71%	87%	0.8

Source: NATSISS (ABS, 2016a).

⁶ The details of these incidents have been redacted from what was provided in the testimony. This is an ethical safeguard to the privacy of the participants, and to reduce the risk of retraumatizing Aboriginal and Torres Strait Islander people who might read this thesis.

7.4.2 *Imprisonment of Aboriginal and Torres Strait Islander with disability*

Another targeted social justice issue that received prominence during the research was the high rates of imprisonment of Aboriginal and Torres Strait Islander people with disability. Over the course of the research, the researcher provided expert witness testimony to a United Nations Committee on Australia's adherence to the Convention Against Torture, a Senate Committee into the Indefinite Detention of People with Cognitive Impairment, and the Royal Commission into the Protection and Detention of Children in the Northern Territory. This involved providing statements on a life trajectory of disadvantage that is experienced by young Aboriginal and Torres Strait Islander people with disability at points in their life leading up to their imprisonment. This life trajectory, referred to by the researcher as 'a matriculation pathway into prison', is discussed further in Section 10.3.1 within the context of the theory and evidence of intersectionality.

As the NATSISS and SDAC are surveys that are confined to private households, and hence exclude people who are currently in detention or other forms of institutional care, intersectional statistical data on Aboriginal and Torres Strait Islander people with disability in detention was not available from the data sources used in this study. Outside the data used in this study, the ABS publishes data from the National Prisoner Census which includes data on demographic and legal characteristics of prisoners such as age, sex, country of birth, Indigenous status, legal status, prior imprisonment, most serious offence/charge and length of sentence being served. The most recent report, *Prisoners in Australia* (ABS, 2017b) shows that incarceration rate for Aboriginal and Torres Strait Islander people was 2,434 prisoners per 100,000 of the Aboriginal and Torres Strait Islander population. By comparison the imprisonment rate for other Australians was 160 prisoners per 100,000 non-Indigenous population. As data on disability is not reported, it is not possible to quantify the intersectional impact of disability upon the rate of imprisonment of Aboriginal and Torres Strait Islander people using the national data set.

Outside this study, a 2015 report entitled *A predictable and preventable path: Aboriginal and Torres Strait Islander people with mental health and cognitive disabilities in the Criminal Justice System* provided an account on the over-representation of Aboriginal and Torres Strait Islander people in detention (Baldry et

al, 2015). There is also jurisdictional data from New South Wales on the health and wellbeing status of people in the juvenile justice system shows that the prevalence of complex disability and poly-victimisation is higher amongst young Aboriginal people compared to other young people,. This is illustrated by the following summary statistics from the *2015 Young People in Custody Health Survey* (Justice Health and Forensic Mental Health Network NSW, 2017):

- 54.2% of young people in juvenile detention are Aboriginal or Torres Strait Islander, which is 24 times the likelihood of being in detention compared to young people who are not Aboriginal (p.11);
- Of young Aboriginal people in juvenile detention, 23.8% scored extremely low on the tests used to assess intellectual ability. A further 39.6% of young Aboriginal people in juvenile detention were assessed as being in a borderline range between extremely low and average intellectual ability (Table 148, p.81);
- 87% of young Aboriginal people in juvenile detention met the threshold criteria for at least one psychological disorder, and 69% met the criteria for two or more (Table 117, p.65);
- 29.8% of young Aboriginal people in juvenile detention had a past head injury resulting in loss of consciousness. Females are also more than twice as likely than males to have sustained a head injury, with 52.6% of young women compared to 22.5% of young men (Figure 25, p.42); and
- 66.0% of young Aboriginal people in juvenile detention reported experiencing at least one form of childhood abuse or neglect (Figure 36, p.74), with more than one-quarter (26.0%) experiencing some form of severe abuse or neglect (Figure 37, p.74).

Given the statistical data on the prevalence of Aboriginal and Torres Strait Islander people with disability having experienced imprisonment, the testimony on this topic was relatively under-represented. Within this study, one participant referred to being placed in detention (Interview 12), and another participant mentioned a family member who had spent time in prison (Interview 23). One explanation for the possible under-

representation of testimony relating to the imprisonment of Aboriginal and Torres Strait Islander people with disability is that whilst the methods of this research facilitated testimony from a ‘hard to reach’ population group, Aboriginal and Torres Strait Islander people with disability who have experienced imprisonment may be an even ‘harder to reach’ population group to be reached through a more targeted research approach that uses nuanced participatory research methods. This is a consideration for further research that is discussed in Section 10.6.6.

7.5 Inequality in access to education

This section presents the findings in relation to ‘intersectional inequality’ in educational outcomes experienced by Aboriginal and Torres Strait Islander people with disability. The main finding on educational inequality is that whilst Aboriginal and Torres Strait Islander people with disability expressed strong aspirations for their ongoing participation in education, their aspirations for educational advancement are unfulfilled.

Education was cited as an important factor in the life journey of the participants in the research, with 36 of the 41 interviews (88%) including some reference to ‘school’. Further, 23 of the interviews (56%) indicated some current or previous experience with the higher education system, with 14 participants making some reference to ‘University’ education (34%), and 16 participants making some reference to either ‘College’ or ‘TAFE’, which is an acronym for colleges of Technical and Further Education (39%). These reflected high levels of participation in the education system by the participant group. The aspirations for ongoing education are further reflected in extracts from the testimony, which include the following comments from two of the participants:

“There’s one thing I want to do before I leave this earth is to have my degree in human rights law and then I’ll be happy with that.” (Interview 1, metropolitan cohort).

“I’m studying social welfare and psychology at [University] and my main goal is to go on and do neuroscience and be able to become a neuroplastician and work in that field.” (Interview 41, metropolitan cohort).

On the other hand, inequality in educational outcomes are reflected in statistical data that shows that Aboriginal and Torres Strait Islander people with disability attain half the level of attainment of Aboriginal and Torres Strait Islander people without disability when the indicator is expressed positively (i.e. that they achieve a certain level of attainment), or twice the level of non-attainment when the outcome is expressed negatively (i.e. that they did not achieve a certain level of attainment). The comparative educational outcomes are presented in Table 7.5 below:

Table 7.5: Education indicators, Aboriginal and Torres Strait Islander people – by disability status

INDICATOR	Aboriginal and Torres Strait Islander people		
	With severe and profound disability	Without disability	Rate (x times likely)
Currently studying	14%	25%	0.6
Certificate III qualification or higher	19%	34%	0.6
Educational attainment below Yr 10	42%	18%	2.3

Source: NATSISS (ABS, 2016a)

Note that school age children were not interviewed as they were outside the selection criteria. As the voices of school age children are not present in the research, there is a strong possibility that there is some understatement in the testimony on the issues around education. However, there were some interviews with parents of Aboriginal children with disability. One participant drew attention to the sectional approach of providing programs are based on selecting educational support based on the child’s need as either an Aboriginal and Torres Strait Islander child or a child with disability, but not both. The impact of ignoring the intersectional needs of an Aboriginal or

Torres Strait Islander child with disability is captured in the following yarning piece featuring an Aboriginal mother of a child with disability.

Yarning piece – “Its all about the boxes”

She is a mother of two children, the eldest of whom has Autism. When it came to getting support for her eldest child at school, she starts to describe how she was compelled to choose between which aspect of support to prioritise – Aboriginal and/or Torres Strait Islander; or ‘special needs’. This ‘choice’ was presented via a selection of boxes she had to tick, which she assumed to would drive how much targeted support funding the school would receive.

“And, you know, I was filling out the school form and it came to the, ‘Do you identify as an Aboriginal Torres Strait Islander person? Please tick this box.’ ‘Does your child have any special needs?’ And, I thought, well, this is going to go two ways. I’m going to tick that Aboriginal box and they’re going to focus on that. And, I’m going to tick that Autism box and then they’re going to focus on that. Which one are they going to prioritise?”

“I made the decision that I would prioritise [my child’s] Autism and – do you know what I mean? Like, that was a really hard decision for me. Because, I’ve always identified [as being Aboriginal] and, you know, that’s our heritage.

“I had to pick a box... I just felt if I focus on this they’re going to focus on that and then he’s going to become a statistic and at the exclusion of the other. So, if I pick this box and not that box they’ll focus on the autism and not the other part. And, if I did it the other way that’s all they would focus on.

“So, I made that choice. And, it was probably the wrong choice at the time. But, you know, I was so scared for [my child] to go into school in general and my experience with the education system down the track is that Aboriginal students are, you know, sort of, put into a group and, sort of, excluded and, you know, the way they manage it is they might not even have an achievement. But,

every week they go to the principal with some sort of work that they've done and they're removed from the class and put in a special group and that's how they're treated."

She then explained how things got further complicated when her second child started school:

"And, the question came up with Aboriginality again when [my second child] enrolled. Because, of course I ticked the box [identifying as Aboriginal]. I'm, like, yes, that's who we are. Tick the box. Don't even think twice about it."

At this point, her description of the how the educational support system works descended into a farce.

"And, then [the school] questioned [my first child's] parentage. Whether there was the same father. You know, how they were related. If [my first child] was not Aboriginal and [my second child] was Aboriginal. So, then I was called up to the school and I had to give an explanation... So, I explained to them and I said, "Look, this is why I did it." So, the box got ticked again and everybody was happy. Because, if there's a box to tick everybody's happy."

"It's all about the boxes. See, if there's no box to tick everything falls apart."

(Interview 30, metropolitan cohort)

7.5.1 *Interrupted pathways in further education*

There were consistent messages drawn from participants' testimonies which isolate some of the factors that contribute to educational inequality. The first of the thematic messages related to an interrupted educational pathway that is experienced by Aboriginal and Torres Strait Islander people in progressing their studies.

A number of participants described their educational pathway as being built in piecemeal blocks, rather than as a continuous pathway of matriculation. The piecemeal blocks were punctuated by large absences from study, typically a result of excess demands of managing their disability concurrently with managing the demands of study. Some of the reasons that participants cited for suspending their study included: problems with transport; disability access on campus; access to Auslan interpreters (Deadly Deaf Mob cohort); and a lack of support for mental health issues (Interview 28). Two participants mentioned that they had managed to complete a succession of certificate level qualifications, as this was a mode of education that could be managed within the physical and logistical demands of their disability (Interviews 8 and 27, metropolitan cohort). Another participant said:

“I’ve always started courses. I never finish them. No, I didn’t finish the first course I was doing.” (Interview 1, metropolitan cohort).

Later in the interview, the participant disclosed that the reason she did not complete their first course at University was because she suddenly acquired a profound disability mid-way through completing her degree, and the combined physical and psychological trauma of acquiring this disability caused her to withdraw from her studies. After a number of years, she had attempted to resume her studies, but having had the flow of her educational pathway interrupted by acquiring a disability, her subsequent attempts to re-enter the University system have faltered.

7.5.2 *Customised supports for individual learning requirements*

A second factor that emerged from the testimony as contributing to educational outcomes for Aboriginal and Torres Strait Islander people with disability was in the timely provision of support that is customised for the students’ personal needs.

There were examples of good practices in learning support that were provided by the participants who had undertaken further study. As the nature of disabilities and hence needs for learning support are diverse, an effective practice that was described by the participants was to establish clear lines of communication between a dedicated support unit and the student to establish their specific support needs, and have the support in place prior to the commencement of studies:

“So, education has been really good because I did my Cert 4 and I had scribes put in place which was really helpful. I’ve only got limited wrist control but I can read a text book but I’m really slow at opening the pages. So, I’d have a scribe in place going through text books, opening up the books, highlighting passages, when the teacher’s going through the notes. And, that’s in TAFE. It’s supposed to be a lot harder in university, I’ve been told, to obtain scribes.”
(Interview 8, metropolitan cohort)

Whilst it might appear obvious that having support in place prior to the commencement will improve outcomes, it is not always the case that Aboriginal and Torres Strait Islander students with disability know who to go to for their cultural support and/or get support for their disability. This was identified as a particular barrier for students commencing study at large complex institutions. This can cause them to fall behind in their academic work from their commencement and may progress to their withdrawal from studies.

One gap in support that emerged through the testimony is support for students with mental health conditions. Whilst it was mentioned that access for students with physical disabilities was a focal point of disability support units in educational institutions, issues of access for students with psychosocial disability have not been fully integrated. One participant spoke of the impact a mental health condition, which is episodic and requires periods of hospitalisation, has had on her capacity to complete her academic studies and the unavailability of support within the institution:

“Staying at university has been really hard for me, in terms of keeping up with assignments and, in the beginning, there was lack of support at the uni, in terms of mental health support. Like, I find that they have a disability centre, but it’s not really catered to people with mental illness.” (Interview 28)

7.5.3 *Additional educational barriers experienced by Deaf Aboriginal and Torres Strait Islander people*

Within the participant group, the Deadly Deaf Mob (Deaf Aboriginal people) were highly vocal on their attitudes to and aspirations for ongoing education. Education was the dominant issue raised by the Deadly Deaf Mob participants, with every one of the participants interviewed citing their experience of being a Deaf person learning in a hearing world.

In addition to the themes referenced above that were raised by the general participant group, three additional issues emerged that were specific to the Deadly Deaf Mob's educational experiences. The first issue is the transitory nature of accessing education, with people having to shift around from school to school, and often going from one school with a Deaf pedagogy which promoted sign language to the next school with different pedagogy that favoured verbal education. Difficulties in accessing specific Deaf education, particularly (but not limited to) in non-metropolitan areas meant whole families had to move:

"Mum moved to [the city] because of my education, because of the barriers that I had out in the country, because there were no resources out there that were available." (Interview 4, Deadly Deaf Mob cohort).

The second issue was access to Auslan interpreters. Access to interpreters is not universal, yet as the two contrasting experiences show, is pivotal to the educational experience of Deaf students:

"I had a hard time in my education because I was in a mainstream school and in that period I didn't have any interpreters available for my education. I didn't have a support worker. So, my – my English – my written English is okay, but it's not the best, you know, it's not at that standard that it should be at." (Interview 40, Deadly Deaf Mob cohort).

"I had a good experience, I didn't miss out on anything, I had an interpreter. The teachers were hearing and I had an interpreter, so I had a really positive experience." (Interview 39, Deadly Deaf Mob cohort).

As is the case with many other needs of people with disability, it is family and community who bear the load of compensating for a lack of interpreter services through systems:

“I’ve got a brother and a sister and my eldest brother who was always my interpreter, I grew up with him, he’s four years older than me, he always interpreted to me.” (Interview 4, Deadly Deaf Mob cohort).

The third theme from the Deadly Deaf mob is their strong desire to learn more about their own Aboriginal cultural heritage. They described an approach to their education which was dedicated to making them proficient learners in a western hearing world. However, a general lack of access to Auslan within Aboriginal and Torres Strait Islander communities has left them isolated from the depth of cultural knowledge that is taught to hearing Aboriginal and Torres Strait Islander people. This has left them with a sense of longing for further cultural learning. This point is expanded upon further in the presentation of results on community and cultural participation in Chapter 9.

7.6 Inequality in gaining employment

The statistical data and testimony on inequality in employment experienced by Aboriginal and Torres Strait Islander people with disability conveys a remarkably similar pattern to the educational inequality found and described in the section immediately above. As in education, whilst Aboriginal and Torres Strait Islander people with disability expressed strong aspirations for gaining employment, their aspirations of becoming employed are unfulfilled.

Again, whilst the NATSISS data did not allow for comparisons with groups outside the Aboriginal and Torres Strait Islander population, the data on education outcomes shows that as a marginalised group within a marginalised population, Aboriginal and Torres Strait Islander people with severe and profound disability are almost twice as likely as Aboriginal and Torres Strait Islander people without disability to be unemployed (1.8 times), and half as likely to participate in employment (0.5 times).

The actual employment rate for Aboriginal Torres Strait Islander people with disability drops below one-third the rate of Aboriginal and Torres Strait Islander people without disability.

Table 7.6: Education indicators, Aboriginal and Torres Strait Islander people – by disability status.

INDICATOR	Aboriginal and Torres Strait Islander people		
	With severe and profound disability	Without disability	Rate (x times likely)
Participation rate	31%	68%	0.5
Employment rate	19%	55%	0.3
Unemployment rate	34%	19%	1.8

Source: NATSISS (ABS, 2016a)

The testimonies reflected the unfulfilled aspirations for employment held by the participant group. 24 of the 41 participants (58.5%) referenced ‘jobs’ during their interview, and the overwhelming majority of their testimony centred on their inability to get them. Whilst the statistical data on employment inequality compares closely to educational inequality, what distinguishes the testimony on the two issues is the heightened presence of institutionalised prejudice as a factor in employment inequality, and the emotional toll that being continually being rejected for employment had on the participants. This was predominantly expressed by the participants as a disability story, more than it related to being an Aboriginal and Torres Strait Islander person. This is illustrated through the frustration of a Deaf Aboriginal man on the arrogance of being rejected from his dream job as a flight steward because he is Deaf:

“I’ve applied for [a major Australian airline] as a [flight steward] and so I asked, you know – I got an interpreter in to help me fill out the forms and – so, we sent that off. And, it failed. And – because, I only had one issue and that was the – the inability to hear. So – and, that’s the problem. You must be able

to hear to work on the planes. And, it really pissed me off. You know, I can do that. I know – I know I can do that. I’ve travelled all over the place. I’ve been overseas continuously. I’ve travelled all over the world. And, I thought to myself, you know what? I would like to work for [the airline]. And, you know, that was my dream and that’s what I wanted to do and I couldn’t do it. It was only because I’m deaf and I couldn’t hear.

“So, you know what job I’m doing now? I’m working as a cleaner.”

(Interview 2, Deadly Deaf Mob cohort)

The pattern of ableist prejudice among prospective employers was found to have a cumulative dehumanising impact upon the participants. Whilst participants spoke of being exposed to other forms of systemic and personal discrimination, as detailed in the following chapter, the sense of unfairness that was felt in their inability to acquire gainful employment was particularly dis-spiriting for the participants. The psychological impact of being excluded from jobs because of a disability was eloquently told in a yarning piece on a young Torres Strait Islander women who has cerebral palsy and can’t get ‘a normal job’.

Yarning piece – Not fitting ‘the brand’

I had met this person through a friend of a friend, in early 2016 not long after we had started the research program, and before commencing interviews. When we first met, she told me that she couldn’t get any of the “Westfield type jobs” as when she turned up for an interview, she would be told that she “didn’t fit their brand”. Hearing this, and the sheer arrogance that some big brand employers show people with disability leaves me with white-knuckled fury. I made a mental note to follow up down the track to ask whether she would be prepared to go on record and be interviewed for the research.

By the time of the interview, just over a year after we first met, I already knew much of her background. I know of her disability diagnosis, although she doesn’t mention it once during the recorded interview. Growing up in an urban area, she is young,

currently at University, and comes across as softly spoken and highly intelligent. The thing that I notice most is how extremely polite she is.

“I grew up with a lot of, kind of, discrimination due to my disability, but not only that, within my high school, because I was of Torres Strait Islander descent, I actually got extra support. So the other students would get jealous in a sense that I would get extra support, and they would kind of discriminate against the group of us that were Indigenous.”

During her high school, being ‘Indigenous’ was more a label than an identity. Things started to change at University.

“Up until then, I didn’t understand why I was getting extra support. And, like, what it meant to be Indigenous. I didn’t really understand until I actually got to Uni, actually did a subject on Indigenous studies... and I kind of got to connect with other people that were Indigenous.”

She tells me that she entered University through a pathway scheme for Indigenous students, and that she has a private tutor who is sponsored by the Uni.

“With my disability, I obviously face a lot of barriers, especially with getting a job. That is a big one. The employment side of things is a big obstacle in the way that, like, I can’t get a normal job at Maccas for example, because if I was to work at a check out what they would need to do is put a chair there for me to sit on. But they don’t like to make these alterations. So it is hard for me to get a job, and for people to look past, get to know the ‘who I am’, instead of looking at the disability.”

The stigmas and false assumptions that other people hold about her and her disability are a constant source of frustration for her. In her case, there is the conflation of her physical disability with intellectual impairment.

“Because I’ve got a physical disability, [people assume] that I must be intellectually impaired. So when I tell them, no, I actually go to University and

actually work [in a policy research support role]... they actually get quite shocked.”

She gives an example of an experience she has had at the employment agency that has her on its books.

“I had an interview with this one agency and this was just to see if I was going to work with them or not. And the person that was actually interviewing me talked to my mum instead of me because she thought that I couldn’t communicate. And mum was like ‘She can talk. You don’t need to talk to me. She’s fully capable of communicating.’”

“Just a horrible experience”, as she describes it, it is one example of many in her life. She is yet to meet an agency, or a person in an agency, who has helped her find a job. It has soured her view on whether employment agencies will ever be able to help her.

“They are amazing at helping you fill out a resume and all that sort of stuff. But when it actually come to finding you a job they can’t do it.”

Her education experience, at least at University, appears in contrast with her attempts at getting some work. Despite the occasional hiccups, usually due to a lack of communication, her education experiences “*have actually been great*”. She gets a regular disability service plan with exam adjustments, and has access to a participation assistant which helps out. She is doing two degrees, and her goal is to become a neuroplastician and a researcher in neuroscience. I jot down a note to look up what a neuroplastician does when we’re done with the interview.

The discussion comes back again to employment. The inability for “*people to actually look past the disability*” is clearly dispiriting for her. Her current casual job has irregular hours, and she would like to be able to get some extra money in.

“I would just love to get a normal job, like a check out chick... All I would need is a chair. Like, just to put those little minor alterations in place so I could do the job... Just get to know me, instead of judging what is on the outside.”

What keeps her strong is converting her lived experience of disability into resilience and a source of motivation.

“What keeps me strong is knowing that I can use my personal experiences to make a difference to the world, to inspire others, no matter how small... Just use all my negative experiences and hardships and turn them into positive. That’s what keeps me going.”

She describes her greatest achievement as getting a casual job where the wisdom of her experiences are valued.

“I was just over the moon when I was accepted to work, so empowered that I’m able to make a difference and educate people.”

(Interview 41, metropolitan cohort)

Many participants indicated that they had undertaken study or a training course in order to improve their employment prospects, but this had not advanced their long-term employment prospects.

“So when I finished school I went to TAFE and studied hairdressing. And that was a one year apprenticeship. And there were so many barriers. I thought it would be fantastic. But – no. The whole industry and the area was full of people who can hear. So I know how to cut and shampoo and do everything. But everyone was hearing and they all spoke, so we had to communicate through writing and paper...”

“I did love that job but ended up leaving.” (Interview 2, Deadly Deaf Mob cohort).

Whilst the people involved in the study uniformly expressed their desire to participate in employment, they also conveyed the high expectations of them. In some instances, the high expectations were self-imposed, typically born from a previous bad

experience in which their skills and qualifications were belittled. Regardless of whether the high expectations were internally or externally imposed, an undercurrent filtered through the narrative that people with disability are constantly having to prove themselves in the workplace in a way that is over and above what is required of people without disability.

“I thought to myself, you know, if I do something completely different, like, move to another city, go to school, you know, try and get a good job or whatever, you know, get involved in TAFE and study and finish year 12 and achieve those goals, and then people would you know, give me the credibility and say ‘Wow, you can do it.’ I’m in my fourteenth job now since I’ve come to [the city]. And, I’ve always been successful in finding jobs and – and, now I – I’m doing a traineeship and I’m getting more and more confident, I’m learning more, I’m going out to do lots of courses and training and – and, especially events.” (Interview 3, Deadly Deaf Mob cohort).

Over time, some participants described a regressive pathway by which the cycle of having to prove themselves yet being rejected for employment descended to despondency. The repetitive nature of this cycle meant that some participants came to expect to be discriminated against when seeking employment:

“It’s difficult to get jobs. And, that’s the main issue. And, it’s difficult to get accepted in main stream societies. And, a lot of people with – who are wheelchair bound have a – found it difficult to get into employment and they still can’t – there’s a lot of them still having problems with disabilities with employment. And, being accepted. Then the other disadvantage is if you’re an Aboriginal person – well, my experience was that if you’re an Aboriginal person you can’t get a job... I was brought up during the old racist Australia days and the white Australia policy and all of that. And, that’s another disadvantage. Trying to make your way in that world.” (Interview 7, metropolitan cohort).

On one hand Aboriginal and Torres Strait Islander people are expressing their desire to advance themselves through education and employment, on the other they are subject to simplistic policy discourses stressing personal agency, sloganised into ‘capacity

building' which supports people to 'go to school and get a job'. The clear message coming from the research is that Aboriginal and Torres Strait Islander people with disability are willing and able to go to school and get a job, but they can't gain or sustain regular employment because of barriers which are both physical and attitudinal. Herein lies the danger in reductionist policy discourse. Policy discourses centering on 'capacity building' target people in what behavioural change theorists might describe as the precontemplative stage of change (Prochaska and Velicer, 1997). They are short and sharp messages, aimed at motivating people who are currently unmotivated in changing their behaviour with a short, sharp call to action (i.e. 'upskill yourself, go to school and get a job'). The issue is that this assessment is not supported by the reality of trying to find secure employment, misreading where people are at in the sense of personal motivation. The participants in this study were shown to have moved beyond the precontemplative stage and are motivated. Furthermore, in failing to acknowledge the core structural impediments in securing employment, motivational discourses paradoxically become acutely de-motivating, as its effect is to fuel the negative stigmatisation for those who can't secure employment.

7.6.1 *'Apprehended discrimination' as a pathway from fear of discrimination to avoidance*

The testimony on employment inequality resonated with the First Peoples disability community when presented to them as part of the community review process. After a presentation for a group of Aboriginal people with visual impairment, an Aboriginal Elder who was blind came to the researcher saying how much that he could relate to the issues of employment, and further saying that he did not apply for jobs when he expected or he "knew" that he would be discriminated against. One such example was his response to job advertisements for customer relations type jobs, many of which included a requirement of having a driver's licence as standard requirement of the job. He said that whilst he saw himself as well qualified and had relevant work experience to do such roles, he said that he didn't have and could never have a driver's licence, so he never applied for jobs including that requirements as he saw it as an excuse to discriminate against him because of his blindness (Community consultation, metropolitan area).

Whilst this example was volunteered to the researcher within a community review context (and hence outside the methods used to collect testimony from participants), it nonetheless provides insights into the psyche of vulnerable people who are repeatedly discriminated against in the employment market. The finding of employment inequality and an observed pathway from a conceptual finding of ‘apprehended discrimination’, a concept which is elaborated upon further in Chapter 8. The concept of ‘apprehended discrimination’ is devised to describe the pathway by which Aboriginal and Torres Strait Islander people with disability move from intuitively fearing discrimination, to rationally expecting to be discriminated against, and ultimately avoiding altogether situations where they might be discriminated against.

7.6.2 *Implications of employment inequality for public policy - ‘It’s about the job giver’*

Improving employment prospects are stated public policy aims under the Australian Government strategies for *Closing the Gap Framework* (Coalition of Australian Governments, 2007) as policy relates to Aboriginal and Torres Strait Islander people, and the *National Disability Strategy* (Coalition of Australian Governments, 2010) as policy relates to people with disability. However, outcomes data on employment shows that the intersectional impact of disability on outcomes for Aboriginal and Torres Strait Islander people have not been adequately addressed in either strategy. There is a dominance of employment programs that are bundled under the euphemism ‘capacity-building’. On the assumption that ‘capacity’ is where the problem lies, they target the upskilling of the job-seeker. By contrast, little consideration is paid to the prejudices of the job-giver as a factor in employment inequality. The compelling testimonial evidence in this section points to prejudice and discrimination as a major source of the problem.

7.7 Inequality in access to health and health services

7.7.1 *Access and the psychosomatic dimensions of health care*

There are multiple dimensions to Aboriginal and Torres Strait Islander health and wellbeing. ‘Health’ as defined from an Aboriginal and Torres Strait Islander

perspective focuses not only on physical health but also encompasses spiritual, cultural, emotional and social wellbeing (Burke et al, 2018; Salmon et al, 2018). 'Health' is more than the absence of sickness (World Health Organization, 1978; National Aboriginal Health Strategy Working Party, 1989); it is the relationship with family and community providing a sense of belonging and a connectedness with the environment. The participants' testimony reflected the interchange between physical, community and spiritual health. Given the breadth in the scope of what 'health' means to Aboriginal and Torres Strait Islander people, this section focuses on access to health services, particularly in relation to somatic health care. Issues of trauma, mental health and psychosocial disability were so pervasive that they warranted a dedicated discussion in Chapter 8 which follows.

In many respects, health status is where the impact of discrimination and inequality in other aspects of life materialise. Life expectancy data for Aboriginal and Torres Strait Islander people is not disaggregated by disability status, so the statistics on self-assessed health status are the best available summary proxy for the overall quality of health experienced by Aboriginal and Torres Strait Islander people with disability. It is here in health that the inequalities experienced by Aboriginal and Torres Strait Islander people with disability are at their starkest.

Table 7.7.1 below shows the main health indicators collected by the NATSISS. Approximately one in seven Aboriginal and Torres Strait Islander people with severe and profound disability assesses their health as excellent or very good (14%). By comparison, approximately one in two Aboriginal and Torres Strait Islander people without disability assess their health as excellent or very good (53%). As a further comparison, the General Social Survey data shows that people without disability in Australian population self-assess their health as being excellent or very good at a rate of more than two in three (69%). Based on this data, the likelihood that an Aboriginal and Torres Strait Islander person with severe and profound disability would assess their health as excellent or very good is one-fifth as likely as someone in the general population assessing themselves as having health which is excellent or very good.

Table 7.7.1: Health status and access indicators, Aboriginal and Torres Strait Islander people – by disability status,

INDICATOR	Aboriginal and Torres Strait Islander people		
	With severe and profound disability	Without disability	Rate (x times likely)
Self-assessed health as excellent or very good	14%	53%	0.3
Serious illness within past 12 months	26%	8%	3.3
Difficulty in accessing health services	27%	11%	2.5
Trust in own doctor	76%	82%	0.9
Trust in hospital	54%	70%	0.8

Source: NATSISS (ABS, 2016a)

The statistical data on accessing health care in Table 7.7.1 shows that Aboriginal and Torres Strait Islander people with disability are 3.3 times more likely than Aboriginal people without disability to have a serious illness. They also experience difficulty in accessing health care services at 2.5 times the rate of Aboriginal and Torres Strait Islander people without disability. It is not clear whether this is because of the high frequency of trips to a health care provider (i.e. high frequency of health care visits means there are more opportunities for something to go wrong), or despite it (i.e. whilst high frequency of visits means there are more opportunities to get things right) or if there is some other significant factor which is an impediment to access.

Trust is the other psychosomatic variable in the provision of health care. Aboriginal and Torres Strait Islander people with disability have trust in their own doctor at a slightly lower rate than other Aboriginal and Torres Strait Islander people (76% compared to 82%), with a greater gap in the comparative levels of trust when it comes to hospitals (54% compared to 70%). On balance the participants in the research spoke about their relationship with their personal doctor casually, although there was one

participant for whom a trusting relationship with her doctor was critical to her sense of personal empowerment:

“The doctor who prescribed me all this medication...but then at the age of 16 he said, ‘All right. You’ve got a choice’. He said, ‘It’s your choice now to get off the medication or continue with it’. And, so I said that I’m getting off it. A few weeks after he asked to see me again just to see how I was going. He said it was the best decision I ever made.

“So, I felt like finally I had a voice, you know, I feel like I could say what I wanted.” (Interview 10, metropolitan cohort).

7.7.2 *Diagnostic overshadowing and the intersection of ableism and racism in health*

Section 6.4.1 found that ‘diagnostic overshadowing’ (Jones et al, 2008; Mason and Scior, 2004; Katteri and Bywood P, 2011) was a factor in the non-diagnosis of disability, particularly in overshadowing of less visible disabilities that co-exist alongside a more visible presenting disability. This research has found that ‘diagnostic overshadowing’ can also apply in the provision of health care services to people with disability symptoms of an illness are attributed to a person’s disability rather than the presenting undiagnosed condition. The disability ‘over-shadows’ or obscures the serious illness, and the serious illness remains undiagnosed. As a version of institutional ableism, it occurs when a treating health care practitioner’s clinical judgement is subconsciously biased by preconceptions, prejudices and assumptions about disability. At a minimum, the quality of care to the patient with disability is compromised, but it also heightens the risk of a catastrophic health event.

The concept of ‘diagnostic overshadowing’ is extended by this research, which found that access to health care by Aboriginal and Torres Strait Islander people with disability is adversely affected by institutional racism as well as institutionalised ableism. One participant, a quadriplegic wheelchair user, spoke extensively on how the quality of health care had been compromised through diagnostic overshadowing, citing a series of incidents across a range of health care settings where practitioners did not

demonstrate a working knowledge of how disability related to their area of clinical practice.

“I’ve had a lot of ups and downs with the health system. So, just a little interaction that I had a couple of weeks ago. Like, because a lot of people just presume, even within the health system, because I’m a quadriplegic. I can’t feel from the chest down. And, I went to a podiatrist and, you know, he’s mucking around with my – with my toes and he’s like, ‘You can’t feel that. You can’t’ – and he’s just presuming that’s, you know, perception of people in wheelchairs. They can’t feel from here down. But I can feel everything bar my right leg sensation wise...”

“And that’s even in hospitals as well. Like, I’ve had interactions with nurses that say, ‘You can’t feel this’ or, ‘You can’t do that.’ I’m like, ‘Hey, no. I can feel my left leg. I know what you’re doing down there. Like, take it easy, all right?’ ‘Just don’t take the mickey and think you know’ So, I’ve had some good experiences but some bad ones as well, just because of what people presume and so forth.” (Interview 8, metropolitan cohort).

Power relations between the clinician and the patient play a role. Intersectionality, which is framed in terms of power hierarchies between people in power and vulnerable population, is also relevant. The power relationship between a clinician and a patient with disability can be greater than between a clinician and a patient without disability. This narrative shows that systemically generated practice trumps patient experience in a westernised model of health care, and ultimately it is the believability of the person with disability that is contested. When institutional ableism intersects with institutional racism, as is the case with Aboriginal and Torres Strait Islander people with disability, the power differential between clinician and patient is greater again. An example of the intersection between ableism and racism, and the heightened risk of catastrophic health event, is an Aboriginal or Torres Strait Islander people person with disability whose health concerns are dismissed as being alcohol related, when the clinical assessment of a health practitioner is biased because of the negative stereotyping of Aboriginal and Torres Strait Islander people and alcohol consumption. This issue came up during the community consultations on this study, when the researcher was informed of a critical incident involving a young Aboriginal man who required emergency treatment for

severe dehydration and hyperthermia. The man involved has Aboriginal tattoos and uses a motorised wheelchair, thus visibly projects his dual identity as an Aboriginal person and person with disability. He was returning home in his motorised wheelchair from an Aboriginal community meeting held outside on a hot day when his body started overheating. As his condition started to deteriorate, he made his way to a bottle shop attached to a pub, being the only place in the vicinity with ice and air conditioning. By the time the ambulance arrived, he was in a state of semi-consciousness, and whilst he could hear what was being said, he was immobile and unable to communicate with them. Even though there was no presence of alcohol in his system and a bottle of water on him that he could not open, he was triaged as suffering from excess alcohol consumption, as opposed to dehydration. He recalls vividly perceiving “*the looks of disgust from the paramedics, all the way through the hospital, the doctors and the nurses*”. It was not until he “*started coming to*” that the exact nature of his medical emergency was correctly diagnosed, and as soon as they realised that alcohol was not a factor, the medical staff “*started backtracking*” (Community consultations, metropolitan area).

Whilst the conditions of this case are a perfect storm for institutionalised ableism and racism, it does highlight the adverse health consequences of failing to follow through with diagnostic protocols in full when vulnerable patient groups are concerned. This is not an isolated incident. There is at least one coronial inquiry where a critical incident resulted in the death of a young Aboriginal woman, in which “premature diagnostic closure” by medical staff was found to have been present.⁷

The following yarning piece is based on an interview with an elderly Aboriginal man from a remote area. In the interview, conducted at a men’s community centre, the participant tells of his experience of the health system in providing aftercare following

⁷ This refers to the coronial inquest into the 2014 death in police custody of Ms Dhu, a young Aboriginal woman in Western Australia. Whilst the Coroner did not rule Ms Dhu’s death as avoidable, the Coroner did find various errors and omissions in the diagnosis and treatment of her condition in her various presentations to a medical facility. Testimony was provided to the inquest that “premature diagnostic closure”, the legal term used by the Coroner, had occurred after police told medical staff that the patient was “faking it”. See: Coroner's Court of Western Australia (2016). *Inquest into the Death of Ms Dhu*.

a knee operation, with the researcher interposing a critical assessment on the quality of health care that was provided in this case in a resource rich nation like Australia. This yarning piece is presented as a conversation between the participant and the researcher, to give the reader the effect of how issues of inequality were progressively disclosed by participants.

Yarning piece – Health care not befitting our nation

Towards the end of the morning, one of the community workers came in and asked whether one more of the men could come in and tell his story, as someone who had been waiting a long time. “Of course”.

In came an elderly man, with a walking stick. He was softly spoken with a gentle demeanour. He said he was sixty, but he looked considerably older. By my reckoning, he had waited about an hour and twenty minutes to speak with us whilst other men from the community centre had come in to tell their story.

Very early in the interview, I got the sense that he was lonely, and just wanted to talk to someone. He started his story by talking about how he worked on a station when he was younger, then came into town with his family. *“That’s where I got disability, down here”*, he said. He started to describe what happened, but talking about it was clearing making him uncomfortable. *“It’s hard to talk about. Yeah. Yeah.”*, he said. *“Okay. That’s fine. You don’t need to talk about it.”*

We switched tack to talk about his family, then talk about some of the barriers he had faced in his life. At this point, he mentioned that he was sleeping rough. *“I live out bush... Just around the town area. Just down – [pause] – we’ve got nowhere to sleep.”*

About ten minutes into the interview, the story drifts back to his health.

RESEARCHER: Do you see a doctor about any health issues?
PARTICIPANT: *Yeah. I went up there [to a regional hospital]. I've got to go – I've got to go back too. I've got this operation... I've got some pins down here.*

At this point the man lifts his trousers, and points to his leg. There is a diagonal bulge covered by a scar which looks to be covering a pin, which is about an inch long and clearly visible. It was quite stark, reminding me of those flat-topped mountains that pop up out of nowhere you can see when you go driving in the outback.

RESEARCHER: Okay.
PARTICIPANT: *I've got a walking stick down here. That's why I can't work. Can't do anything.*
RESEARCHER: So, you've had an operation recently. Okay. I can see the scar over your knee.
PARTICIPANT: *Yeah. Bit sore up here.*
RESEARCHER: It's swollen. Is it sore now?
PARTICIPANT: *Just – I'm right to walk around.*
RESEARCHER: Yeah. Yeah. Just got to take it easy. And, how long ago was that operation?
PARTICIPANT: *Well, that was one month back, with – what's the date today? That was last month.*
RESEARCHER: And, were you in hospital for very long?
PARTICIPANT: *Yeah. Down at [the regional hospital].*
RESEARCHER: And, how long were you actually in hospital for?
PARTICIPANT: *I've been there for two weeks....Just everything got healed up. They put - - They put pin down here.*
RESEARCHER: Okay. I can see the size of the pin over your knee cap there. Have you got to keep going to see the doctor regularly to make sure it's all right?
PARTICIPANT: *Yeah. Yeah.*
RESEARCHER: And, it's working good?
PARTICIPANT: *Yeah. Yep. They'll – they'll be – they'll be calling me up here.*
RESEARCHER: Do they come and see you or do you got to go into town?

PARTICIPANT: *No. I'm going to the big hospital, talk on these video links down to a doctor. Yeah. They'll be calling me maybe after this month. I'll be going back there to have another operation to take – take the pins out...in a month.*

RESEARCHER: One month. All right. And, when do you go... does someone come and get you? Or - - -

PARTICIPANT: *No. They put me on a bus.*

RESEARCHER: They put you on a bus. Okay.

I make a mental calculation that this would be about a six or seven hour bus ride.

RESEARCHER: From out there? From - - -

PARTICIPANT: *From the hospital.*

RESEARCHER: Right. From the hospital. Okay. And, how do you get to – from where you're sleeping at? Because, you said you were sleeping rough. Is that right?

PARTICIPANT: *Yeah.*

RESEARCHER: How do you get there?

PARTICIPANT: *I walk.*

RESEARCHER: You walk?

PARTICIPANT: *Yeah. Walk slowly.*

RESEARCHER: And, how – how many – how long would that take you to walk?

PARTICIPANT: *Well, the hospital's a couple of blocks in. Yeah. Be about 500 metres.*

At this point, I'm registering that an Australian health care system would discharge a sixty-ish year old man from hospital after a significant knee operation into a situation when he is on own his own and sleeping rough.

(Interview 25, remote cohort).

The participant then continued to tell about his life 'sleeping rough', and how his town camp community all look after each other. The nature of the interview turned at this point to focus on inclusion, family and community. As such, the recounting of this

interview resumes as a yarnning piece on cultural inclusion in Section 9.2 entitled “*I want to go home... for my own blood family*”.

7.8 Emerging issues in inequality in accessing the National Disability Insurance Scheme

The National Disability Insurance Scheme is an Australian Government disability support program designed to provide individualised packages of support for people with severe and profound disability. It is being implemented in a schedule a progressive regional rollout. Implementation commenced in July 2013 in a number of trial sites, one of which included the Barkly Shire in the Northern Territory, which also coincided with one site where research interviews were conducted.

An issue of concern in the implementation of the National Disability Insurance Scheme is whether Aboriginal and Torres Strait Islander people with disability would have equitable access to the Scheme, with reference to the heritage issues in their not having equitable access to disability supports systems in the past. Due to the relative newness of the Scheme, there was no statistical data available within the datasets to conduct a statistical analysis to quantify any access issues that Aboriginal and Torres Strait Islander people might be having in accessing the Scheme. Hence the findings in this section are drawn from the testimony of participants, which reveals there are emerging signs that the access inequality that was inherent in previous disability support systems is being carried into the new Scheme.

7.8.1 *Issues of accessibility and communication*

In acknowledging it is still early days in its implementation, the National Disability Insurance Scheme was found to have had relatively little impact on the lives of the participants within the timeframe of the research. The ‘NDIS’ or related words⁸ were referenced in 11 of the 41 interviews (26.8%), for a total of 27 mentions by participants. This included 2 participants who had mentioned that they had previously

⁸ The text search within Nvivo included: ‘NDIS’; ‘insurance’; ‘scheme’; and ‘package’.

worked for the NDIS. It should be pointed out that this data is not intended to be a proxy for data that quantifies the prevalence of accessing the Scheme, but instead to provide some contextual insight into where the National Disability Insurance Scheme fits within the participants' framing of this issue's narrative to the other issues of inequality that are covered by this Chapter.

In referencing the NDIS, not all participants mentioned having direct personal interaction with the Scheme. Two of the participants spoke about their anticipation of the Scheme's contribution to a system-wide approach to communication and support for people with disability. One participant expressed an aspiration that the NDIS would help them navigate 'the system' in positive terms:

"There's no one to guide deaf Aboriginals now into the wider community. And really, that's what the NDIS should be about and making sure that everybody is provided with the individual needs that are needed for them." (Interview 4, Deadly Deaf Mob cohort).

Another participant expressed frustration that the National Disability Insurance Scheme would merely add to the systemic complexity, and highlighted a need for independent sources of communication and personal advocacy:

"Well, the system like it currently is, with NDIS. That's another story. Another long story. It's unbelievable." (Interview 1, metropolitan cohort).

Other participants who referenced the National Disability Insurance Scheme did so with varying degrees of personal engagement, and varying experiences with the Scheme and its processes. Nonetheless, there was not a single participant from within the research cohort who had conveyed that they have completed, or that they understood, the process of getting a package, having a package activated, and being satisfied with the outcome.

One testimony raised concern that whilst access to the Scheme is notionally intended to be needs-based, in practice not having a disability diagnosis would be a barrier to access. This is one of the heritage issues that is grounded in the issue of undiagnosed disability amongst the Aboriginal and Torres Strait Islander population discussed in

Section 6.4. At the time of the interview, the participant was not on a plan, and best described as *“just starting the process”*. The support person attending with the participant spoke to their fear of not being able to access the Scheme:

“The doctor hasn’t given her a diagnosis of what’s wrong with her. And, I’m frightened that she’s going to fall through the cracks and not going to be entitled to a package.” (Interview 11, metropolitan cohort).

During the interview, it further emerged that there were two other members of her immediate family in the same household with intellectual disability, neither of whom had been contacted by the NDIS, and that they too would fall through the cracks:

“I understand that the NDIS is individual. But, from what I hear, they can be flexible, as well. And, I honestly think that she and her two boys are going to fall through the cracks. And, they would need a package that kind of – I know they’re individual, but link into each other. Because if anything happens to her, what’s going to happen to her boys? You know what I mean? They need something in their home. A structure.” (Interview 11, metropolitan cohort).

Another research participant from a remote area, had secured a package for one of her sons who has a severe cognitive disability. In prefacing her discussion on the National Disability Insurance Scheme, she had spoken extensively of the difficulties that her son faced in getting an education, and due to a series of bad experiences including abuse, was not attending the only local school in the area. Despite securing a specific dollar package from the National Disability Insurance Scheme for her son, she remains highly distrustful that the package would be spent on her son and in a way that would benefit him:

“Our people with disability don’t get the money that the NDIS or the government that sends them out here, you know... And, now my son missed out on an education. Out here, I even went down to the NDIS, you know. All I want is for someone to come up there, at least twice or three times a week and – and give my son an education, you know, just – well, he knows a lot but at least teach him some other things that he need to know. He’s got a right to have a one-on-one teacher. I’ve been trying to fight for that for years.

"I went to the NDIS meeting. I spoke up for some money for my son, funding, and I got [a dollar amount of] funding, I got the paperwork up there. [A service provider] got the funding. They never spent a cent on my son out of it.

"When people get us funding there's only certain things they can use that funding for. I'm not allowed to even use ... their funding to take me and my son over there for that. I want a big easel, I want some paintbrushes, I want all these paint things so my son can sit up there and do these things, that'll be good for his hands." (Interview 16, remote cohort).

Other participants said that they were on plan that had helped them personally. Two participants had said that they met with the National Disability Insurance Scheme - *"they've got my story there"*, said one - and had a plan (Interview 24, remote cohort). Whilst they felt that the National Disability Insurance Scheme had provided what they needed, they nonetheless appeared more as passive participants to a bureaucratic process that was happening around them, rather than being fully empowered and in control. With regard to navigating the processes, they turned to someone from within their community, and not a National Disability Insurance Scheme employee, for help:

"Then, I had that artificial leg for eight years, maybe. And then, 2008 I don't feel like using the artificial leg anymore. Yeah. I had to send it back to town and now I start, I didn't know about NDIS. I didn't know about it. Only in 2015 I know about NDIS. When I was walking around now with the crutches now, for that many years. And, 2015, I got myself a new scooter now and I've got the scooter back home there. Yeah. About 2015. Then I know, I realise, they told me about NDIS and that they help me out with, I get that new scooter. I didn't know about NDIS that many many years. Only 2015 and now. I didn't know, they told me someone from NDIS want to see you. I'm thinking, who? I don't even know NDIS. This was 2015, I know NDIS.

"...Sometimes I go next door here. I talk to [a male community worker]."
(Interview 23, remote cohort).

Another participant said that she had had a planning meeting in relation to her two sons. She said that she had just attended a community organisation's information session, and that was helpful. However, there was still an underlying concern that she would be locked into a disability support package that she had negotiated prior to having a fuller knowledge of what additional support could have possibly been available to her:

"Where I'm – yeah. Yeah. I'm in a good place right now and I just want to move forward and hopefully get everything I can out of the NDIS. That's going to be helpful for myself and the boys. But, mainly for them. I want them to live life like everyone else.

"I've had I've had my plan done and, yeah. I have to hear I'm thinking about, oh my god, I want a review ASAP. There's some things I want to change already in there. Just learnt some stuff that I can do, oh, I didn't know I can do that." (Interview 16, remote cohort).

Some participants reported time lapses between initial planning meetings and further communications from the NDIS, leaving them wondering what was going on with their case. One participant with a mobility impairment needing a wheelchair reported long delays in responding to modifications to her unit *"not physically made for disability people but 'elderlies'"* to make it more accessible (Interview 33, remote cohort). An Elder from a regional centre also said that she had had a meeting with the NDIS and asked for a new wheelchair. She was promised this, although she had not heard anything further in the month since the meeting had taken place (Interview 31, remote cohort).

7.8.2 *The interface of structure and personal agency*

Earlier in this chapter, an example of a wheelchair that had been discarded because its rubber tyres had melted highlighted how the efficacy of disability programs that promote personal agency are affected by the structure and environment in which they are deployed. This is an emerging implementation problem for the National Disability Insurance Scheme in Aboriginal and Torres Strait Islander communities for a program that is designed to promote personal choice and agency through a market-based

system, but is being implemented in places where there is inadequate public infrastructure and clusters of multi-faceted deprivation. In short, a market-based disability systems that operates by providing personal choice cannot function if the fundamentals of a market are not in place.

This issue became evident in testimony from the Elders' Forum. Speaking on behalf of their communities, the participants at the Elders' Forum spoke more directly about examples where the application of the market-based model of the National Disability Insurance Scheme is inconsiderate to the social circumstances of Aboriginal and Torres Strait Islander people with disability. These considerations do not include cultural ways of doing business, but also go to an understanding of the core living conditions that exist in some Aboriginal communities. As an example, one Elder from one remote community spoke of an absurdity where Aboriginal people with disability were receiving large disability support packages, but are starving and homeless. One Elder from a remote area in Central Australia said that there were people in their community who have received notional package of support, some valued upwards of \$50,000, which they can't utilise because there aren't any disability services within that remote community. The families are going hungry and need shelter, but they can't buy food and blankets because food and blankets are not seen as meeting the Scheme's technical requirements of being 'reasonable and necessary'.

"...and the other thing that people ask for is really – we call it proper help, and proper help for our families is food – because sometimes we arrive out there, family's got no food, so we need to be able to get food for people, and that's something that the NDIS says is not a reasonable or necessary support. But if you arrive and that family's got no food, that's what you've got to deal with. You can't be talking about that physio that's coming out here in three months' time or – you've got to – it's totally counterintuitive not to respond to what's going on for that family that day..."

"Because the other thing [our Elders] pointed out to me is swags and blankets is something that our families ask for all the time, help with making sure that they've got somewhere warm and safe to sleep at night, and that's a really practical thing and we've done that for years. Like, I've been since 2004 providing swags and blankets to families, and now the NDIS is coming and

they're saying, 'No', they're saying, 'We don't buy swags and blankets for people. That's not reasonable or necessary.' But if you've got nowhere to sleep, of course swags and blankets are reasonable and necessary, so we're having – we've been having lots of arguments with NDIA and saying that they need to change the way that they do business. In Aboriginal communities, it's different, and they need to be able to respond to that difference, because otherwise, in five years' time we're all going to be sitting at a table saying, 'The NDIS didn't help much, did it?' and we don't want that. The NDIS is an opportunity and we want to make sure that Aboriginal people can access that opportunity and get the best out of it.” (Participant, Elders’ Forum).

This above case example points again to how inequality arises when sectionally-based policy attempts to resolve an intersectional issue. The people in this case require secure housing and food security, structural matters that are outside the ambit of the person-centred National Disability Insurance Scheme, but vital for its efficacy. It is the obverse to the case presented in Section 7.3.1 above, in which housing was provided under an remote housing program, but was not built to universal disability accessible standards. In both examples from the testimony, the needs of people requiring an intersectional approach are not touched by well-intentioned but sectionally-based approaches to public policy. In this respect, the emerging signs from this research are that the implementation of the National Disability Insurance Scheme is converging towards the same pattern of systemic inequality that was observed in all other areas of systemic support to Aboriginal and Torres Strait Islander people with disability that were covered in this Chapter.

7.9 Summary findings on social inequality

The second aim of this research asked how is social inequality that is experienced by Aboriginal and Torres Strait Islander people with disability created and sustained. In Chapter 3, a theoretical model that explained the generation and perpetuation of social inequality was conceptualised based on intersectionality and the disempowerment of marginalised groups within marginalised populations. This chapter presented consistent and compelling evidence that as a marginalised group within a marginalised population, Aboriginal and Torres Strait Islander people with disability experience an

intersectional version of social inequality that is acute and pervades all aspects of their engagement with systemic support. When the conceptual model of social inequality is read alongside these results, the finding of ‘intersectional inequality’ that is experienced by Aboriginal and Torres Strait Islander people is both theoretical and empirically robust.

The statistical data and personal testimony presented in this chapter provide the context and compelling evidence of ‘intersectional inequality’ encountered Aboriginal and Torres Strait Islander people with disability compared to other population groups. Across all policy domains without exception, Aboriginal and Torres Strait Islander people with disability experienced at least twice the level of inequality when social health and wellbeing outcomes were compared against outcomes for other population groups. The personal testimony, which included accounts of a young Torres Strait Islander girl with cerebral palsy being told she ‘did not fit the brand’ when applying for jobs; an Aboriginal man with quadriplegia being passed off as drunk when instead he needed emergency medical care; an elderly Aboriginal man being discharged into homelessness after a major knee operation; and an Aboriginal Elder being told that food and shelter were not ‘reasonable and necessary’ as a support for disability in their community, affirmed the gravity of the social injustice through the quality of the experience.

The significance of these findings are profound and broad-reaching. One implication of finding ‘intersectional inequality’ within each and every policy domain is the accumulation impact of social inequality when it is conjoined across the trajectory of a person’s life. This life trajectory mapping of accumulated social inequality, called a ‘matriculation pathway to prison’ is presented in the discussion at Section 10.3.1.

These results have further shown that sectional approaches to social policy are completely inadequate in understanding, yet alone responding to ‘intersectional inequality’ of the gravity that is demonstrated through this research. The empirical results in this research can be directly applied within social policy that affects Aboriginal and Torres Strait Islander people with disability. Beyond this population group, the conceptual model of ‘intersectional inequality’ can be further applied in understanding and addressing inequality in others settings involving other population

groups that have similar experiences of vulnerability and marginalisation. How Australian social policy must adjust to respond to the impact of ‘intersectional inequality’ is discussed further in Section 10.4.

The next chapter moves the focus from inequality to discrimination and social isolation. It will specifically present findings on ‘intersectional discrimination’ experienced Aboriginal and Torres Strait Islander people with disability. The findings on ‘intersectional discrimination’ are related to findings on ‘intersectional inequality’ that are presented in this chapter, but ‘intersectional discrimination’ is qualitatively different in its personal nature to inequality that is systemically generated. The acutely personal nature of discrimination in its various forms, and the impact that these experiences have upon the psychological health and wellbeing of Aboriginal and Torres Strait Islander people with disability, are taken up in the chapter that follows.

8. RESULTS: Social isolation, discrimination and trauma

8.1 Differentiating systemic inequality and social isolation

This chapter presents additional findings in relation to social inequality and its impact upon the health and wellbeing of Aboriginal and Torres Strait Islander people with disability.

There is a relationship between the inequality in accessing systems and services detailed in the previous chapter, and the sense of social isolation that is covered by this chapter. Inequality in accessing systems and support services accumulates and undoubtedly contributes towards an increasing sense of social isolation. However, the person's experiences of systemic inequality and the underlying forces of social isolation are different. Systemic inequality is the product of being denied access to something by a faceless system that is unheeding of need and cannot respond with empathy. The unfairness of these experiences drove an emotive response of frustration and anger from the Aboriginal and Torres Strait Islander people with disability who were interviewed in this study. By contrast, the socially isolating forces described in this chapter, including lack of human contact, exposures to various forms of discrimination and traumas, have the quality of a structural violence (Farmer 2005; Nystrom, 2014) that is inflicted upon a person that dehumanises them and causes them harm. What this chapter aims to do is to quarantine the testimony that gives account to these socially isolating forces, and sadness and despondency that they drive.

The results are presented in three parts. The first part presents data on social isolation in relation to human connectedness. The second part will describe the various forms of discrimination and trauma to which the participants provided testimony. The second part will also show how Aboriginal and Torres Strait Islander people with disability are exposed to various forms of discrimination including racism, ableism and a unique interaction of discrimination that intersects these two forms. It will then show how repeated exposures to discrimination can manifest into a self-exclusionary form of discrimination that is referred to as 'apprehended discrimination'. The third part will move into the nature of trauma and how it presented in participants' testimonies in

various ways. It will show that Aboriginal and Torres Strait Islander people face heightened vulnerability to variants of trauma that include intergenerational trauma, exposure to major traumatic events, and constant micro-retraumatisations. One key finding from these results is an observation that trauma can cluster and transmit within Aboriginal and Torres Strait Islander communities as if it were an infectious disease.

In taking this approach, this chapter bridges the second research question on how social inequality is created and sustained, and the third research question on what is a model of research that actively promotes participation of Aboriginal and Torres Strait Islander people with disability through the direct testimony of their lived experience. The statistical data and the testimony will provide further empirical evidence of ‘intersectional inequality’, reinforcing the findings of the previous chapter. Hearing what discrimination and trauma looks like and feels like from the participants’ testimony will add a depth of understanding about the forces that isolate people socially. This finding connects to the third aims of the research which is how to construct a methodology that facilitates participation in research involving marginalised populations. The researcher’s observations of discrimination and trauma amongst the First Peoples disability community from within a community organisation made the need for a trauma aware approach known from the commencement of this research. These findings have added an evidentiary rigour to principles and practices in a participatory research approach that has evolved from grounded origins.

8.2 Social exclusion and isolation

The findings in this chapter commence with presentation on the data that describe the marginalisation of Aboriginal and Torres Strait Islander people with disability through a series of social exclusion metrics. Social inclusion is not explicitly defined as a category in the NATSISS data, but there are several indicators that are illustrative of the social inclusion or exclusion of Aboriginal and Torres Strait Islander people with disability. This statistical data identifies the level of connectedness that they have with other people, or alternatively their disconnectedness. Statistical data on the likelihood that they or someone close to them has been removed from family, the likelihood of living alone, having daily contact with family and friends, experiencing homelessness and having limited or no access to communications via the internet has been included

within the category of social inclusion outcomes. The data that compares these indicators for Aboriginal and Torres Strait Islander people with severe and profound disability to those without severe and profound disability are presented in Table 8.2 below.

Table 8.2: Social inclusion indicators, Aboriginal and Torres Strait Islander people – by disability status.

INDICATOR	Aboriginal and Torres Strait Islander people		
	With severe and profound disability	Without disability	Rate (x times likely)
Lives alone	14%	8%	1.8
Daily face to face contact with family or friend	35%	45%	0.8
Has experienced homelessness	41%	22%	1.9
Access the internet at home	58%	78%	0.7

Source: NATSISS (ABS, 2016a)

In each of the indicators presented, Aboriginal and Torres Strait Islander people with severe and profound disability experience greater social isolation than Aboriginal and Torres Strait Islander people without disability. The likelihood that, as belonging to a marginalised subgroup of a marginalised population, an Aboriginal and Torres Strait Islander person with severe or profound disability lives alone or has experienced homelessness is almost twice that of an Aboriginal and Torres Strait Islander person without disability (1.8 times and 1.9 times respectively). While the difference is not as marked, the other two indicators of human connectedness, daily contact and internet access, are also exhibited to a lower extent for Aboriginal and Torres Strait Islander people with severe and profound disability when compared with Aboriginal and Torres Strait Islander people without disability.

Evidence of the detrimental impact of social isolation upon social and emotional wellbeing was also present in the testimony. As one participant said:

“I go through my ups and downs, my phases of depression with it, but you don’t let it control your life. It’s hard. There are days when I don’t want to face the day. I’ll just get up, have my shower and I’m going back to bed.”

(Interview 1, metropolitan cohort).

8.3 Racism, ableism and ‘intersectional discrimination’

As people intersecting two marginalised population groups, Aboriginal and Torres Strait Islander people with disability can experience discrimination that is both race and disability related. Section 3.2 discussed in conceptual terms how racism and ableism can occur of their own accord, but also can interact with each other to generate a unique experience of discrimination which is referred to in this research as ‘intersectional discrimination’. This chapter build upon the concepts described in Chapter 2 by presenting how multiple forms of discrimination appeared in the testimony of Aboriginal and Torres Strait Islander people who were interviewed as a part of this research.

In reviewing the testimonial data on discrimination, it should be noted that participants were not directly asked whether they had been discriminated against during the interview. Instead, the participants’ recounting of their experiences of discrimination came as a result of this more general discussion prompt on what barriers they faced in their lives.

Below are two examples drawn from testimonies that illustrate the everyday nature of discrimination as experienced in the lives of Aboriginal and Torres Strait Islander people with disability. The first example comes from a group of participants who live in an Aboriginal Housing complex on the outskirts of a regional centre. The participant lives in a community group of about thirty people, all are Aboriginal, none with access to transport. The centre of town is a few kilometres away and buses don’t come out their way, so he says that he walks into town when he needs something. He says that he sees a counsellor for an hour or so every few weeks for a mental health condition, *“as I am supposed to”*. He then mentions that on the walk back from seeing his counsellor, he often would be racially abused by people in the street and driving past, instantly undoing any benefit of his therapy (Interview 20, remote cohort). This

example also highlights how systemic inequality (in this example, a lack of access to transport) can create an environment that enables personally directed forms of discrimination (in this example, racial vilification).

A second example highlights how race and disability can interact to accentuate the risk of discrimination for people who are Aboriginal and Torres Strait Islander and have disability. The testimony comes from an outer metropolitan area, involving an Aboriginal woman with a cognitive disability and possible undiagnosed hearing impairment, and her son, an Aboriginal man who also has an intellectual disability. The support person, attending with the participant, said that he works at a local disability place. *“He’s a supervisor now. He’s been there a long time,”* and she comments that *“as he is getting older, he’s losing his, you know, his fine motor skills”*, which causes him to lose his balance and fall. She recalls an incident during a shopping trip:

“Because he’s, you know, his balance is off. And, the other day – we’ll put this on the issue, is that [the participant and her son] went to go shopping. And, the security guard at the Shopping Centre... stopped [the son] and said, “No. We don’t like – you can’t come in because you’re intoxicated.” And, he wasn’t intoxicated. That’s just how he is.

“And, they [the security guards] told Woolworths not to let him in. And, I was there. I ripped them. I said, ‘If you can’t tell between a person living with a disability and a person that’s intoxicated.’ I said, ‘You shouldn’t be working here.’ I said to the security guard. And, I said, ‘As for you, [speaking about the Shopping Centre], you can’t discriminate. Can’t discriminate against people living with a disability.’ So, then they let him do the shopping. And, then they came and apologised to [the mother]. I said, ‘Don’t apologise to her. You need to apologise to that young man.’ I said, ‘Because you stopped him’.” (Interview 11, metropolitan cohort).

She mentioned that this type of incident happens regularly. The participant said that when she goes to the club.

“They say, ‘That’s enough. You’ve had enough to drink.’ But I don’t drink.”
(Interview 11, metropolitan cohort).

The support person follows up:

“And, they put her out.” (Interview 11, metropolitan cohort).

Whilst these two testimonies highlight how racism and ableism interact to generate a unique form of ‘intersectional discrimination’, the participants consistently relayed experiences that could be directly attributed to either racism, ableism or an intersectional form of discrimination in response to the prompt, “What barriers have you faced?” Their testimony included exposures of to a range of discriminatory behaviours, which included: being subjected to prejudicial assumptions about what they could or could not do because they were Aboriginal or Torres Strait Islander and/or had a disability; not being believed, because their life experiences were seen as contradictory to what professionally trained people were taught; being viewed as a burden when they had asked for accommodations to be made to enable them to participate in a social activity; and, being called a racist or ableist name out of frustration by the person that they were speaking with at the time of the incident.

The type of daily routines that the participants were undertaking at the time they encountered discrimination highlights how their day to day lives are constantly interrupted by casual exposures to discrimination. Direct references to discrimination contained within the participants’ testimonies spanned a range of ordinary day activities such as: going to the doctor; going shopping; going out for a meal; taking a phone call at work; catching a plane; asking to attend or participate in a community group meeting; and applying for a job.

8.4 ‘Apprehended discrimination’

Participants in the study revealed exposures to racism, ableism and intersectional forms of discrimination. This research identified that as a result of the frequency of their exposure to multiple forms of discrimination a pattern could be determined in the

psychological responses to the threat of discrimination. In particular, participants demonstrated a sequence of psychological responses to discrimination across a continuum. This continuum begins with an intuitive fear of discrimination, develops into an increasingly rational understanding of discrimination that is acquired through increasingly frequent personal exposures to discrimination, and culminates in avoidance of social situations where they might expect to be discriminated against. This pathway from fear of discrimination to avoidance of discrimination could not be adequately explained within existing terminology and concepts. To overcome the limitations in existing terminology, a concept of ‘apprehended discrimination’ has been devised to describe the rational fear of discrimination, and ultimately a self-exclusionary form of avoidance in response to the expectation of discrimination.

The term ‘apprehended discrimination’ was introduced in Section 7.6.1 in relation to employment inequality. In these cases, participants told of being denied employment opportunities because of their disability. During a community consultation, an Aboriginal man who was blind reported that he had stopped applying for jobs that included a default specification that applicants hold a driver’s licence regardless of the nature of the work, as he expected that this would give an excuse for a prospective employer to discriminate against him (Community consultation, metropolitan area). A pattern of migrating through a pathway from fear of discrimination, to an apprehension of discrimination and then avoidance of potentially discriminatory situations was noted across testimonies. The three phases of an ‘apprehended discrimination’ continuum are described below using illustrative examples from participants’ testimonies:

PHASE 1 - Fear of discrimination: The pathway commences with an intuitive understanding of discrimination. As used in describing a pathway of ‘apprehended discrimination’, ‘intuition’⁹ refers to an embodied personal history that is deeply ingrained into a person’s subconscious. In this usage, ‘intuition’ summarises the cognitive response when people reflect and act upon their internalised dispositions, which Bourdieu more deeply explains in his theory of ‘habitus’ (Bourdieu, 1977,

⁹ ‘Intuition’ as referred to in this research is not intended to describe or incorporate a deeper understanding that is spiritually based and is influenced by a connection to Indigenous culture. To emphasise the point of difference to an experientially informed knowledge, culturally informed knowledge that devolves from an Indigenous belief and value system is later discussed in Chapter 9 using the language of ‘cultural and community connectedness’.

1990). In the early stages of understanding, discrimination is externalised, in that participants are drawing from a perceived understanding of discrimination which happens to others, distinct from their own personal exposures to discrimination.

PHASE 2 – ‘Apprehended discrimination’: As people become more personally exposed to discrimination, their understanding of discrimination transitions from an intangible judgment to an increasingly rational thought process, in the sense that every incident adds weight of evidence to their rational judgment of discrimination, its frequency and its impact upon them. ‘Apprehended discrimination’ is the ‘a-ha’ moment when they realise that their perception of discrimination has become their reality, a psychological realisation that invokes an unpleasant physiological reaction.

PHASE 3 - Avoidance of discrimination: There comes a threshold point at which the accumulated exposure to discrimination is so great that the participant expects to be discriminated against, as distinct from being assessed as a chance encounter. Their response is self-exclusion, that is, to avoid situations in which they can be exposed any further discrimination. The psychological response of avoidance is a rational choice, to avoid further harm by being further exposed to discrimination.

The concept of ‘apprehended discrimination’ is illustrated through three examples drawn from the testimonies.

EXAMPLE 1: ‘Apprehended discrimination’ – buildings not meeting disability accessible standards.

The first example is a sequential pathway from a fear of discrimination to a personal avoidance of discrimination involving a single participant relating to a single issue. It involves an Elder with a physical disability, whose status in community meant that he was regularly invited to meetings to talk on Aboriginal issues and culture:

Phase 1- Fear of discrimination: The participant’s initial reference to a fear of discrimination is described intuitively and is and externalised:

“Most of the [meeting] organisers don’t have a disability, ... so they make the bookings on their own ability.” (Interview 7, metropolitan cohort).

Phase 2 – ‘Apprehended discrimination’: The next sequence in his testimony describes his personal experiences of being unable to access buildings because of disability, which helps form his rational thinking on the likely threat of discrimination:

“When I get to the meeting, it’s not accessible or the lifts are out.” (Interview 7, metropolitan cohort).

Phase 3- Avoidance: The third sequence describes his response which pre-empts an expectation of discrimination:

“So, that’s why I don’t bother to go to a lot of meetings.” (Interview 7, metropolitan cohort).

EXAMPLE 2: ‘Apprehended discrimination’ – child safety and education

A second example shows how multiple exposures to discrimination accumulate and lead to avoidance, as exhibited through a single person’s testimony that conjoins many issues. This participant in this example is an Aboriginal woman living in a remote location who has a son with a cognitive disability:

Phase 1 – Fear of discrimination: The participant initially speaks of a historical legacy of distrust of police by the local Aboriginal community. She speaks of past injustices which have framed her intuitive thinking on discrimination:

“The police hung someone here before. The police killed a black person, they hung him in jail here.” (Interview 16, remote cohort).

She then makes reference to a recent incident where an Aboriginal man from her community was assaulted by police, and then makes a direct connection to her son:

“[My son] has a disability and I’m scared for my son.” (Interview 16, remote cohort).

Phase 2 – ‘Apprehended discrimination’: The testimony progresses along the continuum when she raises that she had approached the Department of Education and the police to get help for her son who had been “*interfered with*” at school. She said that this request for help went unheeded, and the undercurrent of her testimony is that it is because they are Aboriginal (Interview 16, remote cohort).

Phase 3 - Avoidance: The apprehension of discrimination has progressed into avoidance – she has withdrawn her son from school for fear for his personal safety, and he is currently not receiving formal education (Interview 16, remote cohort).

EXAMPLE 3: ‘Apprehended discrimination’ – discrimination in employment

The third example relates to discrimination in the employment of people with disability, which was previously referenced to in Section 7.6.2. This example pieces together the testimony of a number of participants to construct a pathway of ‘apprehended discrimination’ on a single issue:

Phase 1 – Fear of discrimination: First, the statistical data demonstrates that there is inequality in employment outcomes experienced by Aboriginal and Torres Strait Islander people with disability compared to the rest of the population, setting a data-based foundation for fear of discrimination.

Phase 2 – ‘Apprehended discrimination’: Within the testimonies, the participants who referenced discrimination in employment had progressed from the intuitive fear of discrimination, and spoke extensively to their personal exposure to discrimination in employment, including a yarning piece in which a young woman with disability says that she is told that she is unable to secure causal employment with high profile corporations as she “*does not fit the brand*” (Interview 41, metropolitan cohort).

Phase 3 - Avoidance: The pathway from ‘apprehended discrimination’ progresses to avoidance, illustrated by an example when a vision-impaired person says that he no longer applies for jobs that have holding a driver’s

licence in the selection criteria (Community consultation, metropolitan cohort). He puts his reasoning down to an expectation that not meeting this criteria, which is a function of having disability, would be used to reject his application without any further consideration, regardless of his merit in meeting all other aspects of the selection criteria.

When a person is constantly overlooked for employment, the effect on personal confidence is debilitating. When someone has their heart set on a career and their life-long ambitions are cast aside because of their disability, it can be dream-shattering. One participant, a deaf Aboriginal man whose goal in life was to be a flight steward, described the feeling of being locked out and isolated:

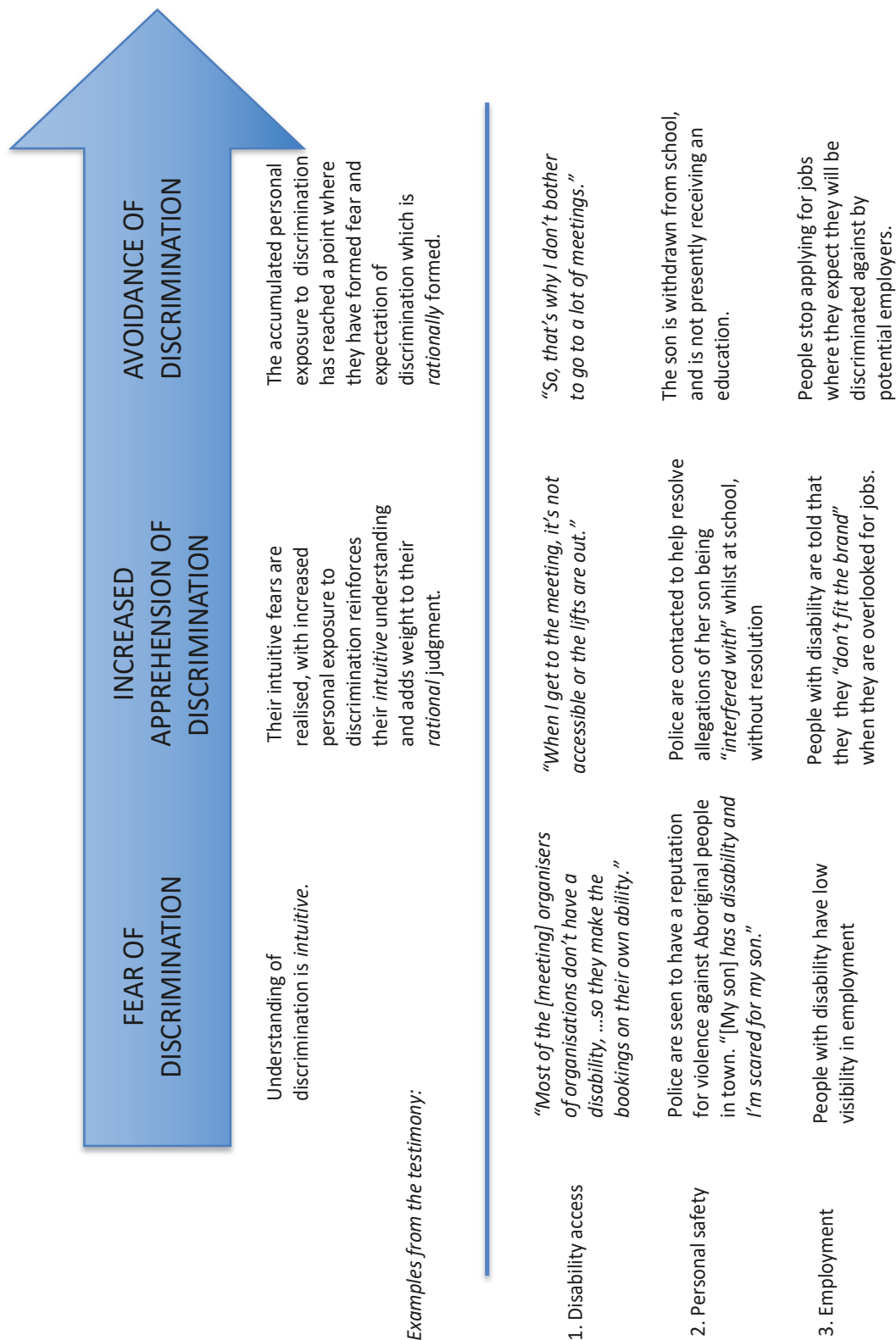
“I’ve applied for [a major Australian airline] as a [flight steward] and so I asked, you know, I got an interpreter in to help me fill out the forms and so we sent that off. And, it failed. And because, I only had one issue and that was the inability to hear. So that’s the problem. You must be able to hear to work on the planes. And, it really pissed me off. You know, I can do that. I know – I know I can do that. I’ve travelled all over the place. I’ve been overseas continuously. I’ve travelled all over the world. And, I thought to myself, you know what? I would like to work for [the airline]. And, you know, that was my dream and that’s what I wanted to do and I couldn’t do it. It was only because I’m deaf and I couldn’t hear.

“So, you know what job I’m doing now? I’m working as a cleaner.” (Interview 2, Deadly Deaf Mob cohort).

Multiply this single experience by many that are observed across a population cohort, and what is created is ‘apprehended discrimination’.

These three examples are consolidated into the Diagram 8.4 below to diagrammatically illustrate the concept of ‘apprehended discrimination’.

Diagram 8.4: 'Apprehended discrimination' - A pathway from fear of discrimination to avoidance



8.5 Exposures to traumatic episodes

As devastating as the impact sustained inequality and discrimination has upon the social and emotional wellbeing of Aboriginal and Torres Strait Islander people with disability, there were even further escalations in their distress that were caused by frequent exposures to traumatic events. The types of trauma that were observed within this research are categorised into three types: exposure to acute traumatic events; intergenerational trauma; and repeated micro-re-traumatisations.

8.5.1 *Exposure to traumatic events*

As referenced in the findings in Section 7.4.1, the types of acute traumas that participant groups experienced included: violence, both physical and threatened; the removal of children from families and communities; and the avoidable deaths of people who were close. The statistical data on inequality in accessing justice showed an intersectional effect with Aboriginal and Torres Strait Islander people with disability being 1.7 to 1.8 times more likely than Aboriginal and Torres Strait Islander people without disability to have experienced violence or been threatened with violence. Additional statistical data in Table 8.5.1 on the rate of child removal and proximity to someone close to them who had died also show an intersectional effect. In relation to the rate of child removal, this statistical data infers that intersecting disability with Aboriginality increases the likelihood of child removal to 1.4 times that of the child removal rate for Aboriginal and Torres Strait Islander people without disability, compounding the child removal rate for all Aboriginal and Torres Strait Islander children that is already 10 times higher than the removal rate for non-Indigenous children (Secretariat National Aboriginal and Islander Child Care, 2018).

Table 8.5.1: Trauma exposure indicators, Aboriginal and Torres Strait Islander people – by disability status.

INDICATOR	Aboriginal and Torres Strait Islander people		
	With severe and profound disability	Without disability	Rate (x times likely)
Removed and/or family member removed from family	50%	37%	1.4
Death of family member or close friend in the past 12 months	37%	25%	1.5

Source: NATSISS (ABS, 2016a).

8.5.2 *Intergenerational trauma*

Within the second category of intergenerational trauma, the removal of children from their family and communities provides the nexus between contemporary practice in Australian Government’s children welfare policy and the colonising practices in Australian history that is defined by ‘the Stolen Generations’. One participant provided a detailed and frank account of raising two sons with autism and intellectual disability as a single mother. The pathway of this testimony incorporated the range of aspects previously mentioned in relation to social isolation that she encountered as a carer of two young men with disability including: communications barriers that her boys experienced in their education; avoidance of public transport; trouble in getting suitable accommodation; inappropriate schooling; experiences of her sons’ fear of going to the doctor, or getting their haircut; wheelchair inaccessible housing. This has manifested into mental health issues of her own, with periodic treatments in a rehabilitation facility. The escalation of her own distress, and in the telling of her testimony, came when the state-based community services agency arrived without notice to remove her children from her care. She spoke of being “*so frightened*” and “*they just intimidated me and I was just frightened and I just – I didn’t know what my rights were really*” (Interview 29, regional cohort). Summarising her emotional response to the removal of her children from her care, and her subsequent interactions with the state government agency, she said:

“Basically, because they were taking the kids away. And then – so, that happened which was very traumatic. Yeah. It was like someone had – it was like my boys had died.” (Interview 29, regional cohort).

This account gives testimony to the sociopathy that is institutionalised into the child welfare system. On one hand, the system is unresponsive to the support and respite needs of families and communities caring for young Aboriginal and Torres Strait Islander children with disability that could act as a preventative measure to their removal. On the other hand, a faceless system is uncaring of the trauma that child removal inflicts upon the child who is removed, and the vicarious trauma inflicted upon the family unit and community. As an unresolved historical trauma, the fear of children being removed from their families and communities continues to loom large in the lives of Aboriginal and Torres Strait Islander people with disability, as was evidenced in the frequency by which the legacy of ‘the Stolen Generations’ was referred to in the testimony by a number of participants:

“I’m very proud of my great-grandmother. She was a part of the Stolen Generation, and she [has severe mental health issues].” (Interview 5, Deadly Deaf Mob cohort).

“You know, we’ve had bad experiences with the Stolen Generation where – you know, the white Australians came in and they took all our children and they took them to the Mission and that’s where my uncle was from. And, I remember once – you know, with the Stolen Generations one of my uncles had disappeared and I remember all the families being really upset during that time.” (Interview 6, Deadly Deaf Mob cohort).

“Like, and I’ve always gained, like, my confidence from, like, because my grandfather from the Stolen Generation and you know, he – the hardships that he went through when he grew up.” (Interview 8, metropolitan cohort).

“I did not know I was an Aboriginal descendant until I was 24. My dad was nearly a Stolen Generation. His mum died after their last sibling was born.... So, that was really, really scary when Dad told me. So, they tried to be as white as they possibly could.” (Interview 27, regional cohort)

“So, basically, how to do I start? So, I’ll start with my mum, ‘cause it sort of stems from there. So, my mum was part of the Stolen Generation. And, she spent, from the age of four until she was 18 in the homes. So, growing up with my mum, sort of, impacted me, as a person.” (Interview 28, regional cohort).

There were other examples in which the traumas of the past have been passed on to current generations, as expressed through the lingering injustice that Aboriginal and Torres Strait Islander communities feel as being dispossessed from their own country. One of the testimonies included a mournful account of an Aboriginal mother who said her young child aged three years old had died of an infection after a tooth extraction. There was no apparent investigation into the reasons why that this death had occurred, or sense that there had been any accountability on the health care professional or systems involved. Within that community alone, there were additional citations of suicide, and a murder of an Aboriginal man and a number of assaults that had not been fully investigated by the police. All of these traumatic episodes were clustered within just three interviews with participants from one Aboriginal housing complex (Interviews 18 to 20, remote cohort). The prevailing sense of injustice that lingered over the community has left them, and the researcher, with the sense that they had been abandoned.

8.5.3 *Repeated micro-retraumatisations*

A third category of trauma exposure observed were repeated micro-retraumatisations. The chapter on ‘intersectional discrimination’ noted the high frequency with which Aboriginal and Torres Strait Islander people were exposed to various forms of discrimination in their everyday life. One example provided was of a young Aboriginal man who described how he would be racially abused on his walks home from the town centre where he lived (Interview 20, remote cohort). Others spoke of being asked to leave shopping centres and eating places (Interview 11, metropolitan cohort). The frequency with which these everyday incidents of racism and ableism occurred acts as a succession of micro-retraumatisations, which accumulate and keep people in a state of despondency.

As is the nature of ‘intersectional discrimination’, these micro-retraumatisations of Aboriginal and Torres Strait Islander people with disability could be inflicted through

racism, ableism, or an interaction of both. Within the testimony, there were differences in how the participants spoke of being socially isolated because they were an Aboriginal and Torres Strait Islander person, compared to how they spoke of being socially isolated as a person with disability. As a person with disability, they spoke of being ignored, as if their existence did not matter. In addition to the physical and environmental barriers, there remains an awkwardness within society talking about disability, and people with disability themselves are the centrepiece of this social awkwardness. This was evident in the testimonies from many of the participants describing how they interacted socially with other people, citing everyday conversations where people talked around them to other people they were with, whilst appearing uncomfortable in speaking with them directly. The social awkwardness of others around people with disability was evident in professional settings, with specific examples provided when doctors and employment agents spoke to a person accompanying a person with disability rather than addressing the person directly. This was also evident in social settings, as described by an Aboriginal man with quadriplegia who commented that people felt uncomfortable talking directly with him:

“But – and, in general public as well, you know? Because, I get people, sometimes when I’m with my wife, like they won’t even talk to me. Like, that might be in a restaurant or another setting, because sometimes they’ll get the idea that mentally I don’t have the capacity.” (Interview 8, metropolitan cohort).

The social awkwardness points to a positioning of people with disability within society, which some disability scholars referred to in Chapter 1 called ‘othering’ (Mik-Mayer, 2016), is a constant for people with disability. The walls of nineteenth century institutions designed to keep people with disability out of sight from the rest of society have been replaced by social walls. People with disability might be physically present, but not valued as equal participants in social functioning. The sadness and frustration that the constant isolation causes people with disability is summarised by one young female participant, who at the conclusion of her interview said:

“I just want to be normal.” (Interview 10, metropolitan cohort).

By contrast, in describing encounters of racism, the participants said that they were recognised, but in being so were subject to intense animus and racial vilification. Whilst the racial dimension was more episodic, when it arose, it did so with an intensity that was personally directed. By contrast, the disability dimension of isolation is omnipresent, in that it is built into their environment such that they could not avoid or escape. However, the participant group were both Aboriginal and Torres Strait Islander and people with disability, so the disability and Aboriginal and Torres Strait Islander dimensions to their social isolation co-exist simultaneously. What the participants described was an overwhelming exposure to discrimination that was both constant (as a person living with disability encountering ableism) and acute (as an Aboriginal and Torres Strait Islander person encountering racism).

These constant and acute exposures to discrimination were seen to manifest into sadness and despondency. There are limitations by which clinical models of mental health can capture the totality of the traumas and psychosocial disability that is caused by chronic social isolation, inequality and discrimination. Nonetheless, the statistical data that is collected by the NATSISS shows that the pattern of intersectionality continues when it comes to self-reported mental health outcomes. As outlined in Table 8.5.3, Aboriginal and Torres Strait Islander people with disability are 5.2 times more likely to experience mental health distress compared to Aboriginal and Torres Strait Islander people without disability. The statistical data also shows a dispensation to self-suppress trauma, as suggested by elevated rates of alcohol and substance misuse.

Table 8.5.3: Mental health indicators, Aboriginal and Torres Strait Islander people – by disability status.

INDICATOR	Aboriginal and Torres Strait Islander people		
	With severe and profound disability	Without disability	Rate (x times likely)
Mental illness	26%	5%	5.2
Drug related problems	9%	3%	3.0
Alcohol related problems	8%	5%	1.6

Source: NATSISS (2016b).

8.6 Trauma as a contagious disease

The research also observed the presence of ‘trauma clusters’, where there were large proportions of people in a small community who displayed signs of trauma. The term ‘trauma clusters’ as used in this study is derived from investigations into clusters of health events where there are greater than expected number of cases that have been exposed to a serious illness or disease (for example, cancer clusters) within a group of people in a geographic area (Center for Disease Control and Prevention, 1990). The tight-knit nature of these communities meant that everyone within that community has had some personal or community exposure to trauma. One noted case was the example cited earlier in this chapter that chronicled a succession of traumatic episodes that were all cluttered within one tight-knit community. The testimonies of these traumas also attested to the lingering dependency that these episodes had left over the entire community.

The vocabulary used within a clinical model of mental health care is not adequate in explaining the overwhelming sense of sadness and abandonment that was observed in communities within this study. Not only was it felt by all of the people within the community; the overwhelming sadness and despondency was also felt by the researcher when visiting those communities. This experience of ‘catching trauma’ is not able to be described using the normal vocabulary of a researcher. The most apt description of the personal experience that came with witnessing intense concentrations people affected by trauma during the research is that it was as if the researcher “crossed a boundary line and entered another world”.

Upon the researcher’s personal experience of ‘catching trauma’, the vicarious nature of trauma that was observed in these small communities is described as operating more like an infectious disease within a community. In some Aboriginal communities visited in the research, the reports of inequality and discrimination were so intense and frequent that daily retraumatisations are almost inevitable. In effect, individuals who have experienced personal trauma are in a community engulfed by trauma.

8.7 Implications for medical models of mental health

Despite the prevalence of community-wide trauma, and its contagious nature, the interventions that people referenced were individually focussed psychotherapy (Interviews 20 and 28). The dominance of cognitive behavioural therapies as a solution for trauma is again an example of a focus on personal agency without consideration of the environment within which the individual exists. Ignoring the environmental context in which people live renders individually focused therapies useless. In this respect, depression and alcohol misuse become trauma suppressants (as opposed to clinical diagnoses as they might be regarded in a clinical model of mental health). Further, the incidence of alcohol and drug misuse in the statistical data presented in Table 8.5.3 suggests that depression and alcohol misuse appear to have greater efficacy as a trauma suppressant than clinical models of cognitive behavioural therapy.

It was rare for participants to use clinical diagnostic terms when describing their mental health status. Despite the high rates of traumatic episodes that the participants were exposed to, only four of the forty-one interviews specifically used the terms ‘depression’ or ‘anxiety’. Indeed, clinical models of mental health appear grossly inadequate in describing the prevailing sense of sadness and abandonment. Many people maintained that they were seeing counsellors, “*as they are supposed to*”, but found them ineffective in relating to their experience, both as an Aboriginal and Torres Strait Islander person and as a person with disability:

“If that person – psychiatrist was a Deaf person, or if they understood me or understood Indigenous people, it might be better. But at the moment I’m trying to work my way back into the Deaf community. I just resigned from work three weeks – a month ago because it was really affecting my mental health. I had anxiety attacks. I ended up in hospital because of anxiety. It became too much for me” (Interview 35, Deadly Deaf Mob cohort).

Others mentioned seeking to compensate for gaps in the clinical model of mental health service provision by sourcing cultural models of healing:

“So, on the coast there’s an organisation called Cultural Healing. It’s an Aboriginal organisation and within that team they have mental health workers.

So, I go to them if I need help. But they're not part of the unit [disability support unit], they're separate" (Interview 28, metropolitan cohort).

8.8 Transcending the despondency through expressions of hope

In defiance to the acute and pervasive inequality, discrimination and trauma experienced by Aboriginal and Torres Strait Islander people with disability, there were fleeting expressions in the giving of testimony where the participants, despite being surrounded by trauma and despondency, continued to carry on and promote hope.

One prominent example was an Aboriginal man from the remote community referenced earlier that had experienced a multi-faceted trauma and disadvantage. One part of his testimony appeared in Section 8.3 above relating to 'intersectional discrimination', and another part of his testimony was referenced earlier in this chapter in relation to contagious trauma. He gave testimony to his experience of seeing a counsellor "*as he was supposed to*". He said that he would spend an hour or so with his counsellor, but then while walking home, people would wind the window of their car down and yell out racial names towards him¹⁰. He said that that this immediately undid any positive feelings he had from his counselling visits, then to return to his community where other people within his community were affected by their own experiences of discrimination and trauma. He spoke of his despondency and feeling of not being able to escape the trauma. Then, in defying these thoughts, he finished his testimony by saying:

"I know that there is something stronger in here", pointing a single finger at his heart, "but I've just got to get there." (Interview 20, remote cohort).

Other testimonies conveyed messages of hope and resilience. This chapter closes with a yarnning piece that comes from a young woman who had spent the first half hour of the interview speaking to her experiences of inequality and discrimination in

¹⁰ The participant recalled the exact racist slurs that he was subjected to during his interview, which out of respect for the participant are not dignified in this thesis by reporting verbatim.

education, health and employment. As the discussion of these topics taper, she makes a disclosure of a traumatic episode that had affected her deeply, before resiliently making her expression of hope in which she says she is not going to let it “*ruin me with sadness*” (Interview 41, metropolitan cohort):

Yarning Piece: ‘Not ruined by the sadness’

The interview is approaching the half hour mark, and with some idle chatter, the discussion is starting to peter out. I look to close out the interview by providing an opportunity to put on the record what she hasn’t already spoken about. Then comes a bombshell disclosure.

INTERVIEWER: “So, this is your story, and I’m just wondering if there’s anything that you wanted to say for the record, that you feel like, you haven’t spoken of already. You don’t have to say anything, but if there’s something that you just kind of go, ‘I want to be able to say this’, given that we’re collecting your story. Is there anything over and above what you’ve spoken about already?”

PARTICIPANT: “*There is one thing. Like, the main thing that keeps me going is, like, my girlfriend actually committed suicide five months ago.*”

The revelation and its timing come as a bolt from the blue, as we had already covered so much personal terrain – education, employment, health, transport – during the interview. It comes at the last moment when things appeared to be winding up, yet it was sitting there all along. It speaks to the intensely personal nature of suicide and trauma, and how its impact can remain buried, despite feeling that you are in on an open and transparent discussion.

The discussion re-opens. It’s like we start over again.

She reveals the closeness of their relationship, and how it had impacted upon her at a time she was having her own health concerns. I remind her that it’s okay for her to stop

if it's making her feel uncomfortable talking about it, but she says it is something she wants off her chest.

"It's like there's a lot of stigma around suicide as well and I think, it needs to be talked about a lot more and a lot more people need to be educated about not only suicide, but mental illness and the whole, like, aspect and everything about it as well. And, just the whole treatment needs to be improved, no matter if it's public or private. It all just needs to be improved."

In the face of the personal impact of multi-faceted discrimination and trauma, she has transformed her personal experiences into a source of strength. It is the authenticity of her lived experience of disability and trauma that shines through as a penetrating insight into how resilience is made intrinsic to people with disability. It does not come across as a belligerent 'stuff you' to the world. Instead, it is a desire that her experiences of distress are a beacon to circumvent the unnecessary distress experienced by others. It is representative of a worldview of humanity that I come across in the disability community, time and time again.

"It really did show me that, like, instead of letting it, like, ruin me with sadness, I just really want to use it to change peoples' lives and to motivate me to get my [University] degree, to get out there and to make change happen to improve the system, and to prevent this from happening to other people... It has really inspired me just to continue and just to continue to improve the system and just to keep going and, yeah. Not only for myself, but for her."

(Interview 41, metropolitan cohort)

8.9 Concluding comments on social isolation, discrimination and trauma

This chapter builds upon the previous chapter's findings of intersectional social inequality by presenting a sustained account of social isolation, discrimination and trauma that is primarily recounted through the personal testimony of the participants. The findings in this chapter cover both the second and third aims of the research. In

relation to the second aim of the research to describe the experiences of social inequality, both the testimony and statistical data again show a multi-faceted and sustained intersectional effect in the social isolation experienced by Aboriginal and Torres Strait Islander people with disability.

The personal testimony presented in this chapter has a separate purpose that connects the research to its third aim. Appreciating the experiences and human impact of social isolation, discrimination and traumas from first-person testimony is vital in constructing a participatory research methodology that is authentic to the nature of social isolation, discrimination and traumas of participants in research that involves marginalised and vulnerable groups. The positionality as a community-embedded researcher meant that the need for a discrimination and trauma aware approach to was innately understood at the commencement the research. What the testimony in this chapter has done is provide the detailed evidence to advance a more elaborate development of participatory research model that involves discrimination and trauma affected populations.

The case examples and yarning pieces at the close of this chapter provide expressions of hope that transcend the sadness and despondency that infects socially isolated people and their communities. The salient point in these expressions of hope is that ‘intersectional inequality’ is not inherent within the identity of a person who is a member of multiple and intersecting marginalised groups. Instead, the inequality that they experience should be viewed as product of the socially isolating forces that they are surrounded by. These expressions of hope, delivered by the participants who have all come from a position of vulnerability, should also give hope to researchers and policy makers outside the community that the problem of social inequality is not intractable.

These expressions of hope provide the segue to the next chapter which is on the cultural and community participation of Aboriginal and Torres Strait Islander people with disability, addressing the fourth and final aim of the research. At this point, the thesis undergoes a change in tone as its focus changes from social inequality to a ‘cultural model of inclusion’ that is generated from distinctively Indigenous values and beliefs.

9. RESULTS: Cultural and community participation by Aboriginal and Torres Strait Islander people with disability

9.1 Introduction to the chapter

The previous two chapters detailed the detrimental impact of inequality, social isolation and discrimination has upon the health and wellbeing of Aboriginal and Torres Strait Islander people with disability. Despite the level of accumulated social deprivation, within the testimony came expressions of hope, indicating that the inequality experienced is not inherent in their identity as Aboriginal and Torres Strait Islander people with disability, but a product of the socially isolating forces that they experience.

These expressions of hope in defiance of inequality provide the entry point to this chapter, which presents the findings of a culture of inclusion that exists within Aboriginal and Torres Strait Islander communities. The finding from the literature review in Chapter 2 that there is no word for ‘disability’ in Aboriginal languages (Ariotti, 1999) points to an Indigenous culture that is inclusive of people with disability, a conclusion that has been supported by other research of Aboriginal communities in Australia (King et al, 2014; Rivas Verlade, 2018) and amongst Indigenous cultures worldwide (Te Pou o te Whakaaro Nui, 2016; Kapp 2013; Rivas Verlade 2018). This study extends upon earlier research into the social construction of disability in Aboriginal and Torres Strait Islander communities, demonstrating the inclusive qualities of their culture as an affirming force in their health and wellbeing, and thus moderating the detrimental impact of social inequality and isolation.

The findings in relation to cultural and community participation by Aboriginal and Torres Strait Islander people with disability comprises two parts. Continuing with the mixed methods approach (Leech and Onwuegbuzie; 2008; Creswell and Plano Clark, 2011; Bowers et al, 2013; Shorten and Smith, 2017) in presenting the results, the first part will present the statistical data and testimony on cultural and community

participation. The statistical data drawn from the NATSISS data will show that across a number of indicators, Aboriginal and Torres Strait Islander people with severe and profound disability participate in community and cultural events at the same rate as Aboriginal and Torres Strait Islander people without disability. This finding is particularly significant as the finding of parity in cultural and community participation is the sole categorical exception to acute and pervasive inequality that Aboriginal and Torres Strait Islander people with disability otherwise experience, as shown in the data for all other indicators presented in Chapters 7 and 8. The testimonies from the participants are then presented to illustrate the nature of cultural and community participation enjoyed by people with disability within Aboriginal and Torres Strait Islander communities, in support of a finding of a culture of inclusion.

The second part of this chapter views participation in this research as an exercise in cultural and community participation by the First Peoples disability community. In noting that the research has been designed and led from within the First Peoples disability community utilising research methods that have been designed for research involving a vulnerable population group, this part looks at the efficacy of the research that was aimed to promote participation through an approach that was both culture and trauma aware. The cultural and community participation outcomes for this research are demonstrated in three ways:

- (i) First, through the unsolicited testimony where the participants' responded to their being involved in the research;
- (ii) Second, through analysis of the interview metrics which demonstrated how the participants were willing to progressively disclose underlying traumas during their interviews; and
- (iii) Third, through the presentation of testimonials on the impact of *Culture is Inclusion* as a publication that has promoted the voices of Aboriginal and Torres Strait Islander people with disability in the public domain.

In demonstrating the participatory outcomes for this research as a First Peoples community-led activity, the second part of this Chapter fuses the third aim of the research of devising a research approach that is authentically participatory of

vulnerable groups, with the fourth aim of the research to explore the inclusive qualities of Aboriginal and Torres Strait Islander culture.

To represent the tonal shift from inequality to inclusion that occurs in this chapter, it starts with a yarning piece, as a reflection on how Aboriginal and Torres Strait Islander culture is the pivot point through which the switch from inequality to inclusion is effected.

9.2 Cultural participation as a pivot point from inequality to inclusion

The notion of a pivot point where the testimony collected in this thesis turned from social isolation to inclusion was observed in the midst of interviews with individual participants. Once such example where this occurred was in the personal story narrated by an elderly Aboriginal man in a remote community who had been discharged from hospital into homelessness following a major knee operation. The health inequality dimension to his story is recounted in the yarning piece entitled ‘Health care not befitting our nation’ within Section 7.7. The yarning piece below picks up his story at the point where the interviews pivots from his experience with the health care systems to a discussion about his family, and how his ‘living bush’ community, a term which he uses to refer to people who live in town camps, all look out for each other.

YARNING PIECE – “I want to go home... for my own blood family.”

(continued from Section 7.7 – ‘Health care not befitting our nation’)

.....He then spoke of what it was like “*living bush*”. He described it as safe, but it was cold and there was no bathroom or running water. He has to get water for himself with a bucket from the local rodeo ground, which is across the road from the camp site. Stating the obvious, I point out that this might be tough going with a crook knee, to which he laughs ironically and readily agrees.

He speaks of a common bond between him and others who live bush and says that they all look out for each other. I ask what would happen if he needed urgent help, and he

said that the people he lived with would call the ambulance to come and get him, as some of them have their own phones. He makes the point he is not the only one in his situation.

“So, we need to tell the government that we’ve got men with a disability, living bush.”

But despite sharing a common bond with his ‘living bush’ community, he speaks with a tinge of regret at his lack of personal space and the infringements upon his dignity. These are basic acts of living that many Australians might take for granted. He said;

“You can’t get breakfast... because when you put it [fresh food] out there you’ve got to hang them up a tree and the crows come and eat, or dogs around there [if it is left on the ground].”

His family checks on him regularly and brings him food and fire wood. It is clear by his demeanor when he speaks of them that his family is his strength. But they live too far away. I ask him why he doesn’t stay with them, and he replies;

“It’s just overcrowded. There’s too many people in kid’s house, can’t fit in”.

These are the words of a humble man who doesn’t want to be a burden.

Despite being relatively young by Australian standards – by my reckoning, he is some twenty-five years younger than the national average life expectancy – there is already a sense of a final destiny creeping into his story. What matters to him in his future is simply a roof over his head and his family around him. When I ask are there things that he would like that would make things better for him, his response is a dignified request.

“I want to go home. That’s all. Yeah. Get – get my family to come. For my own blood family. My daughters.”

(Interview 25, remote cohort)

9.3 Parity in cultural and community participation

This chapter commences with a presentation of statistical data that shows a parity in the participation of Aboriginal and Torres Strait Islander people in cultural and community events.

Parity in cultural and community participation by Aboriginal and Torres Strait Islander people within their communities is reflected in the statistical data as presented in Table 9.3 For all indicators collected by the NATSISS on cultural and community participation, Aboriginal and Torres Strait Islander people with severe and profound disability reported participation in cultural and community events at the same rate as other Aboriginal and Torres Strait Islander people. The parity of participation was shown in all indicators of cultural and community participation that were collected, including involvement in ceremony, speaking an Indigenous language, and other cultural activities. Parity in the participation of cultural and community activities is reflected in the indicators by participation rate of Aboriginal and Torres Strait Islander people with disability which is 1.0 to 1.1 times that of Aboriginal and Torres Strait Islander people without disability.

Table 9.3: Cultural inclusion indicators, Aboriginal and Torres Strait Islander people – by disability status.

INDICATOR	Aboriginal and Torres Strait Islander people		
	With severe and profound disability	Without disability	Rate (x times likely)
Participated in cultural activities	62%	65%	1.0
Involved in ceremony	67%	62%	1.1
Identifies with clan, tribal or language group	67%	61%	1.1
Speaks an Indigenous language	20%	19%	1.1

Source: NATSISS (ABS, 2016a).

The parity of cultural and social participation by people with disability within their own Aboriginal and Torres Strait Islander communities is the sole categorical exception in the data on the inequality that Aboriginal and Torres Strait Islander people with disability experience in their access to systemic support and services (Chapter 7). When the findings on cultural inclusion in this chapter are compared to the earlier findings of social inequality, the contrast infers that Aboriginal and Torres Strait Islander people with disability are included within their community structures, but regress towards social isolation and inequality upon leaving the culturally protective forces of their community and interacting with systems outside.

9.4 “*We go hunting together*” – Personal testimonies on cultural and community participation

This section presents the testimony from the participants on their experiences of inclusion in cultural and community activities and what this means to their social health and wellbeing. As with the testimony previously presented, these illustrative quotes were volunteered by participants in the natural course of their interview and not induced through a direct questioning technique.

There are four themes in the testimony on cultural and community participation. The first theme relates to the differences in the expression of cultural and community participation by people living in remote areas compared to people living in metropolitan areas. The second theme addresses the preservation of dignity that comes when people with disability bear a responsibility in ongoing cultural practices. This second theme was prominent in the testimony of those who were recognised as Elders in their community. The third theme highlights the special place that Aboriginal art has as a medium to facilitate the inclusion of people with disability. The fourth theme highlights the aspirations of participants to learn more about their traditional culture in the place from which they come, but had been denied to them in the past because of their impairment. This fourth theme was prominent amongst the Deadly Deaf Mob cohort.

9.4.1 *Differences in expressions of cultural and community inclusion by people living in metropolitan and remote areas*

Whilst the statistical data has produced a population-wide finding of cultural and community participation, there were differences observed in how the participants spoke of their inclusion based upon where they lived. For participants living in remote areas, cultural and community participation was more likely to be expressed a natural part of daily life. A defining attribute of the cohort from remote areas is that they predominantly lived in self-contained Aboriginal communities. In many cases, their testimony to cultural and community inclusion was obverse to their testimony on their inequality in accessing health services and disability supports.

In comparison, participants who lived in metropolitan areas were more likely to describe cultural and community participation in aspirational terms, which was regularly expressed as a yearning for more education on the culture from the place they identified as the source of their Aboriginal heritage. A defining attribute of the participant group living in metropolitan areas is that they tended to be living away from their Country¹¹ and community with which they identified, and the greater disconnectedness from where they and their family were from meant that they had less frequent exposures to cultural practices. Within the thematic analysis below, a geographical identifier has been attached to each of the illustrative quotes to show the distinction between testimony provided by participants living in remote areas to participants living in metropolitan areas.

9.4.2 *The preservation of dignity in people with disability who bear an ongoing responsibility for cultural practices*

As within their traditional role as cultural custodians in their community, those participants who were recognised as Elders in their community were amongst the most vocal in their promotion of culture. Aspects of the testimony from Elders expressed a longing for the return of traditional Aboriginal and Torres Strait Islander cultures into daily life, lamenting the dilution of traditional structures of responsibility within

¹¹ The term 'Country' has particular cultural significance to Aboriginal people to convey the cultural and spiritual connection have to the place where they are from. In this context, 'Country' is a proper noun and it is appropriate for it to be capitalised.

communities. For some, cultural longing took a form of reminiscing about a time when traditional cultural values dominated social life:

“Sharing and caring was with our people before white people came to this country. Responsibility was with the family and the community.” (Participant, Elders’ Forum)

For others, the reminiscence was far more personal, recalling days when they could do things that they physically could no longer do, but had managed to maintain a spiritual connection with cultural life, just by being there. One of the participants, an Aboriginal Elder who is an amputee and uses a wheelchair, spoke of her younger days when she was hunter-gatherer for her family:

“Hunting. Camping out. Hunting. Always. Then we lived and we raised – I raised my first son so we didn’t go out – we did go out just for a day, come back, go out the next day, go and get bush turtles. Go at night time shooting kangaroo.” (Interview 34, remote cohort).

The Elder then went onto say she said that her mobility impairment means that she doesn’t get into the thick of the hunting, and that role had now has passed to her husband, (who, by her account, isn’t as good at sourcing traditional foods as she was, so sometimes they just have to go to the shop and buy things). However, she continues to maintain a spiritual and emotional connection to the traditional life, which is one of inclusion:

“We go hunting together. He goes out, I sit in the car and wait when he goes out hunting.” (Interview 34, remote cohort).

In describing what she means when she says *“we go hunting together”*, she said that she sits in the car whilst her husband physically goes to find traditional food. She says that as the traditional food gatherer, she calls out her knowledge in how to find food whilst sitting in the car. Significantly, the operative pronoun in her testimony is the use of the collective ‘we’ over use of the singular ‘he’. *“We go hunting”*. Despite not being the one who physically throws the spear, the plural seems to indicate that she is emotionally and spiritually connected to the activity. In this way, she describes

maintaining her personal dignity by maintaining an ongoing role and responsibility in continuing cultural practice, in this case the gathering of food. Her role in cultural practice is thus respected, even though it is someone else who performs the physical task. She feels as though she is part of the activity, irrespective of the degree of her physical participation, and as such is included in this pivotal activity.

9.4.3 *Aboriginal art as a medium for cultural connection and inclusion*

Aboriginal art was mentioned several times in the testimony as holding a particularly special place in cultural life of Aboriginal and Torres Strait Islander people. When participants referenced their personal connection to art, they described it as a medium through which people with disability could be included in a connection to their culture. One participant presented art as a means of communicating between generations, and between Deaf people and the hearing world:

“[My grandmother], she used to teach me a lot of things. You know, she taught me all about Aboriginal art, and she didn’t know how to sign, and I didn’t know how to communicate with her, but I’ve become very successful with my Aboriginal art, so I’m really proud of my grandmother.” (Interview 5, Deadly Deaf Mob cohort).

The affirming properties of art as story-telling emerged as people spoke of their art as a way that they could personally connect with their own personal Aboriginal and Torres Strait Islander heritage. One participant told of his personal story of how he was drawn to a traditional form of Aboriginal art:

“I’ve worked in disability for the last ten years specifically with Indigenous disabilities. So, about eight years ago I started painting. And, I’d always liked painting but, kept saying to my partner at the time, I’ve got these paintings in my head I want to start doing some stuff. For my 50th birthday, he bought me a canvas and paints and said, “Look, stop talking about it, just do it.” And, that totally had a whole new chapter in my life with the art. [I gravitated to] the dot style painting. Traditional stuff. Telling stories.” (Interview 26, regional cohort).

Others had extended their personal connection with culture through art by promoting it as a medium to connect to others and to their community and culture:

“So, some of the good stuff I’m doing now is part of [an Aboriginal] Art Group, that Uncle runs. So, it’s an art group for people with disabilities. So, I’ve done a lot of, like, paintings and stuff that have gone on exhibition so that, sort of, keeps me strong. Because I like my art and I like doing it. I find it really helps with stress.” (Interview 28, regional cohort).

9.4.4 *Special issues in access to cultural education by Deaf Aboriginal people*

Whilst the statistical data and testimony presented on cultural and community practice was predominantly expressed in positive terms, there was one notable exception to this finding. This exception was peculiar to the Deadly Deaf Mob participants, who overwhelmingly, as a cohort, spoke to there the desire for access to cultural knowledge that had been denied to them in their earlier life due to the deafness.

The Deadly Deaf Mob came across as proud of their contiguous cultural identities, with their Aboriginal cultural identity standing side by side with their Deaf cultural identity. This was exemplified from the very first round of participant interviews, when a group of Deadly Deaf Mob stayed after their interviews and were observed standing together around a map that showed the Aboriginal nations of Australia, with each participant pointing on the map to the Aboriginal nation where they were from and finger-spelling its name.

The Deadly Deaf Mob participants had uniformly expressed a lifetime longing for greater education on their Aboriginal culture and heritage. They specifically wanted to know more about their cultural heritage that they say had been denied to them earlier in their life because they were Deaf. They were quite specific as to the cultural knowledge that they wanted to access, and that it had to be cultural knowledge on the Aboriginal cultural heritage from the place from which they identified as coming, and not merely education on Aboriginal cultures in general. Their longing for greater access to cultural education by Deaf Aboriginal people was illustrated by one of the Deadly Deaf Mob participants who expressed a desire to learn about his local Aboriginal culture that he had been deprived of because he was Deaf:

“Can I just say one more thing? I just had a thought, which is really important for all, for the whole community. The biggest key issue that we will all be challenged with is not understanding the history and the culture. So, for example, you know, my family are up at [my home town], and they’ve got caves out there which have a lot of history in there. And, as a kid, I’ve got no knowledge of my history, and that’s only because I’m Deaf, which impacts on who I am today. And, it’s so important for Aboriginal Deaf kids to pass on their traditional beliefs and so that way, because we don’t want them to lose their identity.” (Interview 4, Deadly Deaf Mob cohort).

Another of the Deadly Deaf Mob participants said that access to cultural education had been denied to her as she left her local community where she was born and moved around from one city-based Deaf school to another. She spoke with regret that she had not learned about her culture at a young age, rather than having it left later in her life:

“I do identify myself as an Aboriginal, but I have missed out on so much information. But, I’m now at a stage in my life where I want to learn all about my culture and about my language and about my heritage as an Aboriginal person. And, I know it’s never too late, but I wish I had of learnt that from a very young age.” (Interview 6, Deadly Deaf Mob cohort).

Speaking to a gap in an acceptance of their contiguous cultural identities, another of the Deadly Deaf Mob participants described being accepted by one aspect of her identity, being a Deaf person, but not being accepted on another aspect of her identity, being an Aboriginal person:

“I’ve missed much of my Aboriginal identity; I don’t know that part of myself, of me. I’ve never been taught it, or taught about it, so I feel like while I’ve had the Deaf community, I’m not part of my Aboriginal community.” (Interview 39, Deadly Deaf Mob cohort).

In addition to expressions of longing for greater inclusion through the sharing of cultural knowledge, there were examples of access limitations that Deaf Aboriginal people had experienced in participating in meetings of Aboriginal community organisations. In one example, a Deaf Aboriginal person spoke of wanting to

participate in the local Aboriginal Land Council meetings but had been denied access to an Auslan interpreter (Interview 6, Deadly Deaf Mob cohort). He said that the Land Council had told him that they didn't have the funding to provide an Auslan interpreter, and that was the reason for his exclusion. Taking exception to that explanation, he self-advocated for his right to participate, which he said came as a shock to them *"because they'd never heard about people with disabilities wanting to be involved"*, but through persistence he is now a member and an active participant at Land Council meetings.

"But, the issue I have is the communication and sometimes they do struggle with the fact that I'm a Deaf person. I would like to have an interpreter turn up to NAIDOC Week¹². Maybe we could have a Deaf organisation represented at NAIDOC Week because it represents all the Deaf Aboriginals." (Interview 6, Deadly Deaf Mob cohort).

The denial of access to an Auslan interpreter in this example serves as a point of reflection for Aboriginal organisations to avoid subconsciously mirroring the non-inclusive systems and structures they are required to interface with and are conditioned to seeing on a regular basis.

9.5 Reactions to the participatory research approach

As this research was led from within the community of which Aboriginal and Torres Strait Islander people with disability are a part, this research can be seen as a cultural and community activity in its own right. This second part of the chapter looks at the responses from participants and connected stakeholders in the Aboriginal and Torres Strait Islander and disability sectors, to see the extent to which this research has lived up to its participatory aims. In essence, its purpose is to evaluate how successful the research has been in operationalising an authentic model of emancipatory research. The efficacy by which the research has connection with Aboriginal and Torres Strait

¹² NAIDOC Week is a nationally recognised celebration by Aboriginal and Torres Strait Islander people of their culture that is marked by community events and ceremonies across Australia. It is held in the first full week in July each year. It has particular cultural significance for Aboriginal and Torres Strait Islander people, and increasingly to other Australians.

Islander people is shown in: the unsolicited remarks from participants on being involved in the research; an analysis of the interview metrics; and testimonials in response to the community-focused publication of *Culture is Inclusion*. What these reactions first show is how positively the First Peoples disability community have responded to its participatory aims and methods, and second, how participation in this research as a cultural and community activity has brought people who have shared a similar experience together into a larger First Peoples disability community.

9.5.1 *Engagement of participants to the ‘rock up recruitment’ strategy*

Two aspects will show how the First Peoples disability community have engaged as participants in this research. The first aspect was their willingness to be become a participant in the research, which is illustrated in the breadth of the participant profile, as well as examples from the researcher’s field notes to illustrate how the participant recruitment strategy was received in the research sites. The second aspect is how the participants have positively remarked on being afforded the opportunity to present their testimony on their terms, time and in a place that they feel safe. These remarks extracted from the participants’ testimonies are indicators that the interviewing practices that were devised specifically for this participant group had met a threshold of their trust, which in turn facilitated a breadth and depth in testimony that, by the participants’ accounts, had not been previously provided for them within a research setting.

As specified in Section 5.3, this research used a convenience and purposive strategy for the recruitment of participants. This gave effect to Principle 3 of the research as specified by the First Peoples disability community (Section 4.3), which stated that the research was to be inclusive of all people who wish to participate, subject only to their self-identification as a member of the First Peoples disability community. In terms of the participant profile that was generated and detailed in Table 5.3.5; 47 people were interviewed within 41 interviews, all of whom identified as being Aboriginal or Torres Strait Islander people and living with disability or an immediate family member involved in their care. There was no apparent gender bias in the willingness to participate, with 25 females participating (53.2% of the total participants), and 22 males participating (46.8% of the total participants). There were also a cross-section of participants living in metropolitan New South Wales (11 interview participants),

regional and remote New South Wales (15 interview participants) and remote Northern Territory (10 participants) locations. In addition, there were 11 participants where the interview was conducted in Auslan, and a separate Forum attended by 11 Elders of the First Peoples disability community. Every participant who was asked whether the interview could be audio recorded consented. Finally, there were no issues or complaints that were raised by any of the participants in relation to the ethical conduct of the research to date.

As referenced in Sections 4.5 and 5.3.7, the term ‘rock up recruitment’ was used by the researcher to reflect a willingness to work with established communication structures in Aboriginal and Torres Strait Islander communities, and to make recruitment processes less alienating for prospective participants. The methods chapter (Chapter 5) described the processes that the researcher used to initiate recruitment of participants. What was observed as the research progressed was how ownership of the research processes was transferred from the researcher to the community. In effect, the community assumed greater control of the recruitment processes. There were four examples drawn from the researcher’s field notes that illustrate the transfer of ownership from the researcher to the community, whereby the participant recruited the researcher, rather than the other way around:

Example 1: Deadly Deaf Mob (interviews 2 to 6 in New South Wales; interviews 35 to 40 in South Australia)

The first example involves the Deadly Deaf Mob, who were the first cohort to be interviewed. Early in the research, before interviews had commenced, the convener of the Deadly Deaf Mob’s social network asked the researcher if they could be one of the first participants to be interviewed. It was in these early discussions that our mutual ambition to conduct the interviews in Auslan was forged, as we were both unaware of Auslan being used to promote inclusion in research before. Members of the Deadly Deaf Mob living in the state of New South Wales were invited to participate via their social networking medium. The Deadly Deaf Mob then coordinated the schedule of individual interviews by themselves. They also used the interviews as an opportunity to connect socially. This initiated the introductions of people within the Deaf Aboriginal

community, some whom had not previously met others from their community prior to the research.

Not long after the New South Wales-based interviews for the Deadly Deaf Mob were completed, the convener moved state to South Australia. She then contacted the researcher saying that she said been speaking with her new local community of Deaf Aboriginal people about the research and said that they were very keen to participate. This request from the Deaf Aboriginal community culminated in a second unanticipated round of interviews. Again, these interviews were conducted in Auslan, and again initiated a social interaction of people from the Deaf Aboriginal community, some of whom had not known each other prior.

Example 2: An unannounced visitor (interview 13)

The second example relates to how the ‘Koori grapevine’, a colloquial term used by Aboriginal and Torres Strait Islander people to describe informal communication networks supported by word of mouth, supported the recruitment of participants. In this case, a young Aboriginal girl arrived unannounced at the office of First Peoples Disability Network, in Redfern. She said that her mother worked in the disability sector and had heard about the research, so she said that she had turned up to tell her story. In effect, the ‘rock up recruitment’ approach had been reversed, with the participant ‘rocking up’ to the researcher.

Example 3: Koori Radio (interviews 15 to 17)

The third example demonstrates the effectiveness of ‘rock up recruitment’ as a strategy that is supported by community when it works within Aboriginal and Torres Strait Islander communication networks. It involves a visit to a remote site in western New South Wales. In preparation for the visit, the researcher had forwarded a general notice of the planned research interviews through the First Peoples Disability Network. Upon arrival in the Aboriginal community, a colleague travelling with the researcher went to the local government office saying that we would be interviewing Aboriginal people with disability, to

which the government officer replied that there were none in that town. At the same time, the researcher ‘rocked-up’ to the local Koori radio station and was invited to speak impromptu about the research. By the time the researcher had made the short walk back to where the interviews were conducted, a mother and her child with disability were waiting with their family ready to be interviewed. Another two participants from the Aboriginal community arrived later in the morning.

Example 4: Men’s group in a remote area (interviews 21 to 25)

The researcher was introduced to a men’s group at a remote location, via a mutual contact affiliated with a regional arts community. Prior to the interviews, the researcher had previously visited the research site on a number of occasions in an informal capacity, taking an unspoken background presence at community activities (for example, cooking sausages at community barbecues and sitting in on community meetings). Hence, by the time the interviews were to commence, he was recognised by some of the men’s group, if not well known.

It had occurred to the researcher in his previous visits that in wearing a cochlear implant, some people were mistaking him for being a policeman. As this might be threatening to some prospective participants, the researchers weaved lighthearted comments about being Deaf and not a policeman when introducing the research with the men’s group as a whole. This disclosure initiated a personal introduction to an Aboriginal man from the group who was also profoundly Deaf. The researcher then said that he would then sit in another room, and whoever wanted to come and tell their story, could tell their story in as much or as little detail as they wanted to.

The first participant came into the room after few minutes. When the first interview had ended, the researcher looked out into the hallway and saw that a group of five or six participants were sitting lined up much like a doctor’s waiting room. Unknown to the researcher, an Aboriginal community worker at the centre had driven out to pick up some additional participants from where they lived and brought them so they could participate in the interviews. In total,

five interviews were consecutively conducted over a period of nearly two hours.

9.5.2 *Testimony on the participants' engagement in the interview*

The fourth research principle that came from the First Peoples disability community prescribed in Section 4.3 was that the research needed to be discrimination and trauma informed, acknowledging the unique sensitivities of conducting research that includes people who are both Aboriginal and/or Torres Strait Islander and have disability. The method of doing this described in Chapter 5 comprised an unstructured discussion and a style of interviewing that allowed the participation to 'tell their story' on their terms, time and sense of place.

An underlying aim was to elevate and promote the voices of Aboriginal and Torres Strait Islander people with disability. Whilst not asked question about their reaction to participating, a number of the participants offered comments during their interview responding to the research as a participatory process, independent to the content of their testimony on the issues that were the main focus of the research. These comments are captured in extracts from the testimony below which indicate the efficacy of the research methodology in achieving this underlying aim.

In the very first interview conducted, one participant made a comparative observation about the empowering quality of being asked what was important to them, contrasting the participant-centred questioning to the condescending treatment that they were normally accustomed to:

“There are other people out there who need that support and that encouragement to get up to that level of being happy with themselves and then looking towards a future of, you know, what they can achieve as an individual and where they want to go in life. And, unfortunately, that's never been laid out to people. They say, 'Here's your service. There you go.' They don't talk to you about, 'What else would like to achieve in life?' None of that's included.

“You’ve got your social program. You get your house assistance, you know? You know? The domestic assistance and the personal assistance. You get the shopping assistance but no one ever asked you, ‘What do you want out of life?’ That’s a question that’s been missing. No one’s ever asked that question, that I know of, to people with disabilities, who are quite capable of achieving a degree or that. But, because you’re in a wheelchair, you’re seen as have no intelligence. You can’t hear. You’re talked to like you’re Deaf.” (Interview 1, metropolitan cohort).

Other participants alluded to the degree of comfort that the style of interviewing afforded them, enabling them to speak about personally sensitive matters that they had not told other people close to them, even their closest family and friends. One example is that presented in Section 8.5.2 where a mother spoke candidly on the personal impact of having her two children removed from her care (Interview 29, regional cohort). This interview was conducted over two sessions after the first session was paused to allow the participant to take a break. In resuming the second interview, she said that she wanted to continue to get things off her chest. Another participant who had an anxiety disorder said that he had not told many people about what he was going through out of a fear of being stigmatised. Nonetheless, the interview methodology allowed him the space to speak confidentially about the nature of his condition and the impact that his anxiety disorder had upon his life, revealing candidly things that he had not disclosed even to people who were close to him:

“So, I didn’t disclose anything. Not many people know that story about me. Some of my closest friends, to this day, just don’t believe it.” (Interview 9, metropolitan cohort).

There was significant diversity in the responses of participants to the closing discussion prompt when asked :what matters to you in regards to your future?” In many cases, this was met with long pauses, sometimes “great question”, with an inference from many of the participants that they didn’t know how to answer that, as they hadn’t been asked that before. There was one participant from the Deadly Deaf Mob whose initial reaction was:

“Well, to be honest I can’t think.” (Interview 2, Deadly Deaf Mob cohort).

Then after a period of thinking, he opened up to speaking excitedly about a number of ideas that he had about acting as a mentor and role model for other Aboriginal Deaf children who were possibly experiencing that same issues that he had lived through:

“Look, there’s so many things out there. Like – but, I don’t know which one to choose, you know. I don’t know what to talk about. You know, I’ve got so many different ideas. Like, there’s so many things I could talk about.” (Interview 2, Deadly Deaf Mob cohort).

However, there were the occasional cases where asking about what mattered to a person’s future provoked a response that was tinged with fear and uncertainty. One mother of a child living with severe and profound disability in a remote community, in the midst of her struggles for daily survival, found thinking of the future for her child daunting. When asked what mattered in her child’s future, she replied:

Participant: *“That’s what I worry about.”*
(At this point, the participant started tearing up.)

Researcher: “Are you okay?”

Precipitant: *“No. I ...you know. But, then me family’s here. I don’t know, we just got to work around it.”*
(At this point, the interview stopped)
(Interview 15, remote cohort).

9.5.3 *The ‘twenty-minute rule’ - progressive disclosures of trauma*

One of the observations that the researcher made over the entirety of the interviews was the progressive disclosure of underlying traumas by participants the longer the interview went. The yarnning piece entitled ‘not ruined by the sadness’ in Chapter 8, where a young woman spoke of the suicide of a close friend came at the thirtieth minute of that interview, just as the interview was intending to close.

Whilst every participant’s testimony followed its own unique path, reflecting the diversity of personal backgrounds and experiences, there was a general pattern to how

the interviews flowed. The participants were initially asked “what is your story?”. The purpose of this question was to allow the participant to situate themselves in the interview as they saw fit. In response the participants commenced with a short statement about themselves, family and where they were from. In almost every case, the participant agreed to identify in words, and many of the participant specifically referenced an Aboriginal nation that they identified with within the opening minutes of their testimony, for example:

“I am a Ngarrindjeri woman” (Interview 1);

“Okay. Look, I’ll introduce myself. I’m [female and] I identify myself as Aboriginal and I’m Deaf. My mum and dad, you know, I have two different tribes. I’ve got mum, she’s from [Aboriginal nation name unclear]. I’m sorry I’m not pronouncing that right.” (Interview 6);

“I’m also a proud Wanneroo and Kamilaroi man.” (Interview 8);

“So yeah, I’m, you know, 45 years old. Descendent of the Worimi people.”
(Interview 9);

“Okay. Let me see, I didn’t grow up on country. I’m, my dad was a Wiradjuri man.” (Interview 26);

“Okay. Well, I’m [female and] I’m 19 years old. I’m of Torres Strait Islander descent.” (Interview 41).

By contrast, it was uncommon for participants to refer to their impairment, and exceedingly rare for them to mention a disability diagnosis. This supports a finding that Aboriginal cultural connectedness is primary in an Aboriginal and Torres Strait Islander person’s identity.

The next phase of the interview involved participants speaking on specific issues relating to inequality in their access to services. This testimony was frequented with the issues that they had intuitively prioritised as important to them, illustrated by very recent examples from their personal history. As a guide, the main issues that were most

commonly cited related to events that had occurred to them recently and involved transport, housing, education, and health. These issues of systemic inequality are covered in Chapter 7 of this thesis.

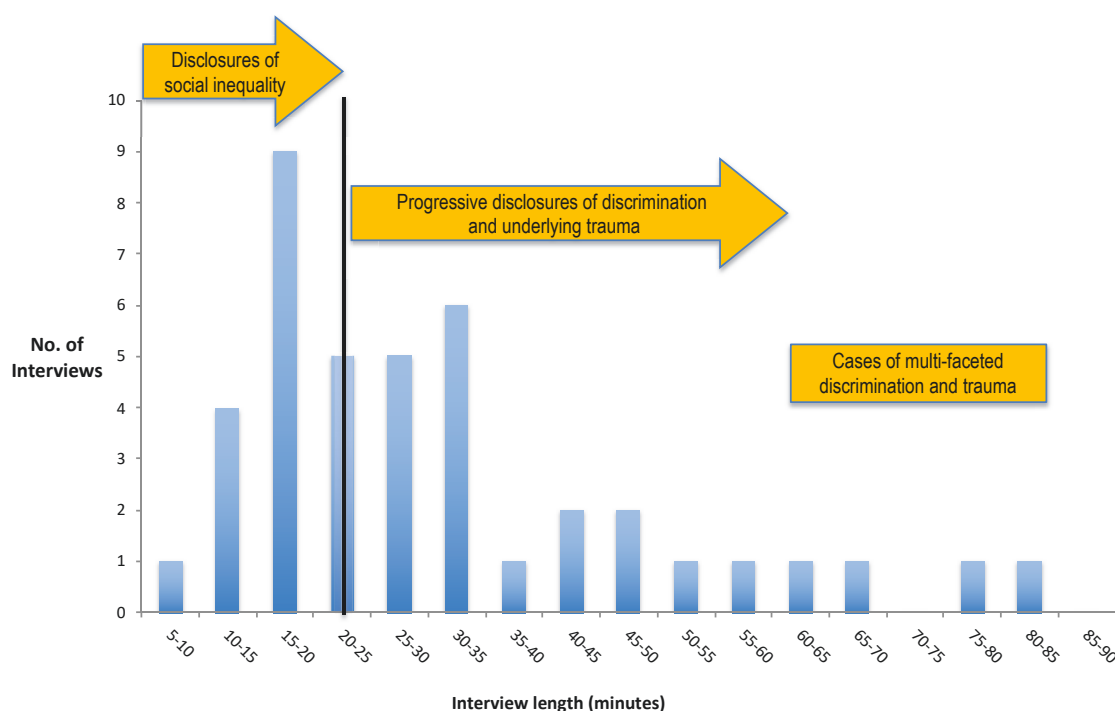
As the interviews progressed further, they tended towards a tipping point, after which the participant seemed more willing to move from specific example of inequality or discrimination to progressively reveal their underlying trauma stories. This tended to occur at or around the twenty minutes mark, where the interview had either exhausted what they wanted to say; or that they made the decision to keep speaking on increasingly personal and sensitivities issues that affected them. These types of issues were covered in Chapter 7 on social inequality.

Interview metrics were collected by the researcher on the length of time for each interview. These interview metrics were taken from the audio recording of each interview and recorded in a deidentified log with the researcher's case notes before they were sent for transcription. Noting that three interviews were not audio recorded, there were data on 38 interviews. Diagram 9.5.3 below shows distribution of the interviews by the length of the interview, bundled into 5-minute time bands, which is completed from the interview metrics. The horizontal axis is 5 time bands: from 0 to up to 5 mins; from 5 minutes up to 10; and so on. The vertical axis displays the number of interviews in each time band. The greatest number of interviews were in the time band from 15 minutes up to 20 minutes, with 9 of the 38 interviews in that category. It was at around that time that the discussion of systemic inequality typically became exhausted.

At around 20 minutes, the interview either ceased, or the participants continued and started to shift their testimony to the more underlying traumas they were affected by. These types of issues were covered in Chapter 8 on social isolation, discrimination and trauma. For most participants, the testimony was exhausted within another 15 to 20 minutes, so the interview was completed within a total of 40 minutes. About one quarter of the interviews went beyond 40 minutes, and these involved increasingly sensitive accounts. There were two cases which disclosed multi-faceted traumas including testimony of exposure to violence, forced participation in human trafficking, child removal, and alcohol misuse.

A depiction of the ‘twenty minute rule’ is in Diagram 9.5.3 below. This shows the distribution of interview by length with reference to the tipping point at which the interview shifted away from testimony of systemic inequality and on to disclosures of trauma.

Diagram 9.5.3: The ‘twenty-minute rule’: Interviews by length and nature of content



As a critical reflection, the researcher has attributed possible explanations to the willingness of participants to progressively disclose their trauma story. One explanation is that the style and tone of the interview were not invasive and the interview was allowed to be controlled by the participant. In being allowed to control the pace of the interview, the participant could ease their way into talking about acutely sensitive matters, knowing that they could retreat or withdraw if they felt unsafe. A second explanation is the significance of the interviewer’s positionality, as in who asked the questions rather than what was asked. As a deaf Aboriginal man coming from within their own First Peoples disability community, the interviewer presented as a reflection at least in part of their own lived experiences. The effect of the researcher coming from their community may have put the participants in the frame of mind that they would not be judged on what they said and believed rather than that they were just

listened to having what they said recorded. This concept of believability is captured by the example above, where an Aboriginal man who has an anxiety disorder said that many of his friends still did not believe him when he told them of his anxiety and its impact that he had revealed in detail during the interview.

The efficacy of this research approach as an authentic emancipatory model of research has implications for how safe and effective research can be practised when it involves vulnerable population groups. Whilst this research case study is specific to the First Peoples disability community, its core principles of facilitating participation through empowering its participants and providing a safe and respectful environment can be applied in research involving other vulnerable groups. These implications are discussed further in Chapter 10.

9.6 Testimonials from community on the impact of *Culture is Inclusion*

The third aspect in evaluating the participation of Aboriginal and Torres Strait Islander people with a disability in this research as a cultural and community activity are the reactions to the book *Culture is Inclusion: A Narrative of Aboriginal and Torres Strait Islander Peoples with Disability* (Avery, 2018). This book was designed principally to fulfil the obligation of reciprocity by producing a resource that the First People's disability community could use to further their self-advocacy, presenting the research and its findings in a form that is accessible by Aboriginal and Torres Strait Islander people with a disability. Whilst the motivation of the book was to give back to the First Peoples disability community, it was anticipated that it could reach a broader audience. As stated in Section 4.6.2, this book was devised as a discursive text aimed at disrupting the prevailing discourse that had erased the involvement of Aboriginal and Torres Strait Islander people with a disability in research and public policy. The disruption sought was to promote their voices into a social setting where their voices were absent. Textually provocative, but also resplendent in Aboriginal art and imagery, it has been promoted as a 'thinking person's coffee table book', seeking to engage a broader cross section of mainstream Australians in inequality as a national issue of social injustice.

Culture is Inclusion was released in July 2018 at the Australian Human Rights Commission. The launch was hosted by Australia's Disability Discrimination Commissioner and was attended by over 110 people. The majority of participants were from the First Peoples disability community and its support network. There were also a number of distinguished researchers from both the disability and Aboriginal and Torres Strait Islander communities in attendance. The Australian Bureau of Statistics sent a delegation and co-sponsored the event, and two members from the National Disability Insurance Scheme were in attendance. Invitations were sent to approximately 30 public sector executives at Commonwealth and State Government that the First Peoples Disability Network were in frequent contact with. However, other than from the Australian Bureau of Statistics and the two representatives from the National Disability Insurance Scheme, no other government officials attended.

Culture is Inclusion was published for sale¹³, which was the first time First Peoples Disability Network had placed monetary value upon a research and advocacy publication, which were normally distributed pro-bono. By the end of March 2019, 244 copies had sold at an average sale of approximately one per day since its launch. The customer base is diverse and expanding, currently including: University libraries, disability service providers, advocacy services, law firms, members of the general public who support First Peoples Disability Network and its research; and even one pre-school. The researcher has also been made aware that extracts from *Culture is Inclusion* are being used as prescribed reading materials in University courses in health sciences and in law.

There are emerging signs that *Culture in Inclusion* has captured the imagination of the community within the purpose for which it was designed. Many of the interactions between the researcher and the readers of the book have been incidental encounters, with the researcher being stopped on a train, at a coffee shop, or after speaking engagements to be told what the book has meant to the reader who has related to the experiences that are narrated in the book on a very personal level. Other readers of the book have taken to social media telling of their reaction, some posting shots of themselves holding the book when it had arrived in the post, tagging the researcher and

¹³ The retail price for *Culture is Inclusion* on publication was \$176.00 AU.

the hashtag #CultureIsInclusion or some derivative. One post-doctoral fellow at an Australian university described *Culture is Inclusion* as:

“a profound work and must read for anyone seriously interested in disability in Australia and Internationally.” (Social media communication, December 2018, Twitter. Used with permission).

Another researcher, a Professor of Education at a Queensland university, also wrote:

“Reading this fantastic book by Scott Avery – Culture is Inclusion. Beautiful words and photos #inclusion #inclusionistas #Disability.” (Social media communication, February 2019, Twitter. Used with permission).

There are two groups with whom the book has particularly resonated. One group are emerging Aboriginal researchers. They have spoken to being inspired by its cultural influence and grounded methodology. Below is one testimonial from an Aboriginal doctoral student following an interaction with the researcher at a coffee shop where the student was studying:

“Culture is Inclusion is such an important publication. I am still working my way through it but I connected with the content within seconds of opening the book. I experience fear of discrimination, apprehended discrimination and avoidance discrimination in a non-linear way, some days I am more sensitive than others and will not have the physiological strength to ‘front –up’ and therefore will avoid. Other days, I brace myself and get through. Until reading Culture is Inclusion I was unable to name it, to me it is just life. Culture is Inclusion has had a powerful impact on me to identify with the content seeing myself and my experiences and empowering me to recognise I am not alone and more importantly it is not a weakness or inadequacy. I’m sure as I get further through the book I will see my family reflected, thank you for sharing our story and putting a voice to our experiences.” (Aboriginal doctoral student, cited with permission).

The other group that *Culture is Inclusion* has resonated with is parents of children with disability. This group includes also children who are not Aboriginal or Torres Strait

Islander. There have been many examples where parents of children with disability have come up to the researcher after a speaking engagement to say that the presentation was the story of their son or daughter, particularly the stories relating to employment inequality and education. Others have seen the book as an opportunity to promote inclusive for their child in education. Below is an unsolicited request that came via social media from a mother of a child with Down Syndrome, requesting the researcher sign a personalised message for her son's teacher in the book that she had purchased for her as a gift on behalf of her son:

“The book is a gift to my son's new teacher in year 4. [My son] is 9 years old and he has Down syndrome. I met with [my son's teacher] yesterday - I wanted her to understand why inclusion for [my son] is important and it was a lovely meeting. She is a Nyoongar woman and brought her own experiences as a child who experienced low expectations and prejudice at school which I hope will help her to support [son's name] inclusion. Every morning she plays the kids a beautiful Nyoongar song. I know she will enjoy your beautiful book and I hope it helps her on this year's journey as my son's teacher.” (Mother of a child with Down Syndrome, with names redacted for privacy purposes. The researcher was granted permission to use this as a testimonial after it was received).

9.7 Political engagement with the research

Whilst engagement with the bureaucratic arm of government is still to take effect, the political arm is starting to engage with the research and the evidence of social inequality that it presents. At a Commonwealth Senate Estimates hearing into the National Disability Insurance Scheme in February 2019, one Senator cited *Culture is Inclusion* and aspects of this research in questions to officials from the National Disability Insurance Agency. The first question was one taken on notice in relation to the utilisation of the National Disability Insurance Agency by Aboriginal and Torres Strait Islander people, which relates to the research findings in Chapters 6 and 7 of this thesis.

Senator SIEWERT: *“Can I go back to the issue of utilisation [of the National Disability Insurance Scheme] by Aboriginal and Torres Strait Islander peoples. You may or may not recall that you've answered a question on notice that I asked last time about utilisation...*

“It relates to the use of people's plans. You probably don't remember but we were having a discussion about the report that Scott Avery produced—a very comprehensive report, as I'm sure you're aware. One of his deep concerns—there's a whole lot of them—is that even when someone gets a plan, they don't use it...

“For some of the states where some of the utilisation is higher, do you have a breakdown between metropolitan and more rural and remote?”

(This question was taken on notice by officials from the National Disability Insurance Agency for reporting back to a future Senate Estimates Hearing).

The Senator then asked a second set of questions relating to the capacity of the National Disability Insurance Scheme to deliver personalised plans where basic public infrastructure is missing. This initiated an exchange between Senator Siewert and Mr Francis representing the National Disability Insurance Agency, that referenced the images of inaccessible housing as pictured in Section 7.3.1; and the testimony from the Elders' Forum presented in Section 7.8.2 that Aboriginal people with disability needed basic needs fulfilled, such as food and shelter before other forms of support could be effective:

Senator SIEWERT: *“And we recognise that you did try to do that. What else are you doing in order to increase the uptake by Aboriginal communities, given the barriers that Scott Avery has so extensively outlined?”*

“One of the big things that Mr Avery articulated—and you've probably seen his presentation, as well as read his report—is that there are some broad, systemic and community issues, like infrastructure.”

Mr Francis (NDIA): *“Yes.”*

Senator SIEWERT: *“And you've probably seen the vivid imagery of the housing that has no ramps.”*

Mr Francis: *“Yes. I have visited—”*

Senator SIEWERT: *“You've visited. I hesitate because I know we've had these discussions before about what is the responsibility of mainstream organisations and the NDIS, but the fact is that people aren't going to be able to use all their package until that's addressed. How are those fundamental barriers being addressed? Otherwise, I don't think that we are going to be able to get full utilisation of a package.”*

Mr Francis: *“...People don't want to talk to the NDIA person, for example, because they're not providing swags and blankets or food. How do you actually get past that to a circumstance whereby, potentially, we can be working better together to provide those sorts of services? I don't have the answer, because—as you've already identified, I think, in the way that you've asked the question—as the NDIA I don't have funds to be able to pay for and supply the swags, blankets and food. But what we can do is better interact with other arms of government to try to put ourselves in the best possible position to position the provision of National Disability Insurance Scheme information within a context, or whereby that's not the primary barrier. But I understand that it is for many people.”*

(Commonwealth Senate Community Affairs Legislation Committee (21 February 2019), Hansard, 21 February 2019, pp 69-70).

This exchange between an Australian Senator and a senior executive of a government services agency highlights the potential for this research as a mechanism of accountability. The implication of the issues that this research has uncovered to government social policy are addressed further in Chapter 10.4.

9.8 Concluding comments: Towards a ‘cultural model of inclusion’ for Aboriginal and Torres Strait Islander people with disability

This chapter presented a finding that Aboriginal and Torres Strait Islander people with disability participate in cultural and community events on par with Aboriginal and Torres Strait Islander people without disability. This finding is supported by statistical data and through positive affirmation of a connection to culture and community through the participant’s testimony. The finding of cultural and community inclusiveness stands in stark contrast to the findings of the acute and pervasive intersectional systemic inequality and social isolation that is experienced by Aboriginal and Torres Strait Islander people with disability that were presented in previous chapters.

The chapter then looked at the participatory outcomes of this research as a cultural and community activity of its own accord. It documented the positive affirmation of the research approach as expressed by participants through their testimony, their willingness to disclose sensitive and traumatic matters, and a building of momentum in engagement by stakeholders on the issues. This research has taken the finding of parity in cultural and community participation and given it a research application. The positive response from community to this research as a genuine participatory model of research has allowed a re-imagining of what research impact really means when it facilitates the participation of people from within a marginalised community. The reimagining of research impact for community-directed and involved research is expanded upon in the discussion chapter that follows.

Most significantly, the finding of the cultural and community inclusion of Aboriginal and Torres Strait Islander people with disability provides a direct line of sight with the narrative of the one-legged Mungo man introduced in the preface to this thesis. The narrative of inclusion symbolised by a single line of right footprints of one-legged man on a hunt with his tribe that were embedded in the clay at Lake Mungo tells of an ancient culture of inclusion that says ‘we go hunting together’. Defying the adversity they otherwise face in other aspects of their lives, this inclusiveness that people with disability have with their Aboriginal and Torres Strait Islander culture and community has on a whole remained intact.

The participants in this research have preserved the one-legged Mungo man’s ancient message of inclusion and reanimated it for a contemporary time through the words of the Elders who stated “*we go hunting together*”.

This is the final chapter presenting the results of the research. The next chapter will summarise the findings, and discuss its implications from research, policy and community perspectives.

10. Discussion

10.1 Summary of the findings

The findings of the past four chapters that were presented in detail have been condensed below into a shortened summary. These findings have both a theoretical foundation and are empirically based. The purpose of this summary is to refresh the findings into a sequential narrative that reflects the breadth of the research as a whole, from which the broad reaching implications of the research can be appreciated. The twelve findings are mapped against the four research questions outlined in Chapter 1, which are:

- Research Question 1: What is the prevalence, nature and social impact of disability amongst the Aboriginal and Torres Strait Islander population?
- Research Question 2: How is social inequality that is experienced by Aboriginal and Torres Strait Islander people with disability created and sustained?
- Research Question 3: What is a model of research that actively promotes participation of Aboriginal and Torres Strait Islander people with disability through the direct testimony of their lived experience?
- Research Question 4: Is there an Aboriginal and Torres Strait Islander ‘cultural model of inclusion’ that actively promotes the social participation of people with disability?

Relating to Research Question 1:

FINDING 1: Based on the best available statistical data, estimates on the prevalence of disability amongst the Aboriginal and Torres Strait Islander population is approximately twice the rate compared to other Australians, is more complex in terms of co-occurring disabilities, and compressed within a shorter life expectancy (Chapter 6).

Relating to Research Question 1 and Research Question 2:

FINDING 2: Aboriginal and Torres Strait Islander people with disability experience a unique form of ‘intersectional inequality’ compared to other population groups, including Aboriginal and Torres Strait Islander people without disability and people with disability that are not Aboriginal and Torres Strait Islander, that is acute and pervasive across all systemic supports (Chapter 3.5; Chapter 7).

Relating to Research Question 1:

FINDING 3: Aboriginal and Torres Strait Islander people are repeatedly exposed to various forms of discrimination in their everyday lives, including racism, ableism and a unique form ‘intersectional discrimination’ that is an interaction of discrimination that is both Aboriginal and Torres Straits Islander and disability related (Section 3.2; Chapter 8).

Relating to Research Question 2:

FINDING 4: Frequent exposures to various forms of discrimination can have manifest into ‘apprehended discrimination’, which is a term devised by the researcher to describe the pathway by which a fear of discrimination transforms into a rational expectation of discrimination, and then onto a self-exclusion or avoidance of social situations where they could be exposed to possible discrimination (Section 7.6; Section 8.4).

Relating to Research Question 1 and Research Question 2:

FINDING 5: The frequency and acuity of ‘intersectional inequality’ and ‘intersectional discrimination’ that Aboriginal and Torres Strait Islander people with disability are exposed to has detrimental impact upon the social health and wellbeing of Aboriginal and Torres Strait Islander people with disability (Chapter 8).

Relating to Research Question 1, Research Question 2 and Research Question 3:

FINDING 6: In addition to frequent exposures to various forms of discrimination, Aboriginal and Torres Strait Islander people with disability have a heightened exposure to social isolation and traumas compared to other population groups (Chapter 8).

Relating to Research Question 2 and Research Question 3:

FINDING 7: Trauma can cluster within small communities that have large proportions of its community that have been affected by it. In these cases, trauma can act like a contagious disease, with whole communities affected by sadness and despondency (Chapter 8).

Relating to Research Question 3:

FINDING 8: Despite the sustained inequality, isolation and discrimination that Aboriginal and Torres Strait Islander people with disability experience, there are residues of hope even amongst those whose exposure to vulnerability is highest (Chapter 8).

Relating to Research Question 4:

FINDING 9: Aboriginal and Torres Strait Islander people with disability participate in cultural and community events at the same rate as other Aboriginal and Torres Strait Islander people. Parity in cultural and community participation is in contrast to the acute and pervasive ‘intersectional inequality’ that is otherwise experienced across all aspects of systemic supports (Chapter 9).

Relating to Research Question 1 and Research Question 4:

FINDING 10: A culture of inclusion that is grounded in Aboriginal and Torres Strait Islander peoples’ beliefs and values mitigates the impact on ‘intersectional inequality’ and discrimination, acting as a moderating force on the social health and wellbeing of people with disability (Chapter 9).

Relating to Research Question 3 and Research Question 4:

FINDING 11: As a cultural and community activity in its own right, inclusion in research can promote the personal healing of participants who come from a vulnerable population group by enabling them to ‘tell their story’ in a safe space, on their terms, and in their own time (Chapter 9).

Relating to Research Question 3 and Research Question 4:

FINDING 12: An authentic model of participatory research can foster inclusion and community connectedness for related populations and stakeholder groups beyond the immediate group of participants involved in the research (Chapter 9).

10.2 Overview of the implications of the research

This chapter looks at the implications of the research from three perspectives: first, in relation to the conceptual development contributed by this study; second, in relation to its implications for Australian social public policy; and third, in relation to participatory research as a catalyst for community healing and wellbeing. These three perspectives are expanded below.

The first perspective taken in this discussion chapter relates to the further development of concepts and theories. A number of concepts developed by the researcher to explain social inequality experienced by Aboriginal and Torres Strait Islander people with disability were conceptualised earlier in the thesis as a foundation for the empirical component of the research. This chapter involves further ‘theorising’ (Swedberg, 2016) to conjoin the concepts presented earlier with the empirical results of the research for a further iteration of conceptual and theoretical development. One term that is expanded upon is ‘intersectional inequality’. This term was introduced in Chapter 3 to explain the interaction of race and disability-related access barriers to create a unique form of inequality experienced by Aboriginal and Torres Strait Islander people with disability in Australia. This chapter will apply findings of ‘intersectional inequality’ across all areas of systemic support, taking it from a point-in-time concept as represented in the statistical data, and converts it into a conceptual understanding of the impact of inequality that accumulates across the life trajectory of an Aboriginal and Torres Strait Islander person with disability.

A second concept elaborated upon in this chapter is ‘apprehended discrimination’. This term was first introduced in Chapter 3, and reintroduced in Chapter 7, to describe the pathway from an intuitive fear of discrimination to an avoidance of discrimination. The examples from the testimony that illustrated ‘apprehended discrimination’ related to the experiences of a Aboriginal and Torres Strait Islander people with disability as one group who have been relatedly exposed to discrimination. This chapter looks at the validity of ‘apprehended discrimination’ as a concept that might explain self-exclusion in other scenarios where fear of discrimination is a factor. This initial development of ‘apprehended discrimination’ as a concept is linked to a discussion on whether the obverse concept of ‘apprehended inclusion’ could conceivably apply.

A third concept expanded upon in this chapter is a ‘cultural model of inclusion’. A ‘cultural model of inclusion’ is postulated by the fourth aim of the research. In this chapter, the empirical findings of cultural and community participation of Aboriginal and Torres Strait Islander people with disability in Chapter 9 are reframed in conceptual terms. This chapter then contrasts a ‘cultural model of inclusion’ derived from Indigenous belief systems to western constructs of disability as expressed by an individual or medical model of disability (Oliver, 1983) and a social model of disability (Oliver, 1983; Shakespeare, 2010). Core to this discussion is where comparative models of disability and inclusion locate deficit within their respective discourses.

The second perspective taken in this discussion chapter relates to the implications of this research for Australian social policy. It will look at the implications of intersectionality (Crenshaw, 1991) for the application of unilateral and unconnected Indigenous policy and disability public policy approaches to addressing whole of population inequality. Using scenarios drawn from the *Closing the Gap Framework* (Coalition of Australian Governments, 2007) policy framework and the National Disability Insurance Scheme, this chapter will undertake a further iteration of the ‘paradox of low hanging fruit’ that was introduced in Chapter 3 to explain why social policies that are unilaterally designed and market-driven will consistently fail to reach the most marginalised of people from within an marginalised population.

The third perspective taken in this discussion chapter relates to the impact of the research in fostering community connectedness for a group have experienced social isolation. This section focuses on the phrase from one of the participants “*we go hunting together*” (Interview 34, remote cohort) as an expression of personal connectedness to family and community, and gives it a community-wide meaning. It compares the findings of social isolation and contagious traumas presented in Chapter 8 to the findings of cultural and community participation in Chapter 9, then asks: if trauma is contagious, can inclusion also be contagious? When framed in conceptual terms, this question looks at how participatory inclusion in research can be the initial cobblestones in an obverse pathway that is from ‘apprehended discrimination’ to ‘apprehended inclusion’.

This chapter then concludes with an agenda for future research involving Aboriginal and Torres Strait Islander people with disability, which uses the structure of this thesis as an architecture for advancing more focused studies on aspects raised. It also looks at recommendations for further research that target the limitations of this research, by taking the philosophy of participatory research with vulnerable population sub-groups of the First Peoples disability community that are even harder to reach than those that have been captured within this study.

10.3 Conceptual advances arising from the empirical results

This next section involves an additional iteration in the development of concepts and theories that have been progressively introduced over the course of the thesis, illustrated with insights from the empirical results. The three concepts that are elaborated upon in this section are: ‘intersectional inequality’ as it is carried over the life trajectory of an Aboriginal and Torres Strait Islander person with disability; the plausibility of ‘apprehended discrimination’ as a concept that can explain self-exclusion as a response to sustained discrimination in other practical scenarios; and a ‘cultural model of inclusion’ derived from Aboriginal and Torres Strait Islander beliefs and values that is in contrast to other socially constructed discourses of disability.

10.3.1 ‘Intersectional inequality’ across the life trajectory

This section refines the explanatory model of ‘intersectional inequality’ that commenced in Chapter 3 and conjoined with the findings of ‘intersectional inequality’ that is pervasive across all aspects of systemic support. In Chapter 7, the results of ‘intersectional inequality’ were organised by discrete policy domains of: accessible communities; justice and personal safety; education; employment; and health and disability services. Here, the results are reconfigured from an analysis that structured by policy domain and into a sequence that represents the stages across a life trajectory of Aboriginal and Torres Strait Islander people with disability. Building on a concept that was introduced in the researchers’ prior work, this is done to demonstrate the accumulated impact of ‘intersectional inequality across the life trajectory’ (Avery, 2016, p.19; Avery, 2018, pp.40-41).

Table 10.3.1 below shows the life stages of an Aboriginal and Torres Strait Islander person with disability. An earlier version of this table was published as evidence to a Senate Inquiry (Senate Community Affairs References Committee, 2016) to illustrate a life trajectory as a ‘matriculation pathway into prison’, to emphasise a pathway where an Aboriginal and Torres Strait Islander child with disability was more likely to enter than prison system than to go into tertiary education. The original version contained the first two rows, one row highlighting the Aboriginal and Torres Strait Islander dimension of inequality, and the other row highlighting a disability dimension of inequality. This research has augmented this framework by adding a third row that presents the relevant findings of ‘intersectional inequality’ from Chapter 7.

Plotting the findings of social inequality in this study across a person’s life trajectory shows that ‘intersectional inequality’ is not a point-in-time concept. Social inequality in one stage of a person’s life trajectory is followed by a likelihood of experiencing social inequality in subsequent stages in their life trajectory. The legacy of undiagnosed or unsupported disability in early childhood years carries forward into the schooling years. The legacy of undiagnosed or unsupported disability in attaining educational outcomes are carried forward into constraints upon their employment prospects. This is compounded by a punitive disciplinary policy in education (O’Brien and Trudgett, 2018) in which disability amongst Aboriginal and Torres Strait Islander children is prejudicially stereotyped in the classroom, as what is colloquially referred to in the First Peoples disability community as ‘bad black kid syndrome’. The legacy of being unable to secure employment carries forward to an increased likelihood of coming into contact with police, and in turn entering the prison system. This analysis is consistent with ‘a school to prison pipeline’ that has been reported amongst marginalised populations in the United States (Kim et al, 2010; Pane & Rocco, 2014). The accumulated legacy of all of the ‘intersectional inequality’ is reflected by the drastically inferior health outcomes compared to other Australians. This is where the concept of a ‘matriculation pathway into prison’ is derived. It is the antithesis of a matriculation pathway as it is understood in education, where success in one stage of an educational pathway establishes a platform upon which future educational attainment can be achieved. In this situation, the opportunities for personal fulfilment during one stage are suppressed, and the loss of opportunity diminishes the prospect of advancement in later stages of their life.

Table 10.3.1: ‘Intersectional inequality’ across the life trajectory of an Aboriginal and Torres Strait Islander person with disability

(Adapted from: Avery, 2016, p.19; Avery, 2018, p 40- 41)

LIFE-STAGE ASPECT	Peri-Natal	Early childhood	Schooling years	Young people	Justice	Health	Ageing
<i>Aboriginal and Torres Strait Islander</i>	Low awareness of disability Environmental factors, increased likelihood of low birth-weight	Low awareness of disability Exposure to trauma Increased likelihood of being removed from family	Low awareness of disability ‘Bad black kid syndrome’ – punitive schooling over supported disability	Less likely to secure employment Increased likelihood of police contact	Denial of rights- over incarceration	Subconscious bias – institutional racism	Reduced life expectancy Disability happens earlier in life and with more co-morbidities.
<i>Disability</i>	Environmental factors in developmental disability	Disability assessments aren’t carried out to the extent that they need to be	Undiagnosed and unsupported disability	Less likely to secure employment	Denial of rights – indefinite detention of people disability	Subconscious bias – diagnostic over shadowing	Inadequate public infrastructure especially in remote communities.
<i>Empirical findings of intersectional inequality that Aboriginal and Torres Strait Islander people with disability experience</i>	Public infrastructure gaps exist, particularly in remote communities (Ch 7.3)	Heightened exposure to being removed from family compared to other groups (Ch 8.2) High rates of unspecified disability; issues in accessing disability diagnoses (Ch 6.4)	Educational supports are not inclusive of both culture and disability (Ch. 7.5) Interrupted education pathways (Ch 7.5.1) Inequality in educational outcomes (Ch. 7.5)	Inequality in gaining employment (Ch 7.6) ‘Apprehended discrimination’ in seeking employment (Ch 7.6.1)	Increased exposure to actual or threatened violence (Ch 7.4)	‘Overshadowing’ in the diagnosis of serious health issues (Ch 7.7.2) Inequality in health outcomes (Ch. 7.7)	Disability is more complex in terms of co-occurring disability and compressed within a shorter life span (Ch. 6)

Whilst a life trajectory approach to understanding accumulated ‘intersectional inequality’ can on one hand paint a bleak picture on the life prospects of an Aboriginal and Torres Strait Islander person with disability, it can also provide a mechanism to isolate the pivot points at which the life trajectory can be altered by a targeted intervention. As the critical analysis in Section 2.4.2 reminds us, intersectionality (Crenshaw, 1991) is about power relativities within the social structure, and is not inherent in the person per se. This analysis was expounded in Chapter 8, where it was shown that ‘intersectional inequality’ is not inherent in the person, but instead a function of the social forces that generate social isolation. Thinking in terms of empowerment, a life trajectory approach is a mechanism to identify the pivot points in a person’s life where they transition from one life stage to the next, and at which they can be empowered through an intervention that positively alters their life trajectory. Infusing intersectionality in this way into policy and practice invites creative approaches to program interventions. Some examples of program interventions might include: a targeted approach to testing for undiagnosed disability among Aboriginal and Torres Strait Islander children upon their entry into school; or at the other end of the schooling spectrum, mandated testing to exclude undiagnosed disability as a factor in education performance before an Aboriginal and Torres Strait Islander child can be expelled from school.

10.3.2 *Extended applications of ‘apprehended discrimination’*

The term ‘apprehended discrimination’ was introduced in Section 7.6.1 and developed as a concept to explain a pathway in which the participants responded to a fear of discrimination by escalating themselves from social participation where they have rationally come to expect to be discriminated against. ‘Apprehended discrimination’ was initially observed in relation to participants’ testimony that they would not apply for jobs when they expected discrimination, and later expanded in Section 8.4 to cover situations that link building inaccessibility to non-participation in consultation meetings, and the link between fears for personal safety and non-attendance at school.

‘Trust’ has been acknowledged by other researchers as factor in the likelihood of participation in disability services by Aboriginal and Torres Strait Islander people (Gilroy et al, 2016; Dew et al, 2018). The issue with presenting ‘trust’ on its own as a factor in non-participation is that it is an amorphous concept, capable of being so

broadly defined that it can avoid the core issue of why distrust exists. The significance of ‘apprehended discrimination’ is that it more concisely targets the issue as a fear of discrimination that transpires into a rational expectation of discrimination. Addressing non-participation merely as a ‘trust’ exercise may initiate broad-based relationship strategies to develop goodwill by Aboriginal and Torres Strait Islander people with other Australians, but doesn’t necessarily amount to changes in behaviours or practices. ‘Apprehended discrimination’ is a much stronger concept, in that it requires dealing with the underlying fear, then expectation, of discrimination.

The concept of ‘apprehended discrimination’ was devised by the research as an observation within the testimony on experiences of discrimination from a participant group of Aboriginal and Torres Strait Islander people with disability. As an explanatory concept in describing avoidance as a psychological response to a rational fear of discrimination, ‘apprehended discrimination’ could also help in understanding an expanded range of scenarios in which a fear of being discriminated against outweighs the potential benefit of social participation. Two scenarios that were outside the scope of this study but are relevant issues for Aboriginal and Torres Strait Islander people with disability are detailed below.

SCENARIO 1 – ‘Apprehended discrimination’ as a factor in the possible under-disclosure of Fetal Alcohol Spectrum Disorders (FASD) amongst Aboriginal and Torres Strait Islander children.

Fetal Alcohol Spectrum Disorder (FASD) is a physical and neurological impairment that affects children whose mothers consumed alcohol during pregnancy (Bower et al, 2017). Research from a population-based prevalence study in a Western Australian Aboriginal and Torres Strait Islander community found a diagnosis of FASD prevalence rate of 12% of all pregnancies that were included within the study, and 77% of the mothers of children diagnosed with FASD had drunk alcohol at levels specified as high risk. (Fitzpatrick et al, 2015). Further research identified barriers in addressing FASD in the Australian context include a heavy drinking culture (Fitzpatrick and Pestell, 2017). Another study found the prevalence rate of FASD to be 36% amongst young people in detention, with specific reference to Aboriginal youth who made up 74% of the study participants (Bower et al, 2018), which is additional

evidence affirming a ‘matriculation pathway into prison’. Internationally, there has been research that has looked at the impact of stigmatisation that surrounds FASD with its connection to alcohol consumption, particularly upon the mother of a child with FASD who might be blamed or shamed (Bell et al, 2016). The stigmatisation around alcohol is particularly acute for Aboriginal and Torres Strait Islander people, as was detected in the testimony in this study. A consequence of stigma related discrimination is that a mother with a child with FASD might be reluctant to voluntarily seek help for her child, as the negative outcomes of expected discrimination outweighs the perceived benefit that the support would provide. ‘Apprehended discrimination’ provides a vocabulary and framework to understanding the steps on the pathway from stigmatisation to self-exclusion of support that can be applied in public health communications.

SCENARIO 2: Under-reporting of Indigenous status and/or disability in administrative datasets.

Chapter 6 referenced the likely presence of non-disclosure of disability in the estimates of disability prevalence amongst the Aboriginal and Torres Strait Islander population. Some of the explanations put forward within this Chapter as possible relation for non-disclosure of disability included a different cultural belief system, or difficulties in obtaining a disability diagnosis. Following the observations within this study of ‘apprehended discrimination’ in relation to inequality in social system of support, it also emerges as a possible explanation self-exclusion from the systems that collect the data needed for planning. The Australian Bureau of Statistics has noted a relatively high undercount in the number of Aboriginal and Torres Strait Islander people who completed the national census, which is estimated as 17.5% of the entire Aboriginal and Torres Strait Islander population (ABS, 2018). This compares to a national undercount for the Australian population of 1.0% (ABS, 2018), indicating that Aboriginal and Torres Strait Islander people as a vulnerable population group were less likely to complete a national census return than non-Indigenous people. There is no equivalent process to determine an undercount of disability, although if the theory of intersectionality were to hold true in this case, it could be expected that an undercount of people who are both Aboriginal and Torres

Strait Islander and live with disability in completing the national census could be higher again.

If there is a fear that the data collected through statistical agencies will be used against them in other ways, for example; in having social security benefits reduced or taken away, or triggering an even more traumatic fear of having their children taken away, then the concept of ‘apprehended discrimination’ would suggest that their dispensation to self-exclude from census and other administrative datasets would be a rational outcome. The significance of a population-wide dispensation towards self-avoidance in participating in population planning data collection is that it affects vulnerable populations most. This is because data on their higher level needs for support relative to others in the population are not adequately captured. In other words, those most in need are those whose needs are most likely not to be counted.

These two scenarios indicate how ‘apprehended discrimination’ has broader application beyond the circumstances that were captured within this research. As the scope of ‘apprehended discrimination’ is extended, so is its explanatory power in appreciating the serious consequences of how self-perpetuating the isolation of vulnerable people can become through their constant exposure to discrimination. Later, this chapter will consider a possibility of whether through a different type of constant exposure, that to inclusion within community, ‘apprehended discrimination’ may be transposed into ‘apprehended inclusion’.

10.3.3 *A ‘cultural model of inclusion’*

This section looks at the implications of finding a parity in the cultural and community participation of Aboriginal and Torres Strait Islander people with disability in respect to the fourth aim of the research that asks whether there is a ‘cultural model of inclusion’ that promotes inclusion of Aboriginal and Torres Strait Islander people with disability. In addressing the notion of a ‘cultural model of inclusion’, the findings that have emerged in this research are contrasted to other interpretative models, namely the individual or medical model of disability (Oliver, 1983, 1990), and the social model of disability (Oliver, 1983, 1990; Shakespeare, 2010).

An ethos of an Australian Indigenous culture of inclusion is symbolised by the one-legged Mungo man on a hunt with his tribe that was introduced in the opening preface of this thesis. An Australian Indigenous culture of inclusion has companionship with Indigenous cultures worldwide. This was shown in the literature in Chapter 2 in finding that a comparable culture of inclusion exists in the cultures of other Indigenous peoples (Rivas Verlade, 2018), including amongst the Maori people of New Zealand (Te Pou o te Whakaaro Nui, 2016) and the Navajo Native American people (Kapp, 2013).

The testimony of the participants in this research also pointed to a higher conceptualisation of social participation that transcended a physical participation in an activity. Testimony such as “*we go hunting together*” (Interview 34, remote cohort), and the yarning piece by an Aboriginal man with disability living bush who said his community all look out for each other (Interview 25, remote cohort), illustrates a different discourse of inclusion that is used by Aboriginal and Torres Strait Islander people in contrast to how the deficit discourse around ‘disability’ is constructed in western societies. A key point of difference in the comparative discourse of inclusion and disability that have emerged in this study is where the respective discourses locate deficit.

To illustrate this point of difference, the cultural inclusion model is contrasted to the individual or medical model of disability (Oliver, 1983) and the social model of disability (Oliver, 1983; Shakespeare, 2010). The social model of disability was differentiated from an individual or medical model of disability in the 1970’s to draw distinction between ‘impairment’, framed as a deficit in biological functioning; and disability, which places a person’s functioning in reference to their physical environment and attitudinal barriers and prejudices they encounter. Both the medical and social models frame disability as a deficit against a perceived optimum human condition. As an interpretive model, the medical model presents disability as a deficit in bio-medical condition. The medical model of disability aims to mitigate the adverse bio-medical impact of what is perceived as a negative cognition, and the utopian end-point is cure. As an interpretive model, the social model of disability presents the deficit in terms of the environment, which may be either the built environment (e.g. housing, footpaths in remote communities) and/or the social environment (e.g. attitudes barriers, stigmas and discrimination). As an interpretive model, the goal of

the social model is to overcome the defects in the environment, and its utopian endpoint is to accommodate people within a fully inclusive community in which negativity in the environment does not exist. To reiterate, in both the medical and social models of disability, the goal is to reduce the impact of a perceived negativity against a perceived optimum.

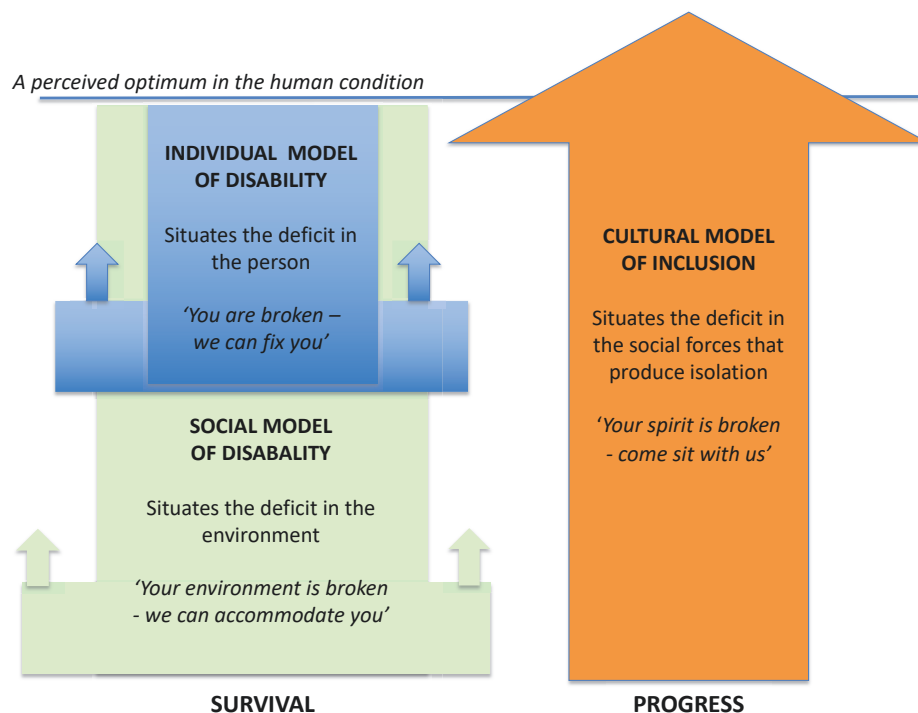
Discursively, the individual or medical model locates the deficit in the person, with a discourse that says 'you are broken, we can cure you'. Representing a relative advancement in human dignity, the social model shifts the deficit away from the person and locates it in the environment, with a discourse that says 'your environment is broken, we can accommodate you'. Despite the difference in where they locate deficit, both the individual and social models of disability are nonetheless framed in a deficit.

A conceptual model of cultural inclusion is philosophically and discursively different to the western philosophies of disability and deficit. Indigenous belief systems do not recognise deficit in humankind in the way that disability models do, and differences in biological and cognitive functioning are accepted as part of the fabric within community. In light of the testimony of cultural and community inclusion, and an absence of words for disability in many Aboriginal languages (Ariotti, 1999), disability is not a concept that is innate in Aboriginal and Torres Strait Islander cultures, whereas inclusion is. The discourse of cultural inclusion does not locate deficit in the person or the environment, but instead locates the deficit in the social forces that produce isolation. It is a discourse that says 'your spirit is broken, come sit with us'.

The comparative discourses for the individual model of disability, the social model of disability and the 'cultural model of inclusion' are diagrammatically illustrated below:

Diagram 10.3.3 Comparative discourses of the Individual Model of Disability, Social Model of Disability, and a ‘Cultural Model of Inclusion’.

(Adapted from: *Culture is Inclusion*, Avery, 2018, Table 9.3.1., p. 191)



The implication of a distinct Indigenous ‘cultural model of inclusion’ is that the Australian public disability policies are established from the assumptions of either an individual model of disability or a social model of disability. As a person-centred approach to disability services, the National Disability Insurance Scheme draws upon the assumptions of an individual model of disability. The *National Disability Strategy* (Coalition of Australian Governments, 2007) has a wider scope covering social determinants of inequality and draws upon the assumptions of the social model of disability. The statistical data on equality in Chapter 8 shows that Aboriginal and Torres Strait Islander people have access to improved individually-based disability supports as well as social infrastructure, so both the individual model and social models remain relevant to improving the quality of life for Aboriginal and Torres Strait Islander people with disability.

However, the testimony in Chapter 8 also showed that Aboriginal and Torres Strait Islander people incur the stigmatisation that comes with living with disability. This is

an extraordinary form of stigmatisation as they have to negotiate disability services models that are antithetical to their Indigenous culture and beliefs. To access services within an individual model of disability, Aboriginal and Torres Strait Islander people must disable themselves in a manner that is foreign to their source culture. To obtain a basic public infrastructure within a social model of disability, Aboriginal and Torres Strait Islander people must disable their communities, risking the stigma that their communities are stereotyped as dysfunctional. In effect, Aboriginal and Torres Strait Islander peoples must walk in two worlds: one world where their culture of inclusion is innate; and another in the western world of 'disability' that they must navigate to access the fundamental support that they need, in some cases for their survival. What 'walking in two worlds' means for Indigenous people in a nation that has been colonised is that the western models of disability can come together with culture within a single individual who can exhibit an integrated medical, social and cultural presentation of disability (Avery, 2018, p.190-191)

The social model of disability acknowledges stigmatisation as a barrier to social inclusion and aims to negate it. What came through in participants' testimony on cultural and community participation is a far more powerful concept, where a 'cultural model of inclusion' is an affirmative force in their health and wellbeing, moderating the effects of stigmatisation, discrimination and inequality that occur in other aspects of their lives. In this respect, the utopian end point of a social model of disability is where the 'cultural model of inclusion' takes flight.

A 'cultural model of inclusion' is not proposed to supplant the individual or social models of disability, both of which are still desperately needed in Aboriginal and Torres Strait Islander communities. Instead, a 'cultural model of inclusion' is proposed to augment the individual and social models of disability to overcome the cultural limitations in what those models of disability can offer to Indigenous people.

The evidence of systemic and 'intersectional inequality' is an overwhelming indictment on the lack of effectiveness that western models of disability support have had in supporting Aboriginal and Torres Strait Islander people with disability. As *Culture is Inclusion* states, "looking at the current state of the evidence, connecting people with their First Peoples culture is most likely to rapidly improve their quality of life" (Avery, 2018, p 190). The challenge now becomes how to integrate a culture of

inclusion into a new age of policies and service practices that are designed for Aboriginal and Torres Strait Islander people with disability. This challenge is addressed by a focused stream of research later in this chapter.

10.4 Implications for Australian social policy

10.4.1 A ‘paradox of low hanging fruit’ revisited

In Chapter 3, a ‘paradox of the low hanging fruit’ was theorised to explain how heightened levels of social inequality are generated to affect marginalised sub-groups within larger marginalised populations. Synthesising intersectionality with neo-classical economic theory, the ‘paradox of low hanging fruit’ explains how the incentives of a neo-liberal approach to social programs tend towards quick realisable gains, or ‘low hanging fruit’, but are disincentivised to tackle harder problems of social access, or the ‘too hard basket’. Hence, people who experience higher access barriers to system supports are rarely reached by the social programs intended for their benefit, and this is how the inequality is perpetuated.

As a group of people intersecting two marginalised populations, Aboriginal and Torres Strait Islander people with disability fall within the category of the ‘too hard basket’, as evidenced by the outcomes of ‘intersectional inequality’ and ‘intersectional discrimination’ presented in Chapters 7 and 8 respectively. The remainder of this section will take this theoretical approach that commenced in Chapter 3 and apply its relevance to two Australian social policy initiatives: first, *Closing the Gap Framework* (Coalition of Australian Governments, 2007) as an example in Indigenous policy, and second, the market-based approach of the National Disability Insurance Scheme as an example in public disability policy.

10.4.2 The ‘paradox of low hanging fruit’ in Indigenous policy - Closing the Gap

As stated in Section 1.5, the *Closing the Gap Framework* (Coalition of Australian Governments, 2007) is an Australian Government initiative to address inequality in health and social outcomes for Aboriginal and Torres Strait Islander population as a

whole, compared to other Australians. Up until the time of writing, addressing the unique circumstances of Aboriginal and Torres Strait Islander people with disability has not been part of the framework. The statistical data on social and health presented in Chapter 7 shows that the inequality that they experience, even compared to other Aboriginal and Torres Strait Islander people continues unabated. Indeed, there has been little shift in the heightened levels of social inequality experienced by Aboriginal and Torres Strait Islander people since it was raised as an issue in the public domain as far back in the early 1990's (Bostock, 1991; Gething, 1995).

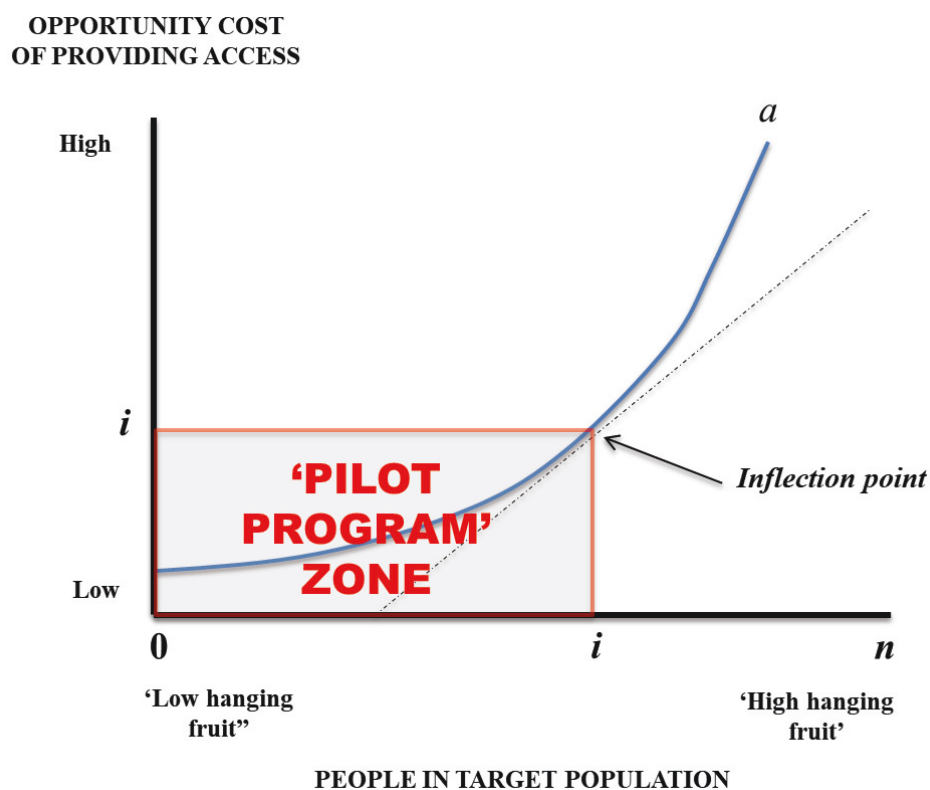
One of the consequences of the 'paradox of low hanging fruit' is that short-term policy making and funding are encouraged over longer term strategic commitment. This observation may provide explanation to the phenomenon of the 'pilot program' in Indigenous programs where small-scale trial programs are implemented as an experimental test to what outcomes might be achieved if implemented on a larger scale. The high prevalence of pilot programs in the Indigenous sector, and high failure rate of programs (as in their inability to receive funding beyond a trial or pilot phase), is a common lament of organisations within the Indigenous sector.

One endemic feature in Indigenous affairs is the positioning of programs to address inequality as pilot programs or trials. Whilst such a position has the benefit of limiting the risk that goes with making a long-term commitment to a program which might not be feasible, there is a downside. As pilot programs typically receive funding support on a small scale with a tight timeframe to achieve outcomes, there is an incentive to maximise the short-term returns by targeting 'low hanging fruit'. This may be particularly evident in short-term political cycles.

There comes a point, the inflection point, where providing access to people beyond the low hanging fruit mark becomes increasingly costly. As the social returns to a program on its further implementation reduces compared to the early stages of implementation, the feasibility of extending programs to those with higher access barriers reduces. If rate of return is the criteria for continuing a program beyond its pilot stage, there is an economic rationale for its discontinuance. Those people experiencing high access barriers become excluded from the program until an economic case is presented for the next short-term pilot program.

To illustrate the practical relevance of a ‘paradox of low hanging fruit’ in the Closing the Gap Framework (Coalition of Australian Governments, 2007), the phenomenon of pilot programs is overlaid onto Diagram 3.3.1 that diagrammatically shows the economic theory that underpins it. This is shown by highlighting the sector of the population that are reached by pilot programs illustrated by the shaded zone before the inflection point in Diagram 10.4.2 below.

Diagram 10.4.2: The ‘paradox of low hanging fruit’ – pilot programs In Indigenous policy



The significance of this diagram is that whilst the intent of Closing the Gap is to reduce inequality in health and social outcomes for the whole of the Aboriginal and Torres Strait Islander population, it rarely reaches beyond an inflection point where the cost of providing access to people exceeds the social return of increased participation. In practice, the policy is designed to improve inequality up to a midpoint for the population, whereas the heightened levels occurs at the extreme end of the population. In other words, it strives for the ‘low hanging fruit’ and avoids the ‘too hard basket’.

This calls for a philosophical shift in how Closing the Gap is designed. In light of the empirical observations of ‘intersectional inequality’ (Chapter 7), the validity of intersectional theory and a ‘paradox of low hanging fruit’ suggest that if there is any prospect to address the entrenched inequality, Indigenous policy must shift its approach from a whole of population philosophy to a nuanced approach that targets identifiable pockets of inequality that exist within the Aboriginal and Torres Strait Islander population. A ‘paradox of low hanging fruit’ explains the need for this, and an intersectional approach can help implement the social change that is needed.

10.4.3 *The ‘paradox of low hanging fruit’ in public disability policy – the market approach of the National Disability Insurance Scheme*

Whilst the National Disability Insurance Scheme is in its infancy in Australia, there are a number of general and reinforcing factors which make it susceptible to the ‘paradox of low hanging’ fruit in which people with high barriers to accessing the National Disability Insurance Scheme are effectively unable to access the scheme (Townsend et al, 2017). A central pillar of the National Disability Insurance Scheme is to enable people with disability to exercise ‘choice and control’ in the planning and delivery of their disability supports (Section 3(a), *Cth, National Disability Insurance Scheme Bill*, 2013). A goal in the design of the National Disability Insurance Scheme is to give people with disability the power to choose service providers to meet their personal needs (Productivity Commission, 2011). This is achieved through the provision of packages directly to the person with disability, through which they can purchase services on a fee for service arrangement. This approach to empowering choice and control through fee for service replaced a disability support payment system where providers of disability supports were principally paid block funding in advance. The transition from block funding paid directly to providers to a consumer-controlled allocation is designed to stimulate new market relationships between people with disability and providers of disability services (Australian National Audit Office, 2016) by increasing the economic power of the person with disability within a commercial transaction.

In addition to the empowerment of people with disability as purchasers, the provision of choice will stimulate the forces of supply and demand to drive price and quantity in the free market. The orthodox neo-classical economic assumptions built into the design

of the National Disability Insurance Scheme are that (i) purchasers have free and equal access to the market and (ii) that suppliers will act rationally in their provision of goods within the markets. In other words, having created a disability market, purchasers and providers will find their way there to negotiate an efficient allocation of disability support services.

The issue with the design of the National Disability Insurance Scheme is that the first assumption of equal access by purchasers (people with disability) does not hold, and the ‘build it and they will come’ approach to access is largely a myth. Even in the most rudimentary sense, there are variations on the market conditions between urban disability markets where there are sufficient providers of disability service for purchasers to make a rational choice; and regional and remote markets, where providers of disability services are limited or in some areas do not exist. On top of the issues of remoteness are additional complexities of intersectionality and other systemic barriers that affect some people with disability more greatly than others.

This creates a problem when the second assumption does take effect – does a provider of disability services limit its services to the low hanging fruit where the economic returns are greatest, or provide services to those people with disability experiencing high barriers to accessing the scheme? If supplier acts rationally in the economic sense, then the incentive is to discontinue supply beyond the inflection point, which means that people with disability with high systemic barriers would be denied access to the National Disability Insurance Scheme through a vacancy in available suppliers. This is the ‘paradox of low hanging fruit’ at the micro-market level.

This analysis can be aggregated to understanding the effect upon the National Disability Insurance Scheme as a national social program. The National Disability Insurance Agency, as administrators of the scheme, have a mandate as act as ‘market steward’ during the transition from government disability support scheme to the National Disability Insurance Scheme for the purposes of minimising “market failures”, which they have defined as “occurrences” in the emerging marketplace that would limit consumer choice and the achievement of the key outcomes of the Scheme. This means that in the short term the Agency will have a more active role in facilitating markets to ensure there is sufficient as well as innovative supply for participants (National Disability Insurance Agency, 2016).

This is potentially a redacted interpretation of ‘market failure’ in that it only partially reflects the market dynamic, because it addresses level of supply without reference to the relative costs of providing incremental access to National Disability Insurance Scheme participants. In economic terms, ‘market failure’ occurs where there is state of continual disequilibrium between the demand for services and the supply of services within a free market. As it refers to a market, it encompasses *rational* behaviour of both the purchasers and suppliers. In any market, it is not economically rational to provide services beyond the inflection point where the marginal opportunity cost exceeds the benefit. If the free market operates as it should, providers will not provide services to those where the opportunity costs of providing them access to the National Disability Insurance Scheme exceeds the benefit.

In focussing its market stewardship on the facilitation of a free market and minimising ‘market failure’, the social program managers of the National Disability Insurance Scheme are reinforcing the economic conditions which contribute to the sustained marginalisation from the Scheme by those people with disability with the most complex social and disability support requirements. In embedding free market rational decision-making rationale in the administration of the National Disability Insurance Scheme, the ‘paradox of low hanging fruit’ is translated from the micro-economic market place to a phenomenon which applies to the entire social program as a whole.

The discussion now moves from implications for Australian public policy, to the implications of the research from a perspective of community.

10.5 Implications from a community perspective

This section looks at the impact that the research has had upon the community. This discussion takes a layered approach to the community perspective on research impact, covering the personal dimensions as expressed by the participant group, the First Peoples disability community as the group that was the focal point of the research; then by other sections of the community who have been touched by aspects of the research.

The first discussion point looks at the implications of how this research was received by the participants, representing a marginalised sub-group in society, and at how researchers can involve other vulnerable population groups in future research activities. The positive impact of participation in research then invites the question of whether research can instigate social change by fostering community connectedness. This second point looks at the affirming role a culture of inclusion has in personal healing and transformation then asks whether it can also act as an agent for broader social transformation. This is described as transposing ‘apprehended discrimination’ into ‘apprehended inclusion’.

10.5.1 Inclusive research involving vulnerable populations

In addition to generating an understanding of the prevalence and nature of disability amongst the Aboriginal and Torres Strait Islander population, this research has been as much about an evolving methodology that enfranchises a marginalised people who have experienced vulnerability through an approach to research that is authentically participatory in its values, design and methods. The participatory aims of this research, as articulated in the third aim, were all about inclusion. This was reflected in the philosophical and methodological alignment at all stages of the research, that involved the First Peoples disability community, undertaken by a person coming from the First Peoples disability community, and hosted by an organisation representing and governed by the First Peoples disability community.

As the setting of this research was Aboriginal and Torres Strait Islander people with disability, the research methodology evolved with their unique circumstances front of mind. It had to acknowledge and respond to the unique types of traumas to which they have been exposed, including racism and ableism. In going into Aboriginal and Torres Strait Islander communities, the researcher and the research process needed to be culturally safe and respectful. Whilst this study observed that Aboriginal and Torres Strait Islander cultures were valued consistently across the participant group, it needed to accommodate differences in how cultures were practiced in different places, particularly when going from research sites in metropolitan areas to research sites in regional and remote areas. It needed flexibility in the language used to talk about the research when going into different Aboriginal communities, and work seamlessly within the bespoke communication networks that existed in some very small remote

locations. These were practical measures that were taken to ensure the research remained grounded in the community that it reflected.

In summary, this research set up a safe space for people who were socially isolated to come and tell their story, but it could not force them to come and tell their story. The participants needed to come to the research on their terms. Allowing the participants to tell their story on their terms required patience, and it was this level of patience that served as form of penance for the alienating forms of research that had preceded it. What the outcomes of this research have shown is that patience has its rewards. The participatory outcomes are unprecedented for the First Peoples disability community within a research setting. The interviews have elicited a richness and depth of testimony from Aboriginal and Torres Strait Islander people with disability, many of whom had said that they have not spoken about these issues in the way they did before.

The significance of this is how problems of social isolation and inequality can be solved. This research shows that the expertise about the problems does not reside within the institutions and systems that have so far failed to reach them. Such institutional research expertise is suited to solving problems of delivering supports to people once they are inside a system. The expertise needed to solve problems of social isolation and inequality resides outside the system and in the communities that experience the isolation.

Therefore, it is not adequate to take institutional models of research that have been practised in the past and attempt to extend its reach into isolated population groups without critique or adaptation (Shivayogi, 2013; Bracken-Roche et al, 2017). This approach will only go so far. These models of research must be complemented with a model of research that is philosophically different and resides within socially isolated community groups. This may be a confronting realisation for institutional models of research, especially in light of the traditional power relationships between the researcher and the researched that was referred to earlier in Chapter 3. Many of the tactical measures used to facilitate participation in this research, described above, were in initial conflict with established institutional practices of research, and required careful negotiations to overcome these resistances. Here, the researcher's positionality of being answerable to the First Peoples disability community foremost become a liberating strength – there was no choice but to persevere through. At its conclusion,

this research has taken a vision of emancipatory research, and has provided a proof of concept for a community-based inclusive model of research that future research involving marginalised and vulnerable groups can build upon.

10.5.2 *From ‘apprehended discrimination’ to ‘apprehended inclusion’*

The next discussion point look at the implications of the testimony from Aboriginal and Torres Strait Islander people on their experiences of social isolation, discrimination and trauma, in some places so pervasive that the trauma was contagious. Running parallel to the sense of despondency felt by people with disability living in Aboriginal and Torres Strait Islander communities, there is also a strong narrative of resilience and survival. The testimony that spoke to hope in defiance of disadvantage presented a tonal shift in the narrative. These expressions of hope presented themselves through a variety of emotions, ranging from anger, defiance, and even humour. There were embers of hope that shimmered through in spite of the inequality that participants experienced across their life. This was characterised by a young Aboriginal man coming from a community in which there were excessively high rates of trauma, when he said:

“There is something stronger in here [pointing to his heart], but I’ve just got to get there.” (Interview 20, remote cohort).

All the Aboriginal and Torres Strait Islander communities and the people who participated were welcoming of the research. People wanted to tell their story, and they were encouraged by others to do so. As detailed in Section 9.5, the participants in some research sites lined up and waited, some in excess of an hour, to share their life experiences through the research. Some of the participants even expressed their gratitude at being able to share their experience.

The destination for this study was ‘inclusion’ as an affirming force in the wellbeing of Aboriginal and Torres Strait Islander people with disability, and not to focus on ‘disability’ as a deficit in their lives. However, getting to this destination required truth-telling on the reality of their experiences. The response by the First Peoples disability community as participant-owners of the research reinforces a process in

which ‘lived experience’ as testimony, of being heard and being believed, is critical in the process of healing and their personal transformation.

It is not just the Aboriginal and Torres Strait Islander population that have embraced the focus on inclusion. The positive responses to this research from stakeholder groups outside the immediate participant groups that were presented in Section 9.6 infer that narrative models of social transformation as used in this research have reach beyond the Aboriginal and Torres Strait Islander disability community, and can be applied more broadly to disenfranchised groups in society.

The tonal shift from disability and inequality to culture and inclusion suggests that some of the observations from the analysis could be reimaged in the alternative. If trauma is contagious, as was observed in Chapter 8, then can inclusion also be contagious? If there is a pathway from a fear of discrimination to self-exclusion, then is there an inverted pathway from expectation of inclusion to active participation? If ‘apprehended discrimination’ is a consequence of constant exposures to discrimination, then can an obverse ‘apprehended inclusion’ be cultivated by repetitious exposure to inclusive practices? These sentiments carried into the concluding chapter, which envisions a role of inclusive research in moving from a trigger for personal transformation to acting as a catalyst of broader reaching social transformation.

10.6 Future research

As the implications of this research are broad and far reaching, so are the opportunities that have been opened up for future research. As a framework that broadly follows the structure of this research, there are five streams of an agenda for further exploring the issues that were raised in this research. In addition to further exploration of issues uncovered in this research, there were limits in the scope of the research. Whilst the participatory methods used in this research were able to penetrate barriers to the participation of a ‘hard to reach’ group in the community, there are even ‘harder to reach’ sub-groups within the First Peoples disability community whose testimony was not captured. Iterating intersectionality research to cohorts within the First Peoples

disability community exposed to even further layers of vulnerability provides a sixth stream of potential future research.

The six streams of a future ‘First Peoples Disability Research Agenda’ (Avery, 2018, pp. 204-205) are categorised as:

- (i) a conceptual framing of the cultural foundations of disability;
- (ii) continued exposition and isolation of the problems of interaction inequality;
- (iii) translation of ‘cultural models of inclusion’ into policy and practice;
- (iv) an Aboriginal and Torres Strait Islander disability informatics strategy
- (v) inclusive research methodologies in other vulnerable population groups ;
and
- (vi) extending intersectional research into a next iteration of ‘harder to reach’ cohorts with the First Peoples disability community.

10.6.1 Stream 1: Conceptual framing of the cultural foundation of inclusion and disability

This first opportunity for further research is to build upon the cultural foundations of inclusion and disability that are sourced from Aboriginal and Torres Strait Islander people and communities (Ariotti, 1999; King et al, 2014; Avery, 2018; Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women’s Council, 2018), and Indigenous peoples worldwide (Kapp, 2013, Te Pou o te Whakaaro Nui, 2016; Rivas Verlade, 2018). One of the motivations in undertaking this research was to address the absence of voices of Aboriginal and Torres Strait Islander people with disability from research and policy. The same can be said in respects to the cultural and social history of Australia, which provided the purpose for publishing a community-oriented version of this research in book form, as *Culture is Inclusion* (Avery, 2018, p.i). A theme that has emerged strongly from this research is that people from within the First Peoples disability community want to tell their stories and see their stories reflected back to them.

Aboriginal and Torres Strait Islander people connect with the narrative of the one-legged Mungo man as it connects their personal existence to an ancient culture of community inclusiveness. This is the narrative that comes from their ancestors. The testimony and yarning pieces from the participants, embodied in this thesis and the book *Culture is Inclusion* provides the same narrative of community-connectedness in a contemporary setting. This shows that research has a role in story-telling. The stories that live in communities sitting between the ancient rhyme of the one-legged Mungo man and the modern day narrative of *Culture is Inclusion* are what further research can uncover.

There is also the social history of the cultural clash that commenced within colonisation. Use of the language of ‘colonisation’ and ‘decolonisation’ has been avoided during the writing of the results, as the participants rarely used these terms in their testimony. What they did speak to was a continuation of the colonialisation experience of Aboriginal and Torres Strait Islander people with disability that intersects two of Australia’s unresolved social injustices, described earlier in as being “dispossessed from both Country and body” (Avery, 2018, p8). The opening overview on the impact of colonisation upon Aboriginal and Torres Strait Islander people with disability as a uniquely dispossessed group was intended to acknowledge colonisation as issue, but it was not possible to do the fullness of it justice within the scope of this thesis. Barring a few exceptions (Hollinsworth, 2006; Gilroy, Ragen et al, 2018), the social narrative of people with disability has been largely excised from research commentary on the impact of colonisation. Furthermore, the disability dimension to reconciliation is subsumed within a larger reconciliation agenda for the Aboriginal and Torres Strait Islander people as a whole. Their entrenched social inequality, isolation and trauma shows that Aboriginal and Torres Strait Islander people with disability require a reconciliation in their own right, which starts with the truth-telling about their place in Australia’s social history.

10.6.2 *Stream 2: Addressing ‘intersectional inequality’ and discrimination*

This research has unveiled that systems designed to support Aboriginal and Torres Strait Islander people have paradoxically caused them harm. In some cases, the harm is attributed to institutionalised prejudice, either racially-based, disability-based, or as an interaction of the two. This knowledge of institutionalised prejudice and harm has

not come from within the institutions and systems, but instead through the testimony of people whose health and wellbeing have been compromised by deficiencies in their supports.

Whilst uncovering systemic inequality and discrimination, the research has been silent on whether the institutionalised prejudice is a product of conscious bias or unconscious bias. This was not possible to determine within the methodology used; these problems are answerable with research that goes back into the institutions and systems and by investigating the decision-making behaviours of the administrators who run them. Nonetheless, this research has made a significant contribution in the possibility that the institutionalised prejudice is a form of unconscious bias by uncovering the evidence of social inequality and presenting it in the public domain. As is said in *Culture is Inclusion*, “so, now you know” (Avery, 2018, p198). The evidence of the social inequality in this research has effectively eliminated the defense of unconscious bias.

Chapter 7 provided an analysis of social inequality that cuts across policy domains that provide supports to Aboriginal and Torres Strait Islander people with disability. What is required in further research is to add depth of knowledge and application within each policy domain. The priority areas of the *National Disability Strategy* (Coalition of Australian Governments, 2007) provide a structure for further thematic studies within the domains of: accessible communities, including transport and housing; personal safety and access to justice; inclusive education; employment outcomes; and access to health services.

Further research in this stream will need to be supported by an Aboriginal and Torres Strait Islander disability informatics strategy to produce the metrics on systemic performance, outcomes and accountability. This is addressed in the fourth stream of the future research agenda below.

10.6.3 *Stream 3: Translating a culture of inclusion into practice and policy*

This stream of future research focuses on implementing the results of the research into government policies and service practices. The model of research co-production in Chapter 3 considered the interface of community with academic partners and technical advisers in applied policy research. This research has provided a proof of concept of

this model of co-production that can be translated into formulating and implementing Indigenous and public disability policy. It is also a model that can be extended by the incorporation of a third interface between community and practice for the co-design of services to Aboriginal and Torres Strait Islander people with disability.

The National Disability Insurance Scheme is of such a size, scale and impact to justify dedicated strategies for its implementation into Aboriginal and Torres Strait Islander communities. The National Disability Insurance Scheme is yet to respond to the prevalence or profile data on the number of Aboriginal and Torres Strait Islander people with disability who are potentially eligible for the scheme that was presented in Chapter 6. This is a starting point from which further policy and service strategies can be developed, including a suitably qualified workforce to provide culturally appropriate disability services that are needed to meet the demand for services by Aboriginal and Torres Strait Islander people. There are also gains to be made through greater connectivity between the person-centred model of disability that the National Disability Scheme is founded upon and addressing the environment and public infrastructure gaps that are required for a person-centred model of disability to operate.

Another aspect that has come through this research is for future research that promotes greater access to technology, particularly in remote areas of Australia. There were examples cited in Section 7.3.2 where Aboriginal and Torres Strait Islander people with disability were supplied with disability aids that were not fit for purpose in the physical environment in which they were used, such as the example of the discarded wheelchair in remote Australia; or were employing work-arounds that were masking failings in systemic supports. The use of technology to solve problems of social inequality has not featured as priority in Aboriginal and Torres Strait Islander disability research, and elevating access to contemporary technology as a right remains a promising but currently unexplored avenue of research.

10.6.4 *Stream 4: An Aboriginal and Torres Strait Islander disability informatics strategy*

This research presented statistical data which for the first time had been disaggregated for the Aboriginal and Torres and Strait Islander people with disability from larger datasets. This statistical data was initially used in Chapter 6 to determine the

prevalence and profile of disability to address the first aim of the research, then to explore issues of ‘intersectional inequality’ in across a range of social health and wellbeing indicators to address the second aim of the research.

As disaggregated Aboriginal and Torres Strait Islander disability data had not been sought for this purpose previously, the data was not configured in a format that enabled a systematic analysis. The process of poly-angulating various statistical datasets has enabled an initial estimate of disability prevalence for the whole of the Aboriginal and Torres Strait Islander population. As the Aboriginal and Torres Strait disability service sector grows, the demand for localised prevalence estimates to support decision making in service planning will also increase. This demand for better data justifies a strategic approach to the production of data of for the Aboriginal and Torres Strait Islander disability population.

The estimates on prevalence and profile used what the researcher has described in Chapter 6 as being the best available data. This was to acknowledge the limitations in the source datasets and unreconciled issues between alternative datasets. There are three unresolved issues that warrant further attention through a strategic approach to Aboriginal and Torres Strait Islander disability data. First, the different data collection methodologies of the NATSISS and the SDAC produce different prevalence estimates. These methodological differences can be reconciled when estimating the prevalence of severe and profound disability amongst the Aboriginal and Torres Strait Islander population, but become more contestable in estimating prevalence using a broader definition of disability (Biddle et al, 2014; Colman et al, 2018). Second, the prevalence estimates have been produced for the Aboriginal and Torres Strait Islander population at a national level. Due the number of respondents in the national datasets, sampling error was not a factor in the statistical analysis undertaken in this research. However, as the prevalence data is disaggregated further into regional and local areas, the sampling error will increase as the number of respondents completing the surveys within an area decreases. This becomes a methodological issue with implications for service planning and decision making in very small and remote areas with low populations. The third issue is how to adjust data for the under-reporting of disability by Aboriginal and Torres Strait Islander people in survey methodology relying on self-identification. This research is the first step in narrowing the focus of possible factors which contribute to under-reporting of disability in datasets that are both social and

cultural. However, how these factors are converted into quantitative adjustments and interpretive models for increased accuracy in decision making requires a continuing program of development.

10.6.5 *Stream 5: “What is your story?”: Inclusive research in other vulnerable population groups*

The legacy of this research is a research methodology that has been developed from first principles through an authentically grounded research process and undertaken from within the community that was the subject of the research. It went to a marginalised group of people and asked them “what is your story?” and followed the research pathway wherever that led.

Whilst the research methods described in Chapter 5 were customised for this research that was conducted in the First Peoples disability community, the principles of the community-directed model of research described in Chapter 4 have a foundation in human rights that is transferability to research that involves other vulnerable population groups. The opportunities for other vulnerable community groups in taking a similar grounded approach and leading their own research are open-ended. Further research of this nature will continue to define and refine a community-based epistemology that comes from marginalised vulnerable people, and further connects research as a strategy in the human rights movement for social change.

10.6.6 *Stream 6: Extending intersectional research into a next iteration of ‘harder to reach’ cohorts within the First Peoples disability community*

This research applied the theory of intersectionality by intersecting two marginalised population groups: one being Aboriginal and Torres Strait Islander people, and the other being people with disability. The findings of ‘intersectional inequality’ and ‘intersectional discrimination’ were empirically shown in the statistical data, testimony and yarning pieces, all of which supported the theory of intersectionality as it applies to the First Peoples disability community.

During the research journey, the researcher encountered people within the First Peoples disability community whose cases represented a level of disempowerment that

was accentuated even beyond intersecting the two marginalised population groups, and pointing to the possibility of further layers of ‘intersectional inequality’. This includes explorations of further intersections based on gender, sexuality, age and education. The research also observed co-existence of various disability types occurring at the same time. This was demonstrated in the statistical data in the disability profile of Aboriginal and Torres Strait Islander population in Chapter 6.4.1. It was also possible that some of the participants interviewed may be living with multiple disability types, although the interview avoiding asking invasive questions on their disability diagnoses, so could not be determined with certainty. Whilst conceptually plausible, it was not within the purview of the research methods or the findings to make any assertion as to whether co-occurring disability types generated an intra-intersectional effect in the further layering of their disempowerment and social inequality. This is particularly so given the high rates of undiagnosed disability that was observed amongst Aboriginal and Torres Strait Islander communities that acts as a barrier to detecting multiple co-occurring diagnoses of disability. What was observed in the research was that the presence of *any* disability was sufficient to generate disempowerment and inequality, and the effect of multiple co-occurring disability types as an intra-intersectionality is a potential area for investigation in future research.

Some further examples of intersections were touched upon in this research, but were not able to be explored in depth. These cohorts are ‘unfinished business’ from this research, which include the following examples:

- The experiences of Aboriginal women living in remote areas and bearing the burden of informal care for people with severe and profound disability in their communities, as highlighted in an analysis of disability prevalence data in Section 6.5.
- The experiences of young Aboriginal and Torres Strait Islander people with acquired brain injury and/or profound cognitive impairment, including the cases of young Aboriginal men with profound cognitive impairment who referred to experiencing multiple degrees of social isolation (Interview 11, metropolitan cohort; Interview 16, remote cohort). It is also known within the Aboriginal and Torres Strait Islander communities that there are young Aboriginal people with acquired brain injury who have been placed in nursing

homes and public hospital wards. The story of their experience has not yet been captured and told.

- The experiences of people within the justice system: Section 7.4 provided statistical data on the rates of imprisonment of Aboriginal and Torres Strait Islander people with disability in the juvenile justice system. However, the qualitative research did not interview people residing in an institutional setting, so the absence of their testimony is a gap in the testimony that was collected in this research.
- The experiences of people who live in town camps and are homeless: Outside of this study, research has identified barriers to equal inclusion of homeless Aboriginal and Torres Strait Islander Peoples with neurocognitive disability in the National Disability Insurance Scheme (Townsend et al, 2017). In the yarning piece in Section 7.7 of this study, one participant stated “*we’ve got men with a disability, living bush*” (Interview 25, remote cohort). His testimony provided one account as a small insight on the experiences of ‘living bush’, intersecting the experiences of homelessness with being Aboriginal and living with disability. This testimony is an entree to a deeper unexplored narrative of people living in town camps, and the urban equivalent of being an Aboriginal and Torres Strait Islander person with disability and experiencing homelessness, sleeping in town parks and under city bridges.

Future participatory research that focuses on the experiences of even more marginalised groups within the First Peoples disability community will expand upon the understanding in this research of how power hierarchies within society permit grave social inequality to go unattended. These are stories that have not been told, consigned as out of sight and out of mind for the broader place. Bringing voice to these people represents the next frontier in a ‘culture is inclusion’ research agenda.

10.7 Summary of research implications

This chapter presented the implications for theoretical and conceptual development, Australian social policy, the community and related stakeholders. Reflecting the

grounded research that was done involving a marginalised group of people that have traditionally been excluded from research and policy, and using an authentic and unprecedented participatory methodology, the results of this research have had profound and far reaching effects. Not only has the research uncovered evidence an acute and pervasive social injustice that many Australian would be oblivious to, it has provided both the hope and means to address and combat it.

Of the many results and implications of this research, the principle of reciprocity that requires giving back to the community that gave so much to this research, means that what this research meant for the inclusion of First Peoples disability community must prevail. What was most remarkable in this research was how the participants, many who had experienced acute personal traumas and discrimination, were so generous in their responses once their fundamental humanity had been respected. The main implication of this research is what can be achieved by giving a platform to the voices of society's most vulnerable.

This thesis now moves to a concluding chapter, which reprises the results of the research against the four aims that were determined at the commencement of the research.

11. Concluding statement...and a gift

11.1 Revisiting the research questions

This research journey started by stating a research problem that aimed to address the social inequality and discrimination that Aboriginal and Torres Strait Islander people with disability experience. Prior to the commencement of the study, the researcher was coming into regular contact with the First Peoples disability community through his connection to a not-for-profit Aboriginal and Torres Strait Islander disability organisation. Whilst cases of social inequality and discrimination were regularly spoken of, these experiences were not reflected in the small amount of research that was in existence. In summary, the voices of Aboriginal and Torres Strait Islander people with disability had been isolated from the public domain.

Despite the inequality and hardship that First Peoples with disability raised within their community setting, the sense of looking out for our community was strong. Their resilience to adversity was a project in the making. From their resilience to adversity came a vision to elevate and promote the voices of Aboriginal and Torres Strait Islander people in research and policy that has been carried all the way through this research. This vision was expressed as four research questions in Chapters 1.2 and 1.3. The four research questions were:

- Research Question 1: What is the prevalence, nature and social impact of disability amongst the Aboriginal and Torres Strait Islander population?
- Research Question 2: How is the social inequality that is experienced by Aboriginal and Torres Strait Islander people with disability created and sustained?
- Research Question 3: What is a model of research that actively promotes participation of Aboriginal and Torres Strait Islander people with disability through the direct testimony of their lived experience?

- Research Question 4: Is there an Indigenous ‘cultural model of inclusion’ that actively promotes the social participation of Aboriginal and Torres Strait Islander people with disability?

The remainder of this chapter summarises how these four research questions have been met throughout the thesis.

11.1.1 What is the prevalence, nature and social impact of disability amongst the Aboriginal and Torres Strait Islander population?

Determining the prevalence and profile using statistical data was selected as a starting point for the research. No prior research or government reporting had attempted to quantify the size and scope of the population of Aboriginal and Torres Strait Islander people with disability, yet this work holds enormous significance in planning for services and workforce.

Reflecting intersectionality theory as discussed in Chapters 2 and 3, it was determined that statistical data that was specific to the population of Aboriginal and Torres Strait Islander people with disability needed to be disaggregated from larger datasets. The technical extraction of data from various datasets was undertaken with the data custodians at the Australian Bureau of Statistics within in a community-directed model of research (Chapter 4.4) that was led by the researcher and who created the model exclusively for this research. The relational model of co-production between the researcher and the Australian Bureau of Statistics is shown in Diagram 4.4.1. The various data sources were described in Chapter 5, along with the expected value formula that was used to estimate the prevalence of disability in the Aboriginal and Torres Strait Islander population.

The results that were presented in Chapter 6 determined an estimate of the prevalence of disability amongst the Aboriginal and Torres Strait Islander population by severity. In using the best available data, a finding that approximately 7.3% (ABS, 2016b) and 7.7% (ABS, 2016a) of Aboriginal and Torres Strait Islander people lived with severe and profound disability is relevant to scoping the discrete population of Aboriginal and Torres Strait Islander people with disability, providing a planning estimate for services and programs that Indigenous and public disability policies have not yet

acknowledged. In addition to providing estimates of disability prevalence, the statistical analysis conducted in meeting this research question has produced a baseline profile of disability in the Aboriginal and Torres Strait Islander population that showed high levels of co-occurring disability types, variation in prevalence by gender and remoteness, and a high incidence of unknown or ‘other’ disability types.

Extracts from the participants’ testimonies pointed to limitations in the statistical data sources. These testimonies give insight into the cultural and social factors behind an under-reporting or non-disclosure of disability, and to the sensitivity required in interpreting the data in the analysis. They also put a human face to the frustration of not being able to access a disability diagnosis that would facilitate access to the medical and disability support that they need.

The research outcomes that have come from this research question have provided baseline data on the prevalence and profile of disability for the Aboriginal and Torres Strait Islander population as a whole. In line with the growth in the disability sector through the National Disability Insurance Scheme, there is an increasing demand for more and better quality data to support localised decision-making in organisations that provide disability services to Aboriginal and Torres Strait Islander people. From an equity standpoint, there is also an appetite for greater accountability and performance monitoring of the systems that provide support. These needs justify the continued development of an Aboriginal and Torres Strait Islander disability informatics strategy, which is proposed as Stream 4 in a future research agenda in Chapter 10.6.

11.1.2 How is the social inequality that is experienced by Aboriginal and Torres Strait Islander people with disability created and sustained?

An explanation of the unique form of social inequality that Aboriginal and Torres Strait Islander people experience was presented throughout this thesis as an interchange between theoretical construction and empirical observation. Addressing this question commenced in Section 2.4 with the introduction of intersectionality theory (Crenshaw, 1991). This was applied as a foundational theory to the circumstance of Aboriginal and Torres Strait Islander people with disability to link social inequality with the power relativities within society that marginalise people from sub-groups who traverse two marginalised populations. This application of

intersectionality was then conjoined with neo-classical economic theory in Chapter 3 to construct a theory of a 'paradox of low hanging fruit'. This concept explained how market-based foundations that underpinned social programs do not reach those groups of people who face relatively high barriers in accessing systems of support. This synthesised theory is then applied to the circumstances of Aboriginal and Torres Strait Islander people with disability to provide a theoretical explanation of why their experiences of inequality are greater compared to other population groups, and why this situation has not altered over time.

This question then turned to the empirical observations of social inequality. This evidence was presented using a mixed methods approach (Leech and Onwuegbuzie; 2008; Creswell and Plano Clark, 2011; Bowers et al, 2013; Shorten and Smith, 2017), presenting statistical data that quantified social inequality concurrently with personal testimony that provided the human context to that experience. Chapter 7 presented the results that found that, as a sub-group traversing two marginalised populations, Aboriginal and Torres Strait Islander people experienced 'intersectional inequality' compared to other population groups, including Aboriginal and Torres Strait Islander people, and people with disability. This finding of 'intersectional inequality' was identified to occur across every system of support for which statistical data were available, and was affirmed in the personal testimony.

Chapter 8 then presented the experiences of 'intersectional discrimination', showing that Aboriginal and Torres Strait Islander people regularly encounter racism, ableism, and a third unique interaction of these two types of discrimination. These results also conveyed the psychological impact of being exposed to discrimination and traumas that are both constant and acute. This impact is felt at the personal level and within whole communities, and in some tight knit communities, these traumas are contagious.

The empirical observations of 'intersectional inequality' were then conjoined in Chapter 10 with the theoretical concepts devised in earlier chapters to develop these concepts further. This showed how 'intersectional inequality' accumulates over the life trajectory of an Aboriginal and Torres Strait Islander person with disability, and constitutes a 'matriculation pathway into prison'. In emphasising that 'intersectional inequality' is not inherent in the person but in the social forces that produce isolation, this life trajectory analysis also provides a mechanism to identify the pivot points in a

person's life where their trajectory can be altered through a program intervention. Finally, the intersectional analysis is applied to some case examples of contemporary Australian Indigenous and disability policy to show the operation of a 'paradox of low hanging fruit' in policy practice, and to propose a philosophical shift in how Australian social policy addresses 'intersectional inequality' affecting marginalised population groups.

The innovation in this research is best expressed by the number of concepts and terms that were devised by the researcher in addressing this research question. The peculiar nature of social inequality and discrimination that was observed during the research could not be explained within the existing vocabulary of research. What was observed in the research was so fundamentally different in nature to how previous research had described these issues as perspectives on Aboriginal and Torres Strait Islander people with disability that a new vocabulary had to be created so that the theoretical explanations of how social inequality is generated and sustained maintained an integrity with the reality of the participants' experiences. As a result of this research, a new vocabulary explaining social inequality now includes terms and phrases such as:

- **'Intersectional inequality'**: This term describes the systemic inequality that Aboriginal and Torres Strait Islander people with disability experience as a group intersecting two marginalised populations compared to either population groups.
- **'Intersectional discrimination'**: This term explains the interaction of racism and ableism as a unique this form of discrimination experienced by Aboriginal and Torres Strait Islander people with disability.
- **'A matriculation pathway into prison'**: This phrase illustrates the accumulated impact of 'intersectional inequality' and 'intersectional discrimination' has across the life trajectory of an Aboriginal and Torres Strait Islander person with disability that results in their increased likelihood of ending up in prison, rather than into education, employment or other areas of personal fulfilment.

- **‘Apprehended discrimination’**: This term was devised to describe the pathway through which Aboriginal and Torres Strait Islander people with disability progress, from an intuitive fear of discrimination to a rational expectation that they will experience discrimination, then self-exclusion as a way to avoid discrimination.
- **‘Paradox of low hanging fruit’**: This concept was constructed to describe how market forces drive access to social programs towards an equilibrium access point and, in not reaching people with relatively high access barrier, it paradoxically increases the social inequality within the populations that the social program is intended to benefit.
- **‘Contagious trauma’**: This term was used describe the level of sadness and despondency that is felt across tight-knit communities, when large proportions of the community are affected by trauma and chronic exposure to discrimination. It was created by the researcher after a personal experience of ‘catching trauma’ whilst visiting a community and interviewing a succession of people who were affected by acute traumatisation.

11.1.3 What is a model of research that actively promotes participation of Aboriginal and Torres Strait Islander people with disability through the direct testimony of their lived experience?

The overarching ambition of this research was to elevate and promote the voices of Aboriginal and Torres Strait Islander people with disability. This ambition was entrenched within this research question from the opening stage of the research and carried through the research with the development of a community-directed model of research from its grounded origins and carried through all stages of the research.

This research question was principally addressed in Chapter 4 and 5 of the thesis. Chapter 4 described the conceptual development of a community-directed approach to research. Critical to this was the positionality of the researcher, who is part of the First Peoples disability community and was embedded within a community organisation for the duration of the research. The community-directed research model was built to

acknowledge the unique circumstances of marginalisation that as a group these people would have encountered. The construction process started with principles that promoted participation and came from the community involved in the research. It then established a community-directed model of research co-production that inverted the traditional power relationships that exist between the researcher and the researched, providing practical empowerment to the participants as owners of the research.

Another feature of the participatory approach was how language was used to relieve the alienation that the participants might feel towards the research. It adapted commonly used phrases in a way that made the First Peoples disability community comfortable with the level of respect with which the research would be conducted. Some of these words included traditional Aboriginal words such as ‘yarning’ and ‘message stick’ to describe the process and relational function of the researcher, in addition to colloquial phrases such as ‘rock up recruitment’ to talk about how the researcher would work seamlessly within the established communication networks that were in place in each community that was involved in the research.

Chapter 5 then describes how the participatory principles and concepts were operationalised in this research. It describes how the ‘rock up recruitment’ processes create a safe environment in which the participant group could provide their testimony on their own terms. It then progressed through a non-invasive interview protocol and style that was premised on one participant-centred question: “what is your story?”

The outcomes of these participatory methods were detailed in the second part of Chapter 9 which showed how the participant group enthusiastically responded to the opportunity to give testimony to their experience on their terms. A total of 47 people with disability participated in the personal interviews, voluntarily providing a richness and honesty in their testimony that some participants said that they had not told anyone before, even their close family and friends.

11.1.4 Is there an Indigenous ‘cultural model of inclusion’ that actively promotes the social participation of Aboriginal and Torres Strait Islander people with disability?

The notion that inclusiveness is innate in Indigenous cultures was introduced in the opening preface of this thesis with the narrative of the one-legged Mungo man on a hunt with his tribe. The literature scan presented in Chapter 2 described how this culture of inclusiveness was disrupted by colonisation whereby Aboriginal and Torres Strait Islander people were “dispossessed from their Country and their body” (Avery, 2018, p8). The evidence of ‘intersectional inequality’ and ‘intersectional discrimination’ in Chapters 7 and 8 has shown that the disruptive processes of colonisation have been ongoing.

Towards the end of Chapter 8 came a tonal shift in the narrative. This shift came through expressions of hope in the participants’ testimony and in the yarnings. The statistical data presented in Chapter 9 showed that Aboriginal and Torres Strait Islander people with disability participate in cultural and community events at the same rate as Aboriginal and Torres Strait Islander people without disability, a finding that is in stark contrast to the social inequality that they experience in other aspects of their lives. This finding, along with the personal testimony from people with disability on their inclusion within community, has reanimated an Indigenous culture of inclusion that acts as a moderating force to the social inequality and discrimination that they otherwise encounter in their lives. An Indigenous culture of inclusion is characterised by a personal expression used by an Elder, “*we go hunting together*” (Interview 34, remote cohort), a comment of inclusiveness that has given this thesis its title.

The finding of an Indigenous culture of inclusion is then developed further in Chapter 10. Contrasting a ‘cultural model of inclusion’ with alternative disability discourses, this ponders whether inclusion can be practised and be expected, as an obverse to how isolation and discrimination have become to be expected. This thesis leaves this reimagined vision as its legacy, one of ‘apprehended inclusion’, where participation within social life is a natural occurrence that all people can encourage and enjoy.

11.2 Future research implications

This research has presented a proof of concept for a model of research that addressed questions of social inequality that are experienced by acutely marginalised groups of people. It has shown that research questions on entrenched disadvantage and marginalisation can be addressed through an approach to research that is authentically inclusive of the people that are affected by social inequality. The impact of this research transcends a greater understanding of social inequality through its research findings. The recognition of the lived experiences of Aboriginal and Torres Strait Islander people as a respected form of knowledge has contributed to their personal and community healing.

The empirical observations of social inequality, ‘intersectional discrimination’ and trauma that were uncovered by this research are reinforced through a robust theoretical and methodological foundation that was developed by this thesis. The development of theory and methodology makes the research teachable beyond the First Peoples disability community who were the focus of this research. In presenting a community-directed epistemology as an alternative to an institutional approach to research, this study invites a critical reflection on the limits of institutional modes of research in addressing research questions of entrenched social isolation and vulnerability. That this knowledge and methodology have come from a community of people who have themselves experienced marginalisation and vulnerability provides an operational blueprint for Freire’s ‘pedagogy of the oppressed’ (Freire, 1972).

There is a link between ‘social inequality’, which is at the forefront of this research, and addressing the underlying ‘social inequity’, which is the next progressive step. The contribution of this research has been to compile the empirical evidence of social inequality, which has been produced through a scientific process and is explainable by a sound theoretical framework. The evidence and data from this research provide a rationally formed conclusion that social inequality exists for Aboriginal and Torres Strait Islander people with disability. From the data and evidence of ‘inequality’, the moral and ethical arguments highlighting the underlying ‘inequity’ can be mounted.

There are practical applications for this research on the immediate horizon. Towards the end of this study, the Australian Government announced a Royal Commission into

the violence, abuse, neglect and exploitation of people with a disability (Commonwealth of Australia Attorney General's Department, 2019). Anticipated to be one of the largest Royal Commissions in Australian history, it will investigate issues of violence, abuse and trauma that affects people who experience acute vulnerability. A research agenda will be required to transform the testimonies of violence, abuse and neglect that people with disability have encountered into learnings and recommendations coming from the Royal Commission. The trauma informed and emancipatory approach of this research provides a methodology where people who have experienced vulnerability can tell their story in a safe place, whilst also acting as a catalyst for personal and national healing.

11.3 “We go hunting together” – A gift of inclusion to others

This research started with a goal to elevate and promote the voices of Aboriginal and Torres Strait Islander people with disability. Its scope was open-ended and bold, and provocatively so. It wanted to be genuine in asking ‘what is your story’, then in following the direction to wherever these stories pointed. Beyond the knowledge that this approach has generated, it wanted to prove what could be achieved by giving voice to people who had been socially silenced. The depth and breadth of what was achieved is testament to what can be achieved in respecting the humanity of our most marginalised citizens by providing them a platform to speak on their existence.

As a researcher coming from within the First Peoples disability community who has been exposed to these issues for a long period of time, these research outcomes are unsurprising. For many people outside the First Peoples disability community, however, this research has become a revelation. It has been confronting for people now exposed to a serious social injustice that is happening in their own country, but that they were oblivious to.

There is another revelation. This has come with the philosophical shift that has occurred with the focus moving from disability to inclusion. This is shown by the reaction of people to the publication of *Culture is Inclusion*. This book has been warmly received, not just within the First Peoples disability community, but well beyond it. In the space of six months the narrative of Aboriginal and Torres Strait Islander people with disability has found a place in University libraries, on course

reading lists, in the offices of disability service providers, in law firms, in preschools, in high schools, in medical research centres, in the waiting rooms of Members of Parliament and Senate, and on the coffee tables of people in Australia and abroad who have an active concern for social justice. The message from our Elder “*we go hunting together*” is a rallying cry for a social movement that connects people within a community who collectively can initiate social change.

There are people who aren’t Indigenous who are looking at the culture of inclusion and saying ‘we want that’. The *Uluru Statement from the Heart* speaks of First Nations children who will “walk in two worlds and their culture will be a gift to their country” (National Constitutional Convention, 2017). Invoking this sentiment, a culture of inclusion that gives spirit force to Aboriginal and Torres Strait Islander people with disability is a gift that is shared with others. The spirit of giving is reflected in the generosity by which the participants in this study freely shared their stories and wisdom, in part for their own process of personal healing, but also so that it would benefit others in their community for them to connect with their story through a shared experience. This research has told of a truth that brings this community closer together. Taken from the closing pages of *Culture is Inclusion*, this gift of inclusion comes in the form of a message to others in society who are experiencing isolation and vulnerability.

“The message of inclusion is: You are not alone. You are our community, and we are yours. If we can come together and stick together, then nothing can divide us”

(Avery, 2018, p.207).

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APPENDICES

Appendix A: Letters of Support from the First Peoples Disability Community:

A1: Mr Damian Griffis, CEO First Peoples Disability Network, January 2016 (submitted with the ethics submission to the New South Wales Aboriginal Health and Medical Research Council).

A2: Ms Joanna Agius, Convener Deadly Deaf Mob, March 2016.

A3: Ms June Riemer, Executive Officer Aboriginal Disability Network New South Wales, April 2016.

A4: Cowboy, Aboriginal Elder, Arlparra (Utopia), Northern Territory, September 2016.

A5: Mr Damian Griffis, CEO First Peoples Disability Network, February 2017 (submitted with the ethics submission to the Human Research Ethics Committee at the University of Technology, Sydney).

Appendix B: Research participant information and consent form.

Appendix C: Information Sheet - Elders Forum, 21 September 2017, Alice Springs Northern Territory.

Appendix D: Safety and distress protocols for research participants and interviewers.

Appendix E: Avery S. (2016a) *Intersectional dimensions on the right to health for Indigenous peoples – A disability perspective*. Prepared for the United Nations Expert Mechanism on the Rights of Indigenous Peoples (EMRIP) study on ‘The Right to Health for Indigenous Peoples’. First Peoples Disability Network (Australia). Sydney.

Appendix F: Avery S. (2016b) ‘The life trajectory for an Aboriginal or Torres Strait person with disability’. In: Avery S, and Keyser P (eds). *Aboriginal and Torres Strait Islander perspectives on the recurrent and indefinite detention of people with cognitive and psychiatric impairment*. (Chapter 2: 6-9). First Peoples Disability Network (Australia). Sydney.

Appendix G: Avery S. (2018) *Culture is Inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability*. First Peoples Disability Network (Australia). Sydney.

Appendix H: A pictorial essay of the research journey.

5. Statement of Approval – First Peoples Disability Network



On behalf of First Peoples Disability Network (FPDN), I confirm that:

- (i) FPDN is an organisation constituted by and for First Peoples in Australia with disability, and its Board of Directors is comprised entirely of First Peoples with disability.
- (ii) FPDN has a strategic objective to build knowledge through community-driven research within its *Strategic Directions 2015-2020*, which has been endorsed by its Board and attached to this Statement.
- (iii) The research proposal 'Living Our Ways – A proposal to establish a First Peoples disability research agenda' is supported by the Board and Executive of FPDN to advance its objectives to conduct community-driven research.
- (iv) FPDN has established an Academic Advisory Panel to provide academic oversight to this project, within the parameters of community-driven research, and obtained a letter of support from the School of Public Health and Community Medicine, University of New South Wales as its principal academic partner which is attached to this Statement.
- (v) FPDN formally supports the candidature of Scott Avery, Policy and Research Director, in the professional Doctorate of Applied Public Health at the University of New South Wales using data derived from this research project.

Damian Griffis
Chief Executive Officer
First Peoples Disability Network

Scott Avery
Policy and Research Director
First Peoples Disability Network



First Peoples
Disability Network
Australia

STRATEGIC DIRECTIONS 2015–2020

OBJECTIVE 6:

KNOWLEDGE BUILT THROUGH COMMUNITY-DRIVEN RESEARCH

We will conduct research to capture the knowledge, expertise and experience of First Peoples with disability and use this knowledge to secure their rights through improvements to policy and practice.

Key result areas

Capture of narratives of lived experiences of First Peoples with disability

We will:

- create opportunities for people to share their experiences of disability as a basis for research
- develop a community-driven research agenda that is informed by the personal and family narratives shared with us during community consultations
- share our knowledge and research results in relevant publications and at policy and research forums
- build capacity in the First Peoples disability research sector by actively supporting First Peoples researchers with disability in all aspects of research.

Collaboration in rights-oriented research

We will:

- establish principles for the co-production of research with other organisations that is compatible with the First Peoples disability community
- establish partnerships with compatible researchers and organisations that have the potential to advance the human rights of First Peoples with disability and their families
- form international research alliances with other Indigenous peoples for the exchange and promotion of knowledge and research.

Outcomes

We have developed a First Peoples disability research agenda.

We have obtained funding for narrative-based community-driven research and taken the role of lead researcher.

Our research papers have been published in relevant journals.

18 March 2016

Mr Scott Avery
Policy and Research Director
First Peoples Disability Network
402/161 Redfern St
REDFERN NSW 2016

Dear Scott

Re: Letter of support from Deadly Deaf Mob for 'Living Our Ways' research

I refer to FPDN's 'Living Our Ways' research which you introduce to Aboriginal and Torres Strait Islander Deaf community at our Deadly Deaf Mob Conference in Penrith In October 2015.

This is to inform you that on behalf of the organising Committee, we are excited by the research and the opportunity to share our life stories and experiences, and hope that it can be used to make a positive difference. Many of the participants of the Deadly Deaf Mob Conference indicated that they would be keen to participate, and the Committee give our consent for you go ahead with your research. This is subject to ensuring that you obtain consent from individual people.

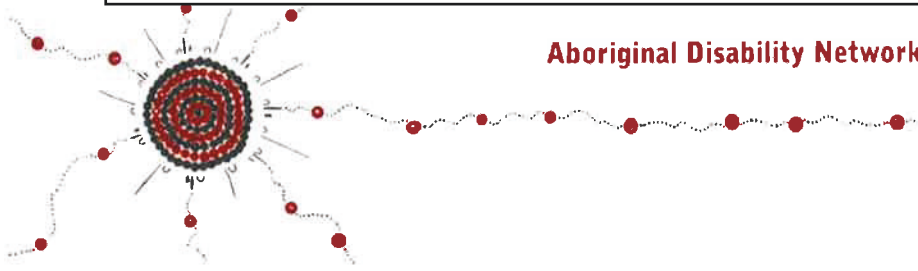
We are happy for you to use this letter of support in your proposals and ethics applications to Aboriginal research bodies. They can email me on artyjagius@gmail.com if they need to confirm our support

We look forward to participating and hearing about the outcomes of the research which we are hopeful we can use in future Deadly Deaf Mob Conferences.

Yours faithfully

Production Note:
Signature removed prior to publication.


On behalf of Deadly Deaf Mob Organising Committee



Aboriginal Disability Network

Network Incorporated
402/161 Redfern Street
Redfern NSW 2016
phone 02 8399 0881
fax 02 8399 1664
enquiries@adnnsw.org.au
www.adnnsw.org.au
ABN 70 535 341 554

1 April 2014

The Chair
Ethics Committee
Aboriginal Health and Medical Research Council of New South Wales

Dear Chair

I write this letter in support of the research that is being conducted by the First Peoples Disability Network in Aboriginal disability in New South Wales.

Aboriginal Disability Network of New South Wales (ADN) is a community controlled organisation has been in existence since 2000, raising awareness of disability in Aboriginal communities. We conduct community forums across NSW to make people aware of their rights and help people access disability supports using our Living My Way resources.

There are no structured disability organisations based in communities, particularly when compared to what is in place for health and legal services. Often people who have disability are isolated in their community. We are hoping to change this by developing ways for Aboriginal people with disability to come together and talk, and we see that this research will help us achieve that goal.

We have been working with the First Peoples Disability Network, our national peak organisation, on this research since our 'Living My Way Conference' we hosted for Aboriginal people with disability and their families in Newcastle in October 2014, when it became apparent we needed a way to capture and share their stories. We have ensured that the research comes from the community, and we will undertake to make introductions to Aboriginal people with disability following our community engagement activities, once we obtaining consent from the community. It is our experience that Aboriginal people with disability are very responsive to the idea of participating in the research by sharing their stories.

I trust that this letter of support addresses any concerns that you might have about the community support for the First Peoples Disability Network's research. Please feel to contact me personally on juner@adnnsw.org.au if you wish to discuss.

Yours sincerely

Production Note:
Signature removed prior to publication.

June Riemer
Executive Officer



7th September 2016

Mr Scott Avery
Policy and Research Director
First Peoples Disability Network
402/161 Redfern St
Redfern NSW 2016

Dear Scott

Letter of Support for “Living My Ways” research.

I refer to First Peoples Disability Network’s ‘Living My Ways’ research program, which seeks to interview Aboriginal and Torres Strait Islander people with a lived experience of disability.

We recognise the First Peoples Disability Network as a community organization, which is run by Aboriginal and Torres Strait Islander people with disability, and have had respectful dealings with them. We have read the research information sheet and consent form attached, and understand its purpose is to obtain our Peoples’ perspectives on matters that can be used to make recommendations to Government and service providers about the needs of people with disability.

We believe that there are many people in our community of who would be willing to participate, subject to their personal consent being obtained.

Production Note:
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I am happy for you to use this letter of support in your proposal and ethics applications.

We look forward to participating in the research and hearing about the outcomes.

Yours sincerely

28 February 2017

Chair
Research Ethics Committee
University of Technology Sydney



To whom it may concern,

Re: Confirmation of support for Scott Avery's PhD research and 'Living our ways' research program

On behalf of the First Peoples Disability Network (FPDN), I write to confirm our organisation's support for Scott Avery's PhD research program at UTS.

FPDN is a community-based Indigenous Disabled Peoples organisation established by, for and on behalf of Aboriginal and Torres Strait Islander Peoples with disability. Our organisation is governed a Board of Directors comprised entirely by First Peoples who have a lived experience of disability. This governance structure makes our organisation unique in Australia if not the world.

Scott Avery commenced with FPDN in July 2014 as our Policy and Research Director. At the time, I provided a formal letter of support as workplace sponsor for him to commence a professional doctorate at the University of New South Wales. In mid 2016, he transferred his research program to UTS to maintain continuity with his research supervisor who had been appointed at UTS. This letter is to confirm FPDN's continued support for his research degree.

Since joining FPDN, Scott has become FPDN's lead investigator on a Commonwealth Government funded program to collect narratives of Aboriginal and Torres Strait Islander people with lived experience of disability. Called 'Living our ways', this research has been welcomed within our community, as it provides a chance for Aboriginal and Torres Strait Islander people with disability to tell their story on their terms, often for the first time. However, as there is a possibility these people may have experienced trauma or discrimination in their lives, it is important that they do not feel compelled to tell their stories again and again for different projects. Accordingly, we formally assign to Scott access to this data and other data that FPDN has collected through community forums for the purposes of undertaking his research degree.

In his role as Policy and Research Director, Scott has always placed our community members' rights and interests foremost. He has established an Academic Advisory Panel which provides independent advice to FPDN as an additional measure of oversight for the research. We have every confidence that Scott will continue to conduct his research ethically and responsibly and for the benefit of the First Peoples disability community.

Yours faithfully

Damian Griffis
Chief Executive Officer, First Peoples Disability Network

CC: Chair, Aboriginal Health and Medical Research Council (NSW)

Research participant information and consent:



About First Peoples Disability Network:

The First Peoples Disability Network is an organisation set-up and run by Aboriginal and Torres Strait Islander people with disability. All of our Board are Aboriginal and Torres Strait Islander people who have a disability of some sort.

We champion the rights of Aboriginal and Torres Strait Islander people with disability and conduct research to show Governments and service providers how to better support the needs in our communities.

Why do we do research?

First Peoples Disability Network does research to help understand what life is like for our mobs. We ask people to share their experiences through story-telling. This way we can hear what life is like through their eyes, and understand what matters to them.

When we get these stories – or ‘narratives’ as we call them in research - we look at them to see if we can find some common issues. We then write a report which will show what matters to you and how the needs of our mobs in communities can be better supported.

Who can I tell my story to?

We will only ask you to share your story if you are conformable in doing so. You can share your story to someone at First Peoples Disability Network or someone within the community you trust who can pass this on to us.

We would like to record your story so we can make sure we capture what you say accurately. If you do not want to be recorded, we can write notes. If we do this, we will show you what we have written to make sure we have it right.

This means you can say ‘no’.

What will happen with my story?

Once you have told us your story, we will write it down. We respect your privacy so we will then go through to make sure everything that can identify you personally is taken out.

The research team at First Peoples Disability Network will then put your story together with everyone else who has told us their story and we will look for similar experiences and issues. We will then write this up in a report and publish it so Government and other researchers have a better understanding of the experiences of Aboriginal and Torres Strait Islander people. We may also use your words to highlight an important point or issue. If we do this we will not identify you personally as having said it.

What happens if I change my mind?

If you change your mind after you have shared your story, let us know within the next three days and we will stop using your story in our research from that point on, and destroy any records we have from you. Once we have removed everything that can identify you from the written version of your story, we may not be able to do that.

Who can ask questions to about the research?

The main point of contact is Scott Avery, who is the Policy and Research Director at First Peoples Disability Network. He can be contacted on (02) 8399 0882 or scotta@fpdn.org.au.

You can also talk to someone from First Peoples Disability Network's community engagement team.

Who can I complain to if I don't like what has happened?

As First Peoples Disability Network is a community organisation, you can complain directly to our Chairperson who Aunty Gayle Rankine, who is a respected Elder in the First Peoples disability community. She can be contacted on (02) 8399 0882 or by email on gayler@fpdn.org.au.

If you are uncomfortable in doing this, you can also contact the **[Insert Region]** Aboriginal Health Research and Ethics Committee who monitors Aboriginal health research in South Australia. They can be contacted on:

Phone: **[Insert Phone No.]**

Email: **[Insert Email]**

Address: **[Insert Address]**

Postal address: **[Insert Postal Address]**

PERMISSION:

I give my permission to First Peoples Disability Network to record me for their research program.

I give my permission for First Peoples Disability Network to use this recording in publications and presentations.

I understand that I can withdraw my permission to use the recording of me by contacting First Peoples Disability Network within three days of telling my story.

Signed: _____ Date: _____

Guardian / carer: _____

Name: _____



INFORMATION SHEET

First Peoples Disability Network 'Living our ways' Elders Forum

DATE AND LOCATION: Thursday, 21 September 2017, Alice Springs NT

About First Peoples Disability Network (FPDN)

FPDN) is a national organisation established by, for and behalf of Aboriginal and Torres Strait Islander people, families and communities with lived experience of disability. With a Board of Directors entirely comprising First Peoples with disability, we are guided by the lived experience of disability in determining our priorities and our way of doing business. FPDN is committed to research and policy development that captures the knowledge, expertise and experience of disability in our communities. We have a long-standing history of advocating for the rights of First Peoples with disability through high-level policy advice to Australian Governments and in international human rights forums.

Background to 'Living our ways' research program

FPDN is undertaking a community-directed research program which is based on the experiences of Aboriginal and Torres Strait Islander people as told through their narratives. We utilise a grounded approach to our research, which means that people can share their experiences in a safe place. This way, we can hear what their life is like for people with disability as told by and on their terms.

In excess of forty-five Aboriginal and Torres Strait Islander people have participated in the research by sharing their stories. These narratives are currently being analysed to find common themes and issues. FPDN will prepare a report on the finding of the 'Living our ways' research which we aim to publish in early 2018.

The 'Living our ways' research program is supported through the National Disability Research and Development Scheme which is administered by the Department of Social Services.

Purpose of the Elders Forum

The Elders Forum is a capstone event to mark an initial phase of an ongoing research agenda which is driven by Aboriginal and Torres Strait Islander people with disability and their communities.

The purpose of the Forum is to provide a community context to the personal stories of disability which have come from the individual participants with a narrative on disability in our communities. Consistent with our grounded approach, the Elders Forum will use discussion prompts rather than structured questions to facilitate free-flowing story telling.

We are aiming to capture the story of disability in communities, how it is presently seen, how it has changed over time, and what does this mean for the inclusion of people with disability in community.

What will happen with the stories that are shared during the Elders Forum?

With the permission of participants, the narratives of disability in Aboriginal and Torres Strait Islander communities that are shared during the Elders Forum will be documented. We respect the privacy of all the participants so we will then go through to make sure everything that can identify anyone personally is taken out.

FPDN will then write up the outcomes of the Elders Forum and include them in within the 'Living our ways' research report, alongside the personal testimonies of Aboriginal and Torres Strait Islander people with disability.

Invited Participants

It is envisaged that 8-10 Elders will participate in the Forum. Elders have been invited from a cross section of Australia to participate, including: a representative from FPDN's Board, the NPY Women's Council in the Northern Territory, and from regions in New South Wales, far north Queensland, the Torres Strait, Barkly Shire in Northern Territory, and Western Australia.

Contact details for the Lead Investigator

The lead investigator for the 'Living our ways' research program is Scott Avery, Research and Policy Director at First Peoples Disability Network. Scott is a Worimi man, and is profoundly deaf (he wears a cochlear implant). He is also undertaking a PhD on Aboriginal and Torres Strait Islander disability at the University of Technology, Sydney (UTS), who are one of FPDN's research partners.

Scott may be contacted with any enquiries on:

Email: scotta@fpdn.org.au

Phone: (02) 9276 4195

Mobile: [REDACTED]

Aboriginal Research Ethics approval and contact details

The Elders Forum is a research activity within the 'Living our ways' research program which has been reviewed and approved by the **Central Australia Human Research Ethics Committee** who monitors research on in Central Australia. They can be contacted with any issues or concerns on:

Phone: (08) 89514700

Email: cahrec@flinders.edu.au

Postal Address: PO Box 4066 Alice Springs NT 0871

Reference Number: HREC-16-435

Safety and distress protocols for research participants and interviewers



The purpose of these protocols:

Many Aboriginal and Torres Strait Islander people have felt social exclusion and experienced trauma and during their lives. Aboriginal people with disability are at risk of experiencing these feelings on two levels, one because of their Aboriginal or Torres Strait Islander identity and another because of their disability. There are many reasons why a person may experience feelings of isolation or trauma, and triggers for these feelings can be quite personal.

These protocols are aimed at the protection and safety of both the participant and the interviewer. The purpose of these protocols are to raise awareness that negative feelings could arise during an interview, provide guidance on how to reduce the risk of this occurring through preparation, and how to respond if the participants or the interviewer start showing signs of distress.

Introducing the research and interview process to potential participants

- Use the prepared research information and consent form (attached) to outline the purpose of the research, the interview structure and how the data will be arranged and used.
- Emphasise that all responses will be de-identified, and they will not be personally identified in any reported.
- Emphasise that the interview is completely voluntary and they can say 'no' at any point in time.
- Listen carefully to any questions. Answer any questions factually and do not try to 'sell' the research.
- If the proposed participant expresses any doubt about participating, do not proceed with the interview until they are completely comfortable and provide their consent to arrange an interview.

Preparing for an interview

- Ask the participant where they would feel most comfortable in conducting the interview. This will create a 'safe space' for the interview.
- Invite them to bring a support person along with them.
- If they do not bring a support person with them, ensure that there is a second person available in close proximity who can seek help if needed.

During the interview

- At the commencement of the interview, go back over the purpose and process using the information and consent form.
- Commence the interview with an ice-breaker question, such as a general question which gets them talking about themselves on their terms. This will help create a relaxed and informal approach to the interview.
- Allow the participant to give their story on their terms. Do not press any point or be judgmental about any of their responses.
- Be alert to non-verbal signs of distress, such as long pauses, hand wringing, or expressions of anger.
- In closing an interview, remind the participants that if they get home and decide that they do not wish have their story included within the research, in part or in full, that they can contact the interviewer and they will remove the parts as requested.

On observing signs of distress

- If the interviewer observes any early signs of distress, pause the interview immediately. Offer to take a break or get a drink of water. If the participant does not wish to proceed, cease conducting the interview.
- If the participant wishes to proceed after a break, continue to remain alert to continuing signs of distress. If these signs continue, stop the interview immediately.
- If the signs of distress become acute, arrange for the support person or a second person to seek help from a mental health professional. Do not leave the participant alone.
- Ensure that professional help is arranged for the participants, and ensure that there is an ongoing follow up on their health and wellbeing.

Debrief

- Feeling of distress can occur after the interview has completed.
- It is important that both the participant and interviewer are provide an opportunity to debrief. This can be arranged through FPDN.
- FPDN also provides a free Employee Assistance Program for its staff.

Further information

- Interviewers are strongly encouraged to complete a two-day Mental Health First Aid course. This can be arranged by contacting either June (juner@fpdn.org.au) or LaiHa (laihaw@fpdn.org.au) at FPDN.



FIRST PEOPLES DISABILITY NETWORK

Intersectional Dimensions on the Right to Health for Indigenous Peoples – A Disability Perspective

**Prepared for the Expert Mechanism on the Rights of Indigenous
Peoples (EMRIP) study on ‘The Right to Health For Indigenous Peoples’.**

February 2016

About First Peoples Disability Network (Australia):

First Peoples Disability Network (Australia) is a national organisation established by, for and on behalf of Aboriginal and Torres Strait Islander people, families and communities with lived experience of disability. The Board of Directors is entirely comprised of First Peoples with disability. We are guided by the lived experience of disability in determining our priorities and our way of doing business.

FPDN is committed to research and policy development that captures and respects the knowledge, expertise and experience of disability in our communities. FPDN aims to be the interface between the First Peoples disability community, policy makers and researchers in order to generate practical measures that secure the human rights of First Peoples within a social model of disability. We have a long-standing history of advocating for the rights of First Peoples with disability through high-level policy advice to Australian Governments and in international human rights forums.

Summary of issues

1. Human right frameworks in which data collection is based on individual aspects of a person's identity (i.e. Indigenous status *or* disability) do not fully capture the composite rights of Indigenous peoples who are also marginalised due to other aspects of their identity.
2. Human rights frameworks and applied public policy should have greater sensitivity to issues of intersectional risk to ensure that the composite rights to health and appropriate care of all Indigenous peoples are secured.
3. Particular consideration should be given to intersectional aspects of institutionalised discrimination. This occurs when people are discriminated against due to multiple aspects of their identity (e.g. an Indigenous person *and* a person with disability). This is a major impediment to securing the right to health and can lead to a denial of vital health services. When it's persistent and extreme, this can result in multiple systemic failures, and can lead to catastrophic health consequences for the person affected.

What does the right to health mean for an Indigenous Person?

'Health' for Australia's Indigenous Peoples focuses not only on physical health but also encompasses spiritual, cultural, emotional and social wellbeing. Health is more than the absence of sickness; it is the relationship with family and community, providing a sense of belonging and a connectedness with the environment:

“Aboriginal [and Torres Strait Islander] health means not just the physical well-being of an individual but refers to the social, emotional and cultural well-being of the whole Community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total well-being of their Community. It is a whole-of-life view and includes the cyclical concept of life-death-life”¹.

The holistic definition of health incorporates broader issues of social justice, well-being and equity as key attributes of health for Aboriginal peoples and is consistent with the World Health Organisation Alma Ata Declaration of 1978:

“Health ... is a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity... [it] is a fundamental human right”².

Human rights provide a framework for addressing the consequences of health inequality experienced by Aboriginal and Torres Strait Islander peoples. This includes recognising the underlying causes of health inequality as well as the inter-connections with other issues.

Embedded in the human rights approach to health is:

- Active participation by Aboriginal and Torres Strait Islander peoples in decision-making at all levels in accordance with the *United Nations Declaration on the Rights of Indigenous Peoples*; and
- Article 24 of the Declaration, read in conjunction with Article 12 of the *International Covenant on Economic, Social and Cultural Rights*, recognises the right of Aboriginal and Torres Strait Islanders “to the highest attainable standard of physical and mental health”, or the right to health.

Intersectional Dimensions on the right to health – an Indigenous Disability Perspective

Intersectionality is an emerging field of human rights research that is influencing public policy. Intersectionality acknowledges that there are multiple dimensions to a person’s identity that frame the layers in which social inequity can accumulate. This involves understanding the right to cultural inclusion as an Indigenous person, as well as the right to inclusion as a person with disability.

An Indigenous person with disability is a member of at least two communities; one pertaining to their identity as an Indigenous person and another pertaining to their disability. Addressing one aspect of a person’s rights in isolation from the composite rights can leave them excluded from another aspect of society important to their sense of identity. This theme of partial exclusion was highlighted by one respondent, an Indigenous person with disability speaking of her decision to suppress her Aboriginality, in an interview provided to FPDN:

¹ National Aboriginal Health Strategy Working Party (1989) *National Aboriginal and Torres Strait Islander Health Strategy*.

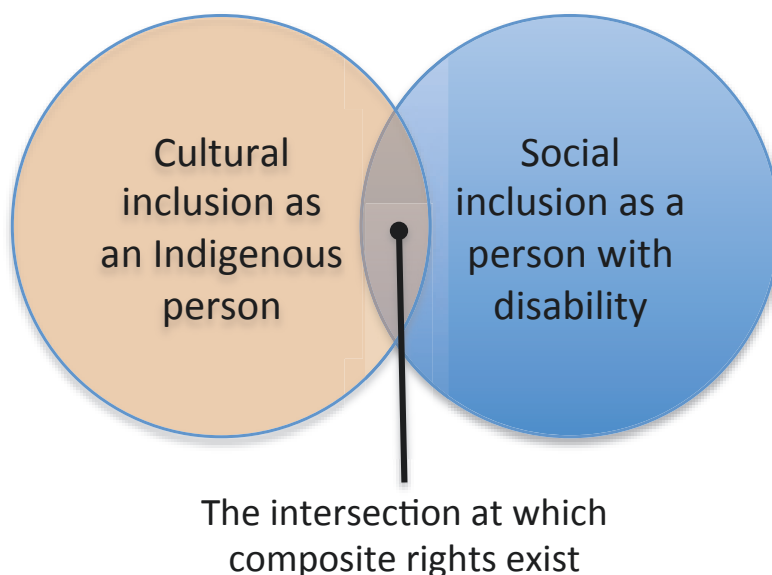
² World Health Organisation (September 1978), Declaration of Alma-Ata, International Conference on Primary Health Care, Alma-Ata, USSR

"I never used to speak about being Aboriginal. With my disability, I didn't want another thing to have to deal with".³

A failure to understand both dual access rights for Indigenous and the rights of a person in effect creates a minority group within a minority group. Aboriginal and Torres Strait Islander people with disability have colloquially referred to the social exclusion because of Aboriginality and disability as experiencing a 'double discrimination'.

An intersection of rights, framed as inclusiveness in both Indigenous and disability contexts, is conceptually illustrated below:

Diagram: The composite rights for Indigenous people with disability



Whilst this particular perspective emphasises disability as an intersectional risk to the right to health for Indigenous Peoples, the concept of also applies in relation to other risk factors, which can have a cumulative detrimental impact. These risk factors can include:

- Gender
- Children and young people
- Exposure to trauma, both acute and inter-generational
- Psychiatric and mental health conditions
- Lesbian, gay, bisexual, transgender, intersex
- Drug and alcohol dependence
- Exposure to family violence
- Deprivation of liberty.

³ Participant at the Aboriginal Disability Network (NSW) 'Living My Way' Conference, Newcastle NSW Australia, October 2014.

The cumulative impact of intersectional risk across the life course of an Indigenous person with disability

Failures in addressing the rights of an Indigenous person in their early years can lead to a further, and often rapid, deterioration in rights over the course of a lifetime.

Here is one scenario as an example:

- An Indigenous mother living in poverty and in a community with inadequate public health facilities is more likely to have a low-birth weight baby compared to non-Indigenous people.
- Low birth weight is a known risk factor for childhood disability and learning impairment.
- The rate of removing a child from their families is significantly higher for Indigenous children compared to non-Indigenous children. In Australia, this disparity is a 10-fold increase in the rate of child removal for Indigenous children.
- Clinical protocols for the assessment for disability, particular cognitive impairments, can require a stable home environment to enable an accurate assessment. If shifting from home to home in an out-of home-care system continually disrupts a child, then an assessment of disability may not occur.
- Medical-based models of disability (not just in health, but also in education) require a diagnosis to trigger supports for a child.

So, when the barriers to access the right to health for an Indigenous person interact with those for a person with disability, the consequence for a child who is Indigenous *and* with disability is a heightened likelihood of going through their early childhood with an undetected and unsupported disability. The effect of this carries forward into their schooling years and places them on a trajectory where they are more likely to matriculate into prison than into tertiary education.

Table: The deterioration of rights across the life course of an Indigenous person

LIFE-STAGE	Peri-Natal	Early childhood	Schooling years	Young people	Justice	Health	Ageing
ASPECT							
Indigenous	Low awareness of disability Environmental factors, increased likelihood of low birth-weight	Low awareness of disability Exposure to trauma Increased likelihood of OOHC – off country, unstable home setting	Low awareness of disability “Bad black kid syndrome” – punitive schooling over supported disability	Less likely to secure employment Increased likelihood of police contact	Denial of rights-over incarceration	Subconscious bias – institutional racism	Reduced life expectancy Disability happens earlier in life and with more co-morbidities.
Disability	Low birth weight and environmental factors in developmental disability	Disability assessments aren’t carried out to the extent that they need to be	Undiagnosed and unsupported disability	Less likely to secure employment Communication impairments, reduced capacity to negotiate conflict	Denial of rights – indefinite detention and fitness to plea for people with cognitive and psychiatric disability	Subconscious bias – diagnostic over shadowing	Inadequate public infrastructure especially in remote communities.

Discrimination as a barrier in securing the right to health

An intersectional approach can be applied to understand how discrimination within the health sector can work to undermine the right to health. For the purpose of this discussion, discrimination is taken to include all forms of unjust or prejudicial treatment of different categories of people, whether intentional or unintentional – i.e. including incidences of subconscious bias.

An Indigenous person with disability can potentially be exposed to at least two categories of discrimination in their interactions with health systems, which impede their right to health:

- Institutionalised racism in the health sector;
- Institutionalised ableism in the health sector.

Institutionalised racism in health service delivery

The prevalence of racism and its adverse impact on health and wellbeing is well documented⁴⁵. The ‘Experiences of Racism Survey’ in Victoria 2011-2012, funded by the Lowitja Institute, showed a relationship between mental health and reported episodes of racism⁶.

⁴ Larson, A.; Gillies, M.; Howard P.J.; and Coffin J., (2007) ‘It’s enough to make you sick: the impact of racism on the health of Aboriginal Australians’ *Australian and New Zealand Journal of Public Health* Vol. 31, Issue 4, pp 322–329.

⁵ Priest N.; Perry R.; Ferdinand A.; Paradies Y.; Kelahe M. (2014) ‘Experiences of racism, racial/ethnic attitudes, motivated fairness and mental health outcomes among primary and secondary school students’, *Journal of Youth and Adolescence*, 43(10):1672-87

⁶ Ferdinand, A., Paradies, Y. & Kelahe, M. (2012) *Mental Health Impacts of Racial Discrimination in Victorian Aboriginal Communities: The Localities Embracing and Accepting Diversity (LEAD) Experiences of Racism Survey*, The Lowitja Institute, Melbourne

In 2012, the National Congress of Australia's First Peoples, Australia's representative body for Australia's Aboriginal and Torres Strait Islander peoples, conducted a broad based qualitative survey on the perceptions of Indigenous people on their interactions with the health sector. This survey found that approximately half (n=81, 49%) of those Indigenous people surveyed indicated experiencing discrimination when accessing a health service in the past.⁷

Racial discrimination presented itself in many forms (with representative narratives):

- i. Racially-based stereotyping, particularly around consumption of alcohol and drugs:

"I'd been walking and went running across the road and slipped and fell arse-over-head. When I went in there to have the x-rays and I told her what happened...She turned around and said to me, you weren't charged up were you? I just thought, well that's the last thing I expected to come out of your mouth. I thought you would have known better than that. Like, she didn't mean it badly. But I didn't say nothing." (Survey participant)

- ii. Well-meaning paternalism – i.e. making racially based assumptions about a person's health risks and status, and subsequently the provision of health care needs:

"I had my second child at another hospital; a birthing hospital. He was above birth weight, a healthy baby. The nurses were unsure about my nationality, so on my discharge day - I was there for a day and a half. The baby had no problems attaching, breast-feeding, weight, everything. I've got no issues whatsoever; I'm in a stable marriage, got a previous healthy child. I know how to look after my child, I'm ready to go home - as I'm leaving with my bag and I'm sitting on the bed and my husband is moving the car, she said, what nationality are you? I said, I'm Aboriginal and she went, oh. She goes, oh, we're allowed to keep you in here. I said, for what reason? She goes, because you're at risk. I said, and how am I at risk? How's my child at risk; please do tell me. All of a sudden, without knowing my race, everything's fine and all of a sudden..." (Survey participant)

- iii. Challenging a person's Indigenous identity on the basis of skin colour:

"She asked what nationality they were and I said Aboriginal...I said their father's from Northern Territory and I'm from Tasmania. She said - she made reference to them not being what she determined a real Aboriginal person. So to me she was saying well they're not black enough to be real Aboriginal kids." (Survey participant)

⁷ These results were presented at the Australian Institute of Aboriginal Torres Strait Islander Studies Conference, Canberra Australia, March 2014. See: http://nationalcongress.com.au/wp-content/uploads/2014/05/140324-AVERY_AIATSIS-Presentation-Member-Health-Survey-and-Racism.pdf

Institutionalised ableism in health service delivery

Institutionalised ableism, also referred to as 'diagnostic overshadowing', describes a bias which obscures undiagnosed illness amongst people with disability. This occurs when health professionals ascribe the symptoms of a patient's illness to their disability, rather than a secondary, undiagnosed illness. People with intellectual disability are particularly susceptible to having their right to health diminished through diagnostic overshadowing⁸.

First Peoples Disability Network (Australia) has a community-driven research program that collects and analyses narratives of disability from Indigenous peoples. Its preliminary results show that institutionalised discrimination, both racially based and disability based, is emerging as an issue:

- One participant interviewed for the research is an Aboriginal woman with one arm, being born without an arm and no legs. She describes going into hospital to have a baby, where the health staff in making judgments based on her disability, missed her real need for support as a first time mother.

"I had my first son, and again there was this whole barrier breaking. The hospital sent OT's [occupational therapists] around to my house, and everyone kept saying "Well, how are you going to look after your baby?" and I was saying "I don't know, I've never been a parent before". (FPDN research participant)

- Another participant in the research succinctly describes how Indigenous people and people with disability have been viewed pejoratively in broader parts of Australian society:

"It wasn't that long ago that being Aboriginal was considered a disability in this country". (FPDN research participant)⁹

The detrimental consequences of intersectional discrimination

In whichever form, institutionalised discrimination can result in the denial of vital health services to people. When there is intersectional discrimination, or prejudice that operates on multiple layers against those who are at risk, the consequences can be catastrophic.

In 2 August 2014, a 22 year-old Aboriginal woman was arrested in Western Australia and taken into a lock lock-up for unpaid fines¹⁰. At the time, police staff made notations into their custody system that she "appears to be suffering withdrawals from drug use". Whilst the matter is subject to an ongoing coronial inquiry, the Inquest has heard that

⁸ See: Katteri R and Bywood (2001) 'Primary Health Care for People With Intellectual Disability'. *PHCRIS Research roundup*. At: <http://www.phcris.org.au/publications/researchroundup/issues/17.php>.

• These interviews were undertaken during the 'Living My Way' Disability Conference, hosted by Aboriginal Disability Network (NSW), Newcastle Australia, October 2014.

• This is the case of Ms Dhu, from South Headland Western Australia. This summary is based on various reports in Australian media. See for example: ABC News (23 November 2015) 'Police thought dying Aboriginal woman Ms Dhu was faking it, coronial inquest told' At: <http://www.abc.net.au/news/2015-11-23/inquest-into-death-of-dhu-in-police-custody/6963244>;

shortly after her arrest, she complained of pain in her ribs and taken to the local health campus. There she was initially diagnosed with 'behavioral issues' and returned to the police lock-up. On a worsening of symptoms, she was returned to the Health Campus where the initial diagnosis of 'behavioral problems' was reissued and again declared fit to be discharged to the police lock-up. Within 18 hours, she became violently ill and in extreme pain, and was again returned a third time to the Health Campus, where she died of septicemia and pneumonia related to an undiagnosed infection from an undiagnosed rib fracture.

For the record, Senior Medical Staff at the health campus denied claims of institutional racism when asked at the Coronial Inquiry.¹¹ However, the very nature of institutional discrimination is that prejudicial behaviours have become normalised over long periods of time so they are embedded in the subconscious and are taken for granted. As part of the institution, they would not be qualified to answer.

As some who was: young, Aboriginal, a woman, subject to poverty, exposed to drugs and alcohol dependency, living in poverty, exposed to family violence and deprived of liberty; this case personifies the multiple intersectional dimensions which heightened the vulnerability of the most marginalised of our marginalised Indigenous peoples. Theoretically, there were multiple opportunities for interventions to secure her right to health, and multiple conventions, treaties and human rights instruments to guard it.

But none did.

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¹¹ Perth Now (26 November 2015) 'Hedland Health Campus denies racism against Ms Dhu at Aboriginal death in custody inquest' At: <http://www.perthnow.com.au/news/western-australia/hedland-health-campus-denies-racism-against-ms-dhu-at-aboriginal-death-in-custody-inquest/news-story/078c5855077b5593a730a9fb4546dcb9>

Appendix F: Avery S. (2016b) 'The life trajectory for an Aboriginal or Torres Strait person with disability'. In: Avery S, and Keyser P (eds). Aboriginal and Torres Strait Islander perspectives on the recurrent and indefinite detention of people with cognitive and psychiatric impairment. (Chapter 2: 6-9). First Peoples Disability Network (Australia). Sydney.

ABORIGINAL AND TORRES STRAIT ISLANDER PERSPECTIVES ON THE RECURRENT AND INDEFINITE DETENTION OF PEOPLE WITH COGNITIVE AND PSYCHIATRIC IMPAIRMENT

Prepared by FIRST PEOPLES DISABILITY JUSTICE CONSORTIUM
An initiative of First Peoples Disability Network (Australia)

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Executive summary

This submission is the result of work by an alliance of the nation's leading authorities on disability justice for Australia's First Peoples. This alliance includes three Aboriginal and Torres Strait Islander national peak bodies, and researchers from six different universities and research institutes. We have come together to present Aboriginal and Torres Strait Islander perspectives on the problem of the indefinite detention of people with cognitive and psychiatric impairment.

This submission presents the best available evidence on what the issues are, the factors that contribute, and most importantly lists the actions that can be taken to alleviate the problem and its consequences.

A lifetime of being detained becomes the reality for too many Aboriginal and Torres Strait Islander people

By the time an Aboriginal or Torres Strait Islander person with disability first comes into contact with the criminal justice system, they will most likely have had a life of unmanaged disability. Coupled with discrimination, based on their Aboriginality and disability, they will have faced barriers from the time they are born, of poverty, early exposure to life in institutions through the child protection system, struggles at school, lack of appropriate health care and an inability to secure employment. Coming into contact with the police, courts, juvenile detention and prisons is normalized in their life trajectory.

As the chapters in our submission highlight, the justice system does little to address these factors and outcomes and in fact often makes them worse. People acquire the label of a prisoner who must be punished, not a person with disability who needs support. When released from prison, the personal, social and systemic circumstances that propelled them into detention or prison will not have changed. Thus many face a cycle of recurrent detention that goes on indefinitely.

An issue which speaks to the heart of injustice towards Aboriginal and Torres Strait Islander people

Aboriginal and Torres Strait Islander people with disability are the most marginalised people in Australian society. Unjust deprivation of liberty, poor health care and poor support intensify the marginalisation of Aboriginal and Torres Strait Islander people and result in serious cases of human rights abuses.

The historical exclusion of Aboriginal and Torres Strait Islander people with disability from society has meant this issue has been kept from the public eye. The resulting lack of public scrutiny has meant that little has been done to redress

these abuses. Only in rare cases does such abuse become publicly evident, usually exposed through vigilant human rights advocacy and in the media, rather than through the operation of checks and balances in the criminal justice system. Take for example the case in which an Aboriginal man with cognitive impairment was imprisoned for over a decade for an alleged offence that never went to trial.

Cases such as this point to a deeper problem of the normalised management of Aboriginal and Torres Strait Islander people with disability by the police and within the justice system. That Aboriginal and Torres Strait Islander people can be imprisoned because of their disability points to the historical injustices that have been going on since colonisation. That this is allowed to continue perpetuates that injustice and hurt.

This is what Aboriginal and Torres Strait Islander people tell the First Peoples Disability Network (Australia), the community-based organisation created by and for First Peoples with disability. This Network, with the active support and assistance of La Trobe Law School, coordinated the contributions to this submission. The mandate to take action comes directly from the First Peoples with Disability community.

A multi-disciplinary approach bringing together experts across life's spectrum

Offering a new life trajectory for an Aboriginal and Torres Strait Islander person with disability requires more than a legal solution. Whilst fair laws are essential and are important checks and balances, the factors that cultivate incarceration for people with disability must also be tackled.

This submission includes contributions that explain issues experienced by Aboriginal and Torres Strait Islander people with disability across their lifecourse. Contributions are from:

- community practitioners and researchers who work with Aboriginal and Torres Strait Islander people and understand the trauma they have been exposed to
- early childhood development experts who know what it takes to put a child with disability on the right course
- organisations which understand the disabling impact of family violence on women
- systems thinkers who can design early disability support for children and families and supported diversion programs as an alternative to prison

- experts in legislation which have a solid foundation in human rights
- researchers and practitioners who have worked with Aboriginal and Torres Strait Islander people post-prison release to prevent recidivism, and
- policy advisers who understand the mechanisms that are needed to translate the evidence into policy reform.

The strengths and support structures within First Peoples' communities have an untapped potential to drive positive change. They best understand the unique trauma that faces First Peoples and how this impacts upon their social wellbeing. Whichever part of the problem you look at, community-based and community-directed services for First Peoples with a disability are fundamental to the solution.

A proposal for Commonwealth leadership

This submission shows how Aboriginal and Torres Strait Islander community organisations can come together with the research community to critically evaluate the evidence and come up with the solutions needed to address the problem of recurrent and indefinite detention. All Australian Governments need to step up to support these solutions.

The reforms outlined by our alliance of experts are crucial to preventing ever more Aboriginal people being captured indefinitely in the criminal justice and reducing spiraling criminal justice costs. This reform agenda has been derived from our evaluation of the available evidence, recognises the federated nature of Australian government, and the respective roles and responsibilities of Federal, State and Territory Governments. The recommendations in this submission focus particularly on the leadership role of the Commonwealth, which can serve as a model for reform in the respective jurisdictions.

There is momentum for change. In November 2015, Ministers attending the Law Crime and Safety Council agreed to establish a working group to bring together the data and develop resources for national use in the treatment of people with cognitive disability or mental impairment unfit to plead or found not guilty by reason of mental impairment.

The Australian Government has also made a voluntary commitment in the United Nations Universal Periodic Review to improving the way the criminal justice system treats people with cognitive disability who are unfit to plead or found not guilty by reason of mental impairment.

The breadth and depth of people's contributions to this and other submissions reflect the personal and collective commitment to provide a fairer, better life for Aboriginal and Torres Strait Islander people with disability who are at risk of being or are already caught up in the justice system. Correcting this injustice is a national priority.

Summary of recommendations

1. A strategic approach is needed to address the factors impacting on Aboriginal and Torres Strait Islander people with cognitive impairment:
 - i. to improve access to their rights upon coming in contact with the justice system
 - ii. to address the social risk factors to alter their life trajectory and reduce the likelihood of their coming in contact with the justice system in the first instance.
2. A strategic approach to the recurrent and indefinite detention of Aboriginal and Torres Strait Islander people with cognitive and mental impairment should be based on the principles of self determination; person centred care; holistic and flexible approach; integrated services; and culture, disability and gender-informed practice.
3. A social model of disability, accommodating the complex social and cultural determinants, should be the basis for defining 'cognitive and psychiatric impairment' as it affects the recurrent and indefinite detention of Aboriginal and Torres Strait Islander people with cognitive impairment.
4. Systems for addressing disability in and related to the justice system must be discretionary to accommodate an individual's level of impairment as well as contributing social circumstances. The principle of discretion should apply in judicial administration as well as disability supports.
5. Aboriginal community-controlled organisations should be resourced to provide specialised and culturally appropriate support to Aboriginal and Torres Strait Islander people with cognitive and psychiatric impairments in detention.
6. Early diagnosis of Fetal Alcohol Spectrum Disorders (FASD) and intervention to prevent engagement with the law.
7. Early recognition that a young person has FASD or other neurocognitive impairments when first engaging with the law so that courts can provide alternative strategies to sentencing and appropriate management to reduce recidivism.
8. Research programs and incentives should develop resources for the better identification and management of cognitive disability,

including FASD, across a range of social policy areas including early childhood and child protection, education and justice.

9. Workforce development strategies are required to increase the awareness of disability and its impact upon justice outcomes for people with disability. These strategies should include culturally compatible practice guidelines, protocols and training programs for public officers and professionals working with Aboriginal and Torres Strait Islander people with disability in the justice and related sectors.
10. Appropriate support services should be provided to Aboriginal and Torres Strait Islander people with cognitive and psychiatric impairments who have experienced violence or trauma, including:
 - i. screening for past experiences of trauma, including family violence, sexual assault or other forms of gender-based violence
 - ii. counselling and emotional and psychological support to help survivors on their roads to recovery, and
 - iii. legal support to help them access their rights and obtain justice.
11. Systems for diversion onto supported disability programs should be established at critical points of contact with the criminal justice system, with linkages to the National Disability Insurance Scheme.
12. The Commonwealth should adopt a lead role in the creation of national legislative standards for legislation and regulatory frameworks affecting individuals who have been declared mentally impaired or unfit to plea. The national standard legislation should at a minimum provide for:
 - i. judicial discretion to impose an appropriate order depending on the circumstances of the case, including level of impairment and contributing social circumstances
 - ii. special hearings that include input from Aboriginal and Torres Strait Islander community representatives to test the evidence against a mentally impaired accused who is unfit to stand trial. This should entail a procedure for determining whether, on the evidence available, the accused committed the objective elements of the offence so that if it cannot be proven that the accused committed the objective elements of the offence, the accused is discharged

- iii. minimum procedural fairness requirements such as a right to appear, right of review, right to written reasons for decision and right to information
 - iv. finite terms for custody orders (and release orders) – the duration of the order should be no longer than the duration of the sentence that would have been imposed if the accused had been convicted of the offence
 - v. determinations about release of mentally impaired accused from custody or community release orders should be made by the relevant board with an annual right of review before the Supreme Court.
13. The Commonwealth should provide a support program for Aboriginal and Torres Strait Islander people with cognitive impairment, as a 'safety net' when these services are not made available at all levels of courts within the State and Territory jurisdictions.
 14. Establish a working group to establish interface principles between state and territory based post-release programs with the National Disability Insurance Scheme, based on the effective features of the *throughcare* model.
 15. Establish a multi-disciplinary 'Policy Translation Group' including Aboriginal and Torres Strait Islander representatives to advise on translating evidence emanating from Community knowledge and academic research into policy.
 16. These recommendations form the basis of a National Disability Justice Strategy with a dedicated focus on the rights and circumstances of Aboriginal and Torres Strait Islander people.

2

The life trajectory for an Aboriginal or Torres Strait Islander person with disability

Scott Avery, Policy and Research Director – First Peoples Disability Network (Australia)

Key issues:

- Aboriginal and Torres Strait Islander people with disability are at heightened risk of encountering indefinite detention due to the complex interaction of personal and social factors affecting both their Indigenous and disability status.
 - By the time that an Aboriginal or Torres Strait Islander person has come into contact with the justice system, they are likely to have had a lifetime of unmanaged disability.
 - A strategic approach is needed to address the factors impacting on Aboriginal and Torres Strait Islander people with cognitive impairment:
 - to improve access to their rights upon coming in contact with the justice system
 - to address the social risk factors to alter their life trajectory and reduce the likelihood of their coming in contact with the justice system in the first instance.
1. An Aboriginal or Torres Strait Islander person with disability is a member of two communities; one pertaining to their identity as an Indigenous person and another pertaining to their disability. Addressing one aspect of a person rights in isolation from the composite rights can leave them excluded from another aspect of society important to their sense of identity.
 2. Intersectionality is a field of human rights research which is an emerging influence on public policy. Intersectionality acknowledges there are multiple dimensions of a persons identity as a frame for understanding the layers in which social inequity can accumulate. This involves understanding the rights to cultural inclusion as an Indigenous person as well as the rights of inclusion as a person with disability. A failure to understand both dual access rights for Indigenous and the rights of a person in effect creates a minority group within a minority group.
 3. The social exclusion that can occur because someone is both Aboriginal or Torres Strait Islander *and* has disability has colloquially been referred to as experiencing a 'double discrimination' by Aboriginal and Torres Strait

Islander people with disability. Whilst more overt forms of discrimination (such as vilification) are more easily detectable, there is also institutional or systemic biases which act against the rights and inclusion of Aboriginal and Torres Strait Islander peoples. For example, the incidence and impact of institutional racism in the health sector has been well documented, and its findings could readily apply to the justice system.⁴

4. Institutionalised forms of discrimination sits within the subconscious of those charged with responsibility for undertaking public functions – a policy which is not intended to be discriminatory can become discriminatory when interpreted by an official based on their own levels of awareness, assumptions and subconscious prejudices about Aboriginal and Torres Strait Islander people and/or people with disability.
5. Failures in addressing the rights of an Indigenous person in their early years can lead to a further, and often rapid, deterioration in rights over the course of a lifetime. Here is one scenario as an example
 - An Indigenous mother living in poverty and in a community with inadequate public health facilities is more likely to have a low-birthweight baby compared to non-Indigenous people.
 - Low birthweight is a known risk factor for childhood disability and learning impairment.
 - The rate of removing a child from their families is significantly higher for Indigenous children compared to non-Indigenous children. In Australia, this disparity is a 10-fold increase in the rate of child removal for Indigenous children.
 - Clinical protocols for the assessment for disability, particular cognitive impairments, can require a stable home environment to enable an accurate assessment. If shifting from home to home in an out-of-home care system continually disrupts a child, then an assessment of disability may not occur.
 - Medical-based models of disability (not just in health, but also in education) require a diagnosis to trigger supports for a child.
6. So, when the barriers to access the right to health for an Indigenous person interact with those for a person with disability, the consequence for a child who is Indigenous *and* with disability is that they are at heightened likelihood of going through their early childhood with an undetected and unsupported disability. The effects of this carries forward into their schooling years and

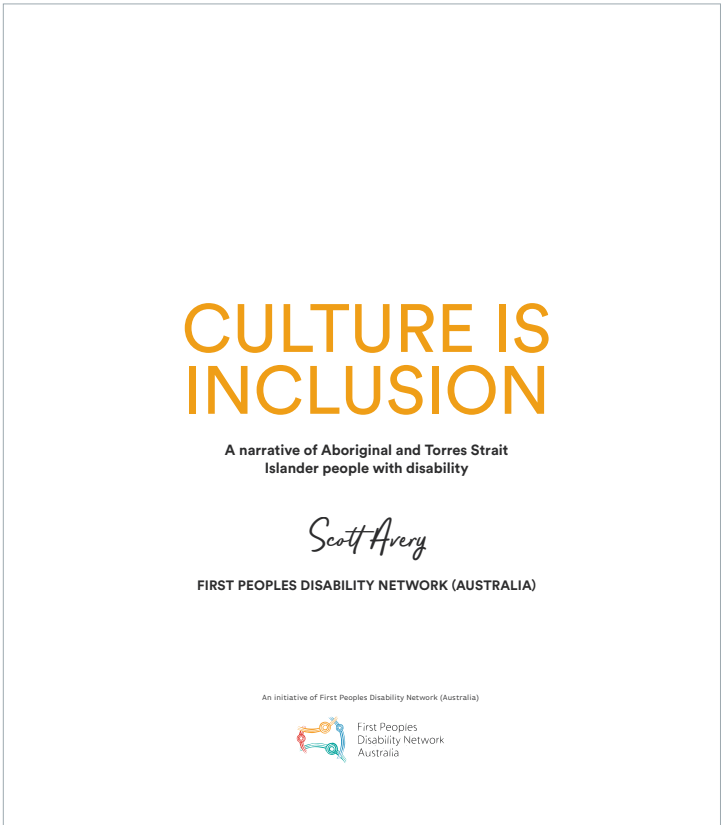
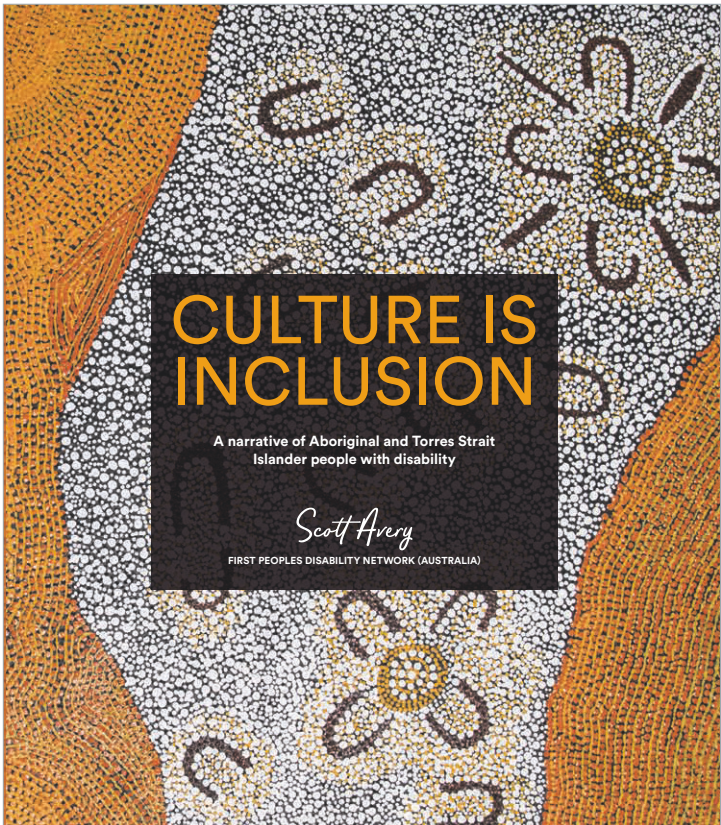
places them on a trajectory where they are more likely to matriculate into prison than into tertiary education.

7. Whilst this particular perspective emphasises disability as an intersectional risk to the rights, health and wellbeing for Aboriginal and Torres Strait Islander people, the concept also applies in relation to other risk factors which can have a cumulative detrimental impact. These risk factors can include:

- gender
- children and young people
- exposure to trauma, both acute and inter-generational
- psychiatric and mental health conditions
- lesbian, gay, bisexual, and transgender
- drug and alcohol dependence
- exposure to family violence
- deprivation of liberty.

Table 1: The deterioration of rights across the life trajectory of Aboriginal and Torres Strait Islander people with disability

LIFE-STAGE							
ASPECT	Peri-natal	Early childhood	Schooling years	Young people	Justice	Health	Ageing
Indigenous	Low awareness of disability Environmental factors, increased likelihood of low birthweight	Low awareness of disability Exposure to trauma Increased likelihood of OOHHC – off country, unstable home setting	Low awareness of disability “Bad black kid syndrome” – punitive schooling over supported disability	Less likely to secure employment Increased likelihood of police contact	Denial of rights – over-incarceration	Subconscious bias – institutional racism	Reduced life expectancy Disability happens earlier in life with increased co-morbidities
Disability	Low birthweight and environmental factors in developmental disability	Disability assessments are not carried out to the extent that they are needed	Undiagnosed and unsupported disability	Less likely to secure employment Communication impairments, reduced capacity to negotiate conflict	Denial of rights – indefinite detention and fitness to plea for people with cognitive and psychiatric disability	Subconscious bias – diagnostic over-shadowing	Inadequate public infrastructure, especially in remote communities



CULTURE IS INCLUSION
A narrative of Aboriginal and Torres Strait
Islander people with disability

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Aboriginal and Torres Strait Islander readers are advised that this narrative includes the voices of people who have passed away.

Aboriginal and Torres Strait Islander people are further cautioned that this research contains personal testimony and content that some people may find distressing.



PROLOGUE

THE MISSING CHAPTER

Back in my younger days, I remember reading the classic Australian novel *Picnic at Hanging Rock*. I love my Australian history and I'm always up for a good mystery, and this book did not miss. The lingering question of what happened to the schoolgirls who vanished from their picnic without a trace, its historical setting, the whole 'Australian-ness' came together in one story, captivating in a way that was truly special. Later made into a classic Australian movie, the haunting image of Miranda and her friends walking up the crevasse in the rock, never to be seen again, sucked me right into a timeless mystery of 'What on earth happened to them?'

Some years later and I was at the University of Wollongong library, searching the sorting shelf for a textbook. Sitting right on top of the shelf is a paperback book, begging to be picked up. It is *The Secret of Hanging Rock*, claiming to be the missing chapter that unveils the mystery of Hanging Rock. There's a missing chapter?! As the story behind the story goes, it claims that the author Joan Lindsay had removed this final chapter from her original piece at the request of her publisher, as a device to create the literary effect of an unanswered mystery. My economics assignment could wait, I took it back to my desk and read it from cover to cover. It gives the game away. Now I had an answer, if not the answer. But when I finished reading, I was torn. Whilst the unsolved mystery introduced the mystical to the original book, there also came a sense of betrayal that there was another part to the story that had been kept from me from the start. But now I know.

Much older again, and I have since discovered that there is another chapter of a story that has been ripped out of a much larger, grander book. It's the story of people with disability in Aboriginal and Torres Strait Islander communities. This is a story that has been excised from the book of Australia's social history. If you go hunting for the disability

story amongst the realm of material on the impact of colonisation on Aboriginal and Torres Strait Islander people, then you'll find that the chapter is missing. The history of people with cognitive impairments locked up in mental institutions from the mid 1800s onwards is also hidden. In modern times, the pages on disability have been excluded from the book of Australian Indigenous policies, such as Closing the Gap. And whole chapters on disability have been ripped from every single inquiry into why so many Aboriginal and Torres Strait Islander people end up in prison. Within Australia's social record, Aboriginal and Torres Strait Islander people with disability have similarly just disappeared.

The ambition of this book is to be that missing chapter. It aims to unveil a mystery unknown to many Australians – the story of Aboriginal and Torres Strait Islander people with disability. It goes directly to the source for its material, Aboriginal and Torres Strait Islander people with disability themselves.

How to read this document

This publication, *Culture is Inclusion*, is an outcome of a research project that promotes the voices of Aboriginal and Torres Strait Islander people with disability within research and policy. The research project, which commenced under the working title, *Living our Ways*, is an exploratory study into the issues that affect Aboriginal and Torres Strait Islander people with disability, as told by them through their testimony.

Led by the First Peoples Disability Network, a community-controlled Aboriginal and Torres Strait Islander disability organisation, it creates a 'narrative' of Aboriginal and Torres Strait Islander people with disability by combining their personal testimony gathered through interviews with statistical data sourced from Australian Bureau of Statistics. This data is brought to life with the distinctly Aboriginal concept of 'yarning', where vignettes are extracted from the testimony to show how many issues come together in the daily life of one person. The research is presented in ten chapters.

Chapter 1 introduces the cultural and social background to the research. It entails a brief history of inclusion and disability in Indigenous cultures going back to ancient times. It then provides a snapshot on the impact of colonisation from a disability perspective. It concludes with the emergence of the rights-based movement to draw attention to the marginalisation of Aboriginal and Torres Strait Islander people with disability in Australian society.

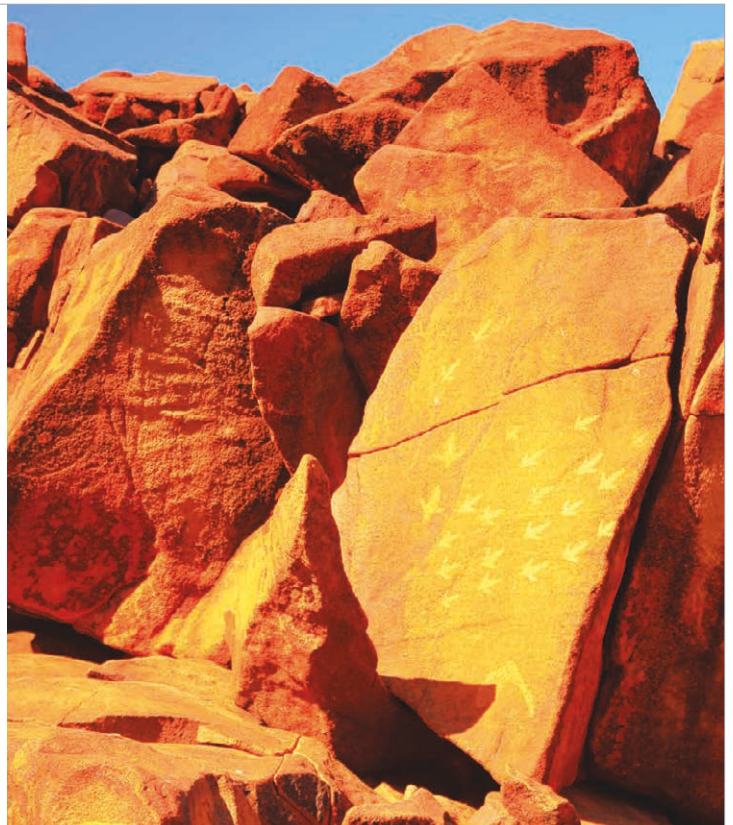
Chapter 2 outlines the key concepts and terms used throughout the research. It includes definitions for the use of some common terms within this research. It conceptualises how the 'narrative' was developed, by integrating the testimony from interviews with participants, statistical data, and 'yarnings'. It establishes a vocabulary of new concepts where existing terminology could not adequately explain the experiences of Aboriginal and Torres Strait Islander

people with disability. 'Intersectional inequality' and 'apprehended discrimination' are two concepts that have been described in this chapter, and are used in later chapters to explain the research.

Chapter 3 builds on the conceptual model of community-directed research by outlining how the principles for participatory research were put into research practice. It describes the role of an Academic Advisory Panel providing academic guidance on the conduct of the research. It then discusses a relational approach with the Australian Bureau of Statistics in securing technical advice on the statistical data that was used in the research, and outlines the factors that have made this relationship a benchmark of engagement between an Aboriginal and Torres Strait Islander community organisation and a government agency.

Chapter 4 commences the presentation of the research findings. This chapter presents the statistical data on the prevalence and profile of disability in the Aboriginal and Torres Strait Islander population. It also draws upon the testimony of research participants for a focussed discussion of issues that emerged from the statistical data analysis. These issues include: the availability of disability diagnoses in Aboriginal and Torres Strait Islander communities; the 'overshadowing' of co-occurring disability; and the intersection of gender and remoteness in Aboriginal and Torres Strait Islander disability data.

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Chapter 5 exposes the discrimination faced by Aboriginal and Torres Strait Islander people with disability attributable to racism, ableism and a unique form of 'intersectional discrimination'. Using illustrative quotes from the testimony of participants, it explores the concept of 'apprehended discrimination' to describe the pathway in which an expectation of discrimination can lead people into avoiding situations where they might be exposed to discrimination.

Chapter 6 is an analysis of the social, health and wellbeing inequalities experienced by Aboriginal and Torres Strait Islander people with disability. The statistical data and participants' testimony have been presented thematically and organised according to the priorities of the Australian Government's National Plan to Improve Outcomes for Aboriginal and Torres Strait Islander People with Disability.

Chapter 7 is dedicated to the implementation of the National Disability Insurance Scheme (NDIS) in Aboriginal and Torres Strait Islander communities. Whilst implementation of the NDIS in Aboriginal and Torres Strait Islander communities was in its formative days when this research was conducted, several concerning issues emerged that warrant a further focussed investigation.

Chapter 8 details the staggeringly high detrimental impact that accumulated experiences of discrimination, trauma and social exclusion have on the mental health and wellbeing of Aboriginal and Torres Strait Islander people with disability. It can make for difficult reading, even harder for the people living it. But within the testimony, there still glows embers of hope.

Chapter 9 shifts the tone from social exclusion to a culture of inclusion. It presents a crucial finding of the research: that despite the inequalities experienced in other aspect of their life, Aboriginal and Torres Strait Islander people with disability participate in community and cultural activities at the same rate as other Aboriginal and Torres Strait Islander people. It discusses the implications of a 'culture of inclusion' as a moderating force on the health and wellbeing of Aboriginal and Torres Strait Islander people with disability, and prescribes a model for inclusive policy and practice.

Chapter 10 brings the themes and issues discussed in the previous chapters together to form a concise First Peoples disability research agenda and a direction for further research activity and policy development. This is the ultimate deliverable for the research project and its concluding recommendation.

The first stop in the narrative journey of Aboriginal and Torres Strait Islander people with disability is Lake Mungo in Far West New South Wales, where footprints of a one-legged man on a hunt with his tribe were discovered. More than twenty thousand years old, these footprints have survived the harshest elements.

These footprints survived for a reason.
They survived to tell us a story.

Executive Summary of research findings

1. Disability in Aboriginal and Torres Strait Islander communities is twice as prevalent, more complex in terms of co-occurring disabilities, and compressed within a shorter life expectancy compared to other Australians.
2. Aboriginal and Torres Strait Islander people with disability experience unique form of 'intersectional discrimination' and social inequality that is an interaction of discrimination that is both Aboriginal and Torres Straits Islander and disability related.
3. Frequent exposures to various forms of discrimination can have cumulative impact and can manifest into 'apprehended discrimination'. This is a pathway in which a fear of discrimination transforms into a rational expectation of discrimination, and it can lead to a person avoiding social situations where they could be exposed to possible discrimination.
4. The statistical data and testimony of participants show that intersectional inequality is acute and pervasive across all supports for Aboriginal and Torres Strait Islander people with disability; including disability services, health, education, employment housing and transport.
5. The impact of intersectional inequality as a detrimental impact upon the social health and wellbeing of Aboriginal and Torres Strait Islander people with disability.
6. The sole category that is an exception to the inequalities experienced by Aboriginal and Torres Strait Islander people with disability is their social participation within their own communities. Rates of participation by Aboriginal and Torres Strait Islander people in cultural and community activities are on par with other Aboriginal and Torres Strait Islander people.
7. A culture of inclusion is a moderating force on the social health and wellbeing and has a mitigating impact on intersectional inequality.

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1

CULTURAL AND SOCIAL PRESENTATIONS OF DISABILITY BY ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE

1.1 'NO WORD FOR DISABILITY' IN ABORIGINAL LANGUAGES

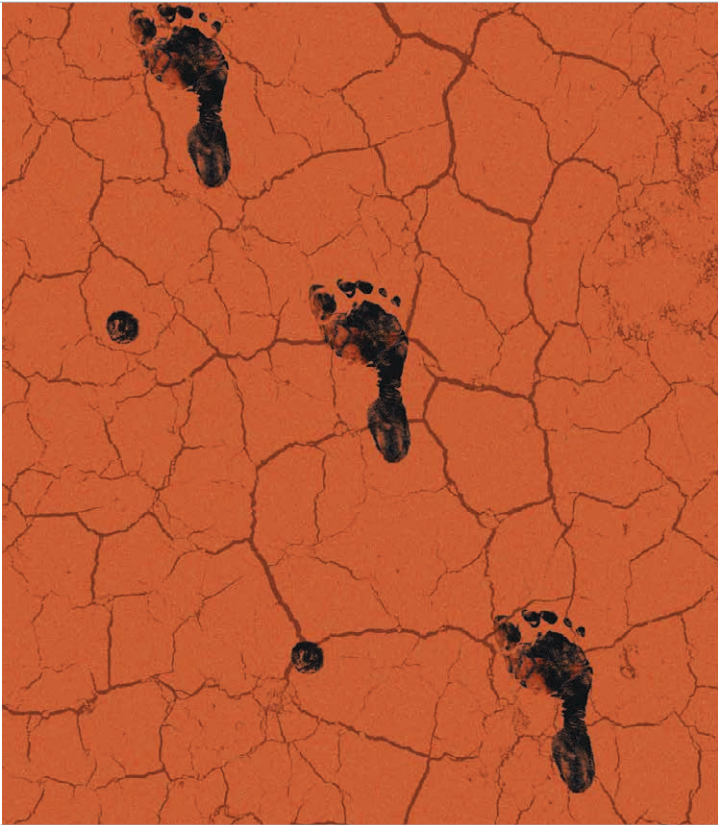
To understand 'disability' in Aboriginal and Torres Strait Islander communities today, you need to cast your mind back 20,000 years to ancient times.

The archaeological site at Lake Mungo, part of the Willandra Lakes Heritage site in south west New South Wales, contains the oldest footprints found in Australia, giving insight into Aboriginal society in ancient times¹. Amongst the collection of footprints is a single track-line of one right footprint deeply impressed into the clay, but no corresponding left footprint was discovered. Trackers from the Pintubi people of Central Australia, traditional custodians of the land, were sought for their advice on what this meant. Looking at the track, they told the archaeological research team, "yes, this is definitely a one-legged man"². Using sophisticated scientific modelling techniques, further analysis by the archaeological team indicated that the one-legged man was possibly moving as part of a hunting pack and moving at pace, upwards of an incredible twenty kilometres an hour.³ Using traditional knowledge, the Pintubi people, skilled in reading the nuances in

the track-lines, suggested that the one-legged man simply threw away his walking stick and hopped at speed to keep pace with the hunting pack.

The story of the one-legged Mungo man actively participating in a hunting group is symbolic of the diversity and inclusion in First Peoples cultures. It is derived from a belief system and worldview of humanity in which biological, physical and intellectual differences are accepted as part of the fabric of society.

1 Webb S. (2007), 'Further research of the Willandra Lakes fossil footprint site, southeastern Australia' Journal of Human Evolution 52, 711-71.
2 Markey S. (2016), 'Australia's 200,000 year old human footprints' National Geographic, 24 May 2016
3 Webb S. (2007).



The small amount of published research on disability in Aboriginal and Torres Strait Islander communities all settle on a conclusion that 'disability' is not a concept that readily translates in Aboriginal languages and cultures. Ariotti's study observing the Anangu people of the Northern Territory describes a community where there is no word for 'disability' in their native Pitjantjatjara language⁴. Instead, there are words in the native language which describe various impairments, such as blind ('kuru pati'), deaf ('pina pati'), to hobble around ('lurpani') or to have back pain ('witapijara'). It was observed that the Anangu people did not use these words in a pejorative way. Instead, these words are factual references to a person's functioning capacity within a community in which there is an acceptance of diversity and difference.

Another study by King et al involving Aboriginal people working in an urban Indigenous-specific respite centre for people with diabetes-related disability speaks of "invisibility of their disability experience"⁵. This phrase makes reference to a society in which the centrality of Indigenous culture, being a person who is Aboriginal, overshadows the physical, objective nature by which an impairment may be viewed. Accordingly, the Aboriginal people involved in the study did not readily accept the categorisation of being a person with disability, as disability was viewed as a non-Indigenous concept. The hierarchy of Aboriginal identity above disability in an Aboriginal person's sense of belonging is paraphrased by a

participant in the study as being "Indigenous first, disabled second"⁶. Gilroy et al⁷ studied services providers' attitudes towards Aboriginal and Torres Strait Islander people with disability and concluded that there were diverse conceptualisations of disability in the Aboriginal population, often described as "normal" and "part of living", and that an acknowledgement of disability, or lack thereof, was a key influencing factor in whether Aboriginal people accessed disability services.

There are parallels to Aboriginal and Torres Strait Islander people's worldview of human capability and diversity with other Indigenous peoples worldwide. Culturally, there were no equivalent words in the Maori language for disability or many diagnostic labels that apply, such as autism. The Te Pou o te Whakaaro Nui⁸ is a project to update and create Māori language used in the mental health, addiction and disability sectors with language that is not judgmental, and uses Maori's words 'whaikaha', meaning 'to have strength, otherly abled' as an equivalent for 'disabled'; and 'takiwatanga', meaning 'his or her own time and space' as an equivalent word for 'autism'. In another hemisphere, the Navajo Indigenous people of North America lacked a word for 'disability' until an acculturalisation through western influences, instead living by a concept of 'Honzo' to describe someone who is walking in harmony with all that is around them⁹.

First Peoples expressions of humanity and diversity are more than just observances of functional linguistics. They speak of a belief system that values a person's centeredness over biomedical and physical differences, and acceptance of difference as within the natural order of the world. It is a belief system that governs their behaviours, and comes with such a long-standing track record that it need not be consciously taught. Rather it is modelled through Indigenous people's attitudes towards other members of their community.

The contemporary dilemma for Aboriginal and Torres Strait Islander people is that their culture and belief system of human functioning and diversity is so radically different from the Western construct of disability dominant in Australia and other Westernised nations. The Western system constructs disability as a deficit against a perceived 'normal level of functioning', and "an individual deficit/problem that has to be fixed, rehabilitated or prevented."¹⁰ Philosophical reflections aside, the cultural dichotomies present a contemporary dilemma for Aboriginal and Torres Strait Islander people. 'Do you have a disability?' is a question that is culturally insensitive for Indigenous peoples.

4 Ariotti L. (1999) 'Social Construction of Anangu Disability', Australian Journal of Rural Health, Vol. 7, 216-222.
5 King J.A., Brough M., and Knox M (2014) 'Negotiating disability and colonisation: the lived experience of Indigenous Australians with a disability' Disability and Society, Vol 25, No.5, 738-750.
6 King et al (2014) at 744.
7 Gilroy J., Donnelly M., Colmar S., Parmenter T. (2016) 'Twelve factors that can influence the participation of Aboriginal people in disability services' Australian Indigenous Health Bulletin 16(1).
8 Te Pou o te Whakaaro Nui (2016) Te Reo Hāpai – The Language of Enrichment. Accessed at: <https://www.tepou.co.nz/initiatives/te-reo-hapai-the-language-of-enrichment/>169
9 Kapp S.K. (2013) 'Navajo and Autism: the beauty of harmony'. In: Moving Beyond Boundaries in Disability Studies: Rights, Spaces and Innovations. Moore M. Ed, p77-90, Routledge, at p 82-83.



10 Berghs, M., Atkin, K., Graham, H., Hatton, C., and Thomas C. (2016), 'Implications for public health research of models and theories of disability: a scoping study and evidence synthesis, Public Health Research, No. 4.8.

The understatement of disability

He comes from a town where there has been a spate of young people who have recently died by suicide.

The local community is stunned, they can't explain it. An Aboriginal organisation that specialises in healing and wellness programs, are running a community session to try to work through the trauma.

He had turned up for two days running, one day for the healing session and the day prior for a yarn-up that focussed on disability. There's a small group of about ten or so people, and he has come with someone. Judging by the emotion that surrounds him, it is someone who is close to him, perhaps his wife or partner, but the deal is it's his story and I don't want to intrude by asking.

He starts the interview by saying that he had "sort of had a motorbike accident", twelve months ago nearly to the day of the interview. It was the 'sort of' motorbike accident that had left him with a broken neck, broken, leg, and spinal cord injury that means that he cannot use one arm. It was the 'sort of' accident that had kept him in bed for six months and he lost about twenty kilos of muscle.

Twelve months after the accident, he is still trying to get his life on track. It's been six months since he has been able to stand at all, and he's now at the stage where he is starting to walk up and down stairs. He

is still unsteady on his feet and at high risk of falling over. Something as simple as a stick on the ground, or carrying a bottle of milk, becomes a major obstacle.

Despite the nature of the injuries he remains upbeat. He says that he doesn't have access to any formal rehabilitation, and what he does, he does himself. "I haven't had any rehab or anything. I had a little bit of rehab at hospital but I don't have rehab now. I'm supposed to still go to it, but I just get up and walk." Despite not using these words, he is inferring that he does his own rehab, even despite the traumatic nature of his injuries. Given the nature of his injuries, both visible and self-described, I double-check that he is not receiving specialised rehabilitation and ask what he does on his own. "[I] Get up and walk, and walk, and walk, and that's my exercise for the whole day, you know. I just – that's the only thing I think that's going to build my leg back and build all the muscle back."

He is back working at the local school where he was working prior to the accident. I ask how that came about "Well, went and asked them, "Can I come back?" And, they was happy to bring me back so, I thought, [I can come] back a little, a little bit, as much as I can." The headmaster at the school worked his schedule around so he could get back to work in a safe and accessible workplace. "[The headmaster said] I've got to stay on the bottom level for the first term that I was back, so that was pretty good, so I didn't have to climb any stairs or anything like that. He knew where I was coming from, I suppose." There's a sense that feeling valued and understood by people around him has had as much therapeutic value as any physical therapy he had received. "He's – he's excellent. He's – my employer's a really, really good person. Yeah. I – I enjoy working over there."

The 'he' in this story is not just him personally, it has had a tremendous impact on those closest to him. His companion is visibly distressed during the healing workshop. His healing is driven by a strong obligation to family, and he speaks of his children. "One's away playing footy, so – yeah. Better get back to work to support him down here".

We finish our discussion. I turn off the recorder and we walk back to the community healing session. On the way back, we talk about how it would have been nice to have had more people turn up to the healing session and disability workshop, especially given the recent events in the community. With me lamenting the researcher's peril of turning off the recorder too early, he responds with a succinct comment embodying the hope that exists in the face of trauma, and survival in the face of obstacles. "It's like throwing pebbles in the pond. Throw them in, and it will all ripple out".

1.2 DISPOSSESSION OF COUNTRY AND BODY: A POST-COLONIAL HISTORY OF TRAUMA EXPERIENCED BY ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE WITH DISABILITY

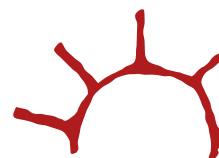
European colonisation caused catastrophic shocks in Aboriginal and Torres Strait Islander societies¹¹.

The process of colonisation has had multiple and continuing impacts on the Aboriginal and Torres Strait Islander population¹². First, massacres and the introduction of foreign diseases drastically reduced the Aboriginal population in the first decade following European contact. Second, the imposition of guns, alcohol, tobacco and sugar as agents of colonisation resulted in hugely increased levels of disablement among the surviving population and their future generations, which has had a long-term impact on population health status. Third, the colonisation itself was founded on the imperial legal doctrine of 'terra nullius', literally meaning 'nobody's land'¹³. To morally justify the dispossession of the native inhabitants from their land, Aboriginal and Torres Strait Islander people were treated as subhuman and viewed as inferior by their European conquerors. The humanity of Aboriginal and Torres Strait Islander people was effectively denied, and the impact of racial discrimination affecting the rights, inclusion and social structure of Aboriginal and Torres Strait Islander people is still evident in Australia today.

Colonisation had a particular impact upon Aboriginal and Torres Strait Islander people with disability, centring them at a convergence of armed aggression dispossessing them from their land as Aboriginal people, alongside their social 'othering'¹⁴ as people with disability. Colonisation commenced in period in history known as the Enlightenment, an intellectual and political movement which emerged in Europe in the late 18th and early 19th century, characterised by scientific thought, reasoning, and the promotion of personal liberty¹⁵. An influential thinker in Britain at the time was Scottish economist Adam Smith, whose book the Wealth of Nations¹⁶ included a theory of market economics. Amongst the key ideas of the theory of market economics is a concept of 'human capital', which equates people to physical resources in a production process. A corollary of 'human capital' is the notion of a 'disabled person', an idea that was socially constructed to categorise those people that were perceived to be unable to participate in the market economy, or raw materials in a production process and discarded as not meeting a standard specification. These were the emergent ideas at the time and became the foundation for the social and political economy of the new colony.

Hence, the native population of Australia faced cultural upheaval on multiple fronts. Over and above the violent aggression of colonisation was the establishment of a social order completely at odds with their cultural values of diversity and inclusion.¹⁷ Some Aboriginal people, already subjugated by armed force¹⁸ and the pejorative influences of the early colonial press¹⁹, also acquired a new label of 'disability', adding another dimension to their dehumanisation, further marginalising them even amongst their own people. In the two and a half centuries since, Aboriginal and Torres Strait Islander people with disability have been vulnerable to the worst of the worst in the social engineering that has taken place post-colonisation: whether it is the over-incarceration of Aboriginal and Torres Strait people²⁰; the institutionalisation of people with disability in mental asylums and institutions, and the structural violence that occurred within them²¹; the removal of children from their families during the Stolen Generations and beyond²²; or exclusion from equal participation in a market economy²³. In appreciating how enshrined the forces of their exclusion have become, the current status of Aboriginal and Torres Strait Islander people with disability is a reminder that the echoes from a distant past still resonate loudly today.

The magnitude of the impact of colonisation upon Aboriginal and Torres Strait Islander people with disability cannot be covered in the scope of this project. It is, however, important to note here the history of colonisation and its impact on Aboriginal and Torres Strait Islander people with disability. The exclusion, dispossession, violence, racism and discrimination has caused, and continues to cause, significant trauma and suffering. These experiences of trauma were pervasive and sustained, and have been passed down and compounded through generations. In essence, the 'trauma story' of Aboriginal and Torres Strait Islander people with disability is an impairment uniquely experienced by Aboriginal and Torres Strait Islander people who have been dispossessed from both Country and body.



¹¹ (David, Barker and McNiven; Hocking, 2005; Kidd, 1997)

¹² Trudgen, R. (2000). Why warriors lay down and die. Darwin: Aboriginal Resource & Development Services.

¹³ Johnston, E. (1991). Report of the Royal Commission into Aboriginal Deaths in Custody. Canberra: Australian Government Publishing Service.

¹⁴ Frost, A. (1981). 'New South Wales as terra nullius: The British denial of Aboriginal land rights.' Australian Historical Studies, 17(77), 513-523.

¹⁵ Reynolds, H. (1987) The Law of the Land. Penguin Books Australia.

¹⁶ Mik-Mayer, N. (2016) 'Othering, ableism and disability: A discursive analysis of co-workers' construction of colleagues with visible impairments'. Human Relations. Volume: 69 issue: 6, page(s): 1341-1363

¹⁷ Reeves, C. (Ed) (2010) A Cultural History of the Human Body in the Enlightenment. Berg Publishers

¹⁸ Smith, A. (1776) The Wealth of Nations. Public domain.

¹⁹ Hollinsworth, D. (2006). Race and racism in Australia. Melbourne: Cengage.

²⁰ Gilroy, J., Ragen, J. and Meskosha, H. (2018) 'Decolonizing the dynamics of media power and media representation between 1930 and 1950: Australian Indigenous peoples with disability.' In: Ellis, K., Goggin, S. and Haller, B. (eds.), Routledge Companion to Disability and Media. New York: Routledge.

²¹ Reynolds, H. (2015). Forgotten War. Sydney: NewSouth Books.

²² Johnston, (1991).

²³ Sweet, M. (2017). Acknowledgement: A social journalism research project relating to the history of lock hospitals, lazarets and other forms of medical incarceration of Aboriginal and Torres Strait Islander people. PhD thesis. Canberra: University of Canberra

²⁴ Human Rights and Equal Opportunities Commission. (1997). Bringing them home: National Inquiry into the separation of Aboriginal and Torres Strait Islander children from their families. Sydney.

²⁵ McGlade, H. (2012). Our greatest challenge: Aboriginal children and human rights. Canberra: Aboriginal Studies Press.

²⁶ Hunter, B. (2000). Social exclusion, social capital, and Indigenous Australians: Measuring the social costs of unemployment. Canberra: ANU.

To morally justify the dispossession of the native inhabitants from their land, Aboriginal and Torres Strait Islander people were treated as subhuman and viewed as inferior by their European conquerors.

The humanity of Aboriginal and Torres Strait Islander people was effectively denied, and the impact of racial discrimination affecting the rights, inclusion and social structure of Aboriginal and Torres Strait Islander people is still evident in Australia today.



1.3 ABORIGINAL AND TORRES STRAIT ISLANDER DISABILITY IN PUBLIC POLICY

Aboriginal and Torres Strait Islander disability policy sits at the nexus of two strategic policy frameworks:

- 'Closing The Gap on Indigenous Disadvantage' framework²⁷; and
- the National Disability Strategy²⁸.

The prevalence of disability in the Aboriginal and Torres Strait Islander population is significantly higher than in the general population. If you are an Aboriginal or Torres Strait Islander person, you are 2.1 times as likely to have disability than if you are not an Aboriginal or Torres Strait Islander person²⁹. The latest data from the 2014-2015 National Aboriginal and Torres Strait Islander Social Survey (NATSISS), shows that 45% of Aboriginal and Torres Strait Islander people are living with disability or a long-term health condition. The reported prevalence of severe and profound disability is 7.7% of the Aboriginal and Torres Strait Islander population aged over 15 living in private households³⁰.

Given the high prevalence of disability amongst Aboriginal and Torres Strait Islander people and its significance in both social and economic terms, not enough is known about the true extent and nature of disability. Whilst data on social and health outcomes have been available for Aboriginal and Torres Strait Islander people, and people with disability as discrete populations, disaggregated data to understand the

unique experiences of people who are both Aboriginal and/or Torres Strait Islander and have disability have historically not been accessible. The unavailability of disaggregated data has meant that there has been a limited awareness of disability as a determinant of social and health outcomes for Aboriginal and Torres Strait Islander people, and disability is largely absent from the Australian Government's Closing the Gap Framework to address Indigenous Disadvantage and related Indigenous policies such as the National Aboriginal and Torres Strait Islander Health Plan. Similarly, the unique needs of Aboriginal and Torres Strait Islander peoples have only recently been formally acknowledged within the National Disability Strategy with the release of the Australian Government Plan to Improve Outcomes for Aboriginal and Torres Strait Islander People with Disability in November 2017³¹. This Plan provides an impetus for focussed responses to the unique needs of Aboriginal and Torres Strait Islander people with disability, and the presentation of evidence on what drives the social inequalities they experience is organised according to the five priority areas for action under the Plan.

The 'Closing the Gap' framework is an overarching policy monitoring and evaluation framework that the Australian government devised to reduce the difference in life expectancy and other social outcomes between Aboriginal and Torres Strait Islander people and other Australians within a generation. The framework that initiated 'Closing the Gap' as a Government policy initiative included targets for reducing the gap in:

- life expectancy;
- mortality rates in children;
- school attendance;
- literacy and numeracy;
- year 12 attainment; and
- employment outcomes³².

The significance of targets under the Closing the Gap framework is that they were negotiated and agreed between the Commonwealth and State and Territory Governments through the Coalition of Australian Governments (COAG), with the intent to align the policy efforts of all Australian governments in a given priority area. Closing the Gap targets are underpinned by National Partnership Agreements which contain performance related funding measures. Despite the impact of disability in attaining other Closing the Gap indicators, there is at the time of writing no stand-alone target to reduce inequality in disability related outcomes under the Closing the Gap Framework. Instead, disability is grouped with chronic disease as a 'headline indicator', which is a second-tier priority under the Closing the Gap Framework³³. This recognises that a long-term whole

of government response is required to address a determinant of inequality in life expectancy, health and social outcomes, but not to the extent that there is an overarching performance measure and aligned funding stream.



²⁷ Coalition of Australian Governments (2007) National Indigenous Reform Agreement (Closing the Gap). Accessed at: http://www.federalaffairsrelations.gov.au/content/indigenous-reform/national-agreement_ssept_12.pdf

²⁸ Coalition of Australian Governments (2010) National Disability Strategy 2010-2020. Accessed at: https://www.dss.gov.au/sites/default/files/documents/05_2012/national_disability_strategy_2010_2020.pdf

²⁹ Australian Bureau of Statistics (ABS) (2016) National Aboriginal and Torres Strait Islander Social Survey, (NATSISS) 2014-15 (Release 4714.0).

³⁰ ABS (2016), NATSISS 2014-15.

³¹ Commonwealth of Australia - Department of Social Services (2017) Australian Government Plan to Improve Outcomes for Aboriginal and Torres Strait Islander People with Disability. Accessed at: https://www.dss.gov.au/sites/default/files/documents/10_2017/dss0001_atstl_disability_plan_accessible_v1.pdf

³² Coalition of Australian Governments (2007) National Indigenous Reform Agreement (Closing the Gap)

³³ Productivity Commission (2016) Overcoming Indigenous Disadvantage Key Indicators Report.. Report Accessed at: <http://www.pc.gov.au/research/ongoing/overcoming-indigenous-disadvantage/2016/report-documents/oid-2016-overcoming-indigenous-disadvantage-key-indicators-2016-report.pdf>. Refer Headline Indicator 4.9, 54.4

1.4 THE COMMUNITY BASED ORIGINS OF THE 'LIVING OUR WAYS' DISABILITY RESEARCH PROGRAM

The purpose of the research program reported here is to understand the issues affecting Aboriginal and Torres Strait Islander people from their viewpoint. The program was given the working title: 'Living our ways' to reflect this.

The project began at the First Peoples Disability Network (Australia) (FPDN), which is a community-based representative disability organisation established by and for First Peoples with disability, their families and communities. As a First Peoples disability organisation, FPDN's governance is unique in Australia because it is governed by a board and executive of Aboriginal and Torres Strait Islander people with an intimate experience and knowledge of disability, either through having a personal experience of disability, through supporting a close family member with disability or as a leader within the Aboriginal and Torres Strait Islander community with a history of dedicated support to people with disability. The housing of the research program in a community-controlled disability organisation is instrumental in keeping the research program grounded to the needs, values and decision-making practices of the community.

The concepts and principles used in this research can be traced to the emergence of a focused First Peoples disability rights movement. In 1991, Uncle Lester Bostock, esteemed Aboriginal Elder and leader of the First Peoples disability rights movement, presented the Meares Oration in which he spoke of the 'double disadvantage' that people who were both Aboriginal and living with disability experienced. As a person with a physical disability, Bostock noted that "when we look at access and equity to service agencies and access to the workforce, Aborigines are at the lowest rung of the servicing ladder."³⁴ The con-

cept of 'double disadvantage' as observed by Bostock forms a basis for the framing of issues of access by First Peoples with disability as 'intersectionality' in this report.

The First Peoples disability rights movement emerged as a distinct community when the Aboriginal rights movement and disability rights movement converged. In 1999 there was a gathering of Aboriginal people with disability in Alice Springs with representation from all States and Territories. An agreed priority at the gathering was for those present to return home and to establish States and Territory based representative Aboriginal disability organisations. Some state-based organisations survived on the back of fledgling funding, notably the Aboriginal Disability Network in New South Wales, but most attempts to establish disability organisations in other States and Territories floundered because of a lack of tangible support from governments. The Aboriginal Disability Network New South Wales (ADNNSW) became an incorporated entity in 2002. ADNNSW was the precursor to the nationally constituted First Peoples Disability Network (Australia) incorporated in 2010.

Between 2004 and 2005, the Aboriginal Disability Network New South Wales undertook a broad-based community consultation on the needs of Aboriginal and Torres Strait Islander people with disability. Bostock, now the inaugural chair of an incorporated

Aboriginal Disability Network, and Damian Griffiths, current CEO of FPDN, visited 33 Aboriginal communities across New South Wales to produce the seminal report, 'Telling it Like it is',³⁵ which chronicled high levels of unmet need, a lack of service provision and extreme poverty in Aboriginal communities. Consulting directly with Aboriginal and Torres Strait Islander people with disability, and a fiduciary obligation to the First Peoples disability community to 'tell it like it is', are two core ethical principles that this research project has inherited from this original work.

Despite a distinct First Peoples disability rights agenda emerging through a process of development led by the community, the research to support the rights agenda was being conducted parallel to, and not within community. An audit of disability research in 2014 located 39 papers in scientific literature and 30 papers in 'grey' literature³⁶, the majority of which constituted bio-medical disability research conducted in Aboriginal and Torres Strait Islander communities. The search inclusion criteria failed to incorporate the knowledge and expertise of the First Peoples disability community and its leaders, highlighting the gaps in scientific searching techniques to identify research activities and the priorities identified by the community.

The failure of research institutions to appropriately recognise and respond to the voices of those being researched increasingly frustrated the efforts of the First Peoples disability community seeking to have their rights acknowledged and respected. While well-meaning, research that amplified the voices

of outside researchers, service providers and other intermediaries over the voices of First Peoples with disability themselves rendered invisible their expressions of real need. In asserting their dual rights of participatory decision-making and self-determination, enshrined in the Convention of the Rights of Persons with Disabilities³⁷ and the United Nations Declaration on the Rights of Indigenous Peoples³⁸, the First Peoples disability community determined it was no longer content to be a subject of the research priorities and projects of others, but would instead assume the leadership role in the progression of research that affected them. In December 2014, the Board of the First Peoples Disability Network declared its strategic intent to own the First Peoples disability research agenda in partnership with its community³⁹. The 'Living our ways' research program is an outcome of this strategic commitment to undertake research by the community for the community. This report is its inaugural publication.

As a person with a physical disability, Bostock noted that "when we look at access and equity to service agencies and access to the workforce, Aborigines are at the lowest rung of the servicing ladder."³⁴

³⁴ Bostock L. (1991) *Access and equity for people with a double disadvantage*, Australian Disability Review, Vol. 2, pp. 3-8.

³⁵ Bostock L., and Griffiths D. (2005) *Telling it Like it is: A report on community consultations with Aboriginal people with disability and their associates throughout NSW, 2004-2005*. Aboriginal Disability Network New South Wales.

³⁶ Centre for Disability Research and Policy (2014). *Report of Audit of Disability Research*. University of Sydney, Supplement at p.21.

³⁷ United Nations (2006) *Convention on the Rights of Persons with Disabilities* (A/RES/61/106).

³⁸ United Nations (2007) *United Nations Declaration on the Rights of Indigenous Peoples* (A/RES/61/295).

³⁹ First Peoples Disability Network (2015) *Strategic Directions 2015-2020*.



1.5 THE RESEARCH BRIEF

First Peoples Disability Network received funding under the Commonwealth Government's National Disability Research Development Scheme to fund one full-time researcher for two years to listen to and record the lived experience of Aboriginal and Torres Strait Islander people with disability through their narratives.

First Peoples Disability Network was the community base for the project and provided additional services for the project in-kind. The University of Technology Sydney and University of New South Wales have provided ongoing support for this project and supported the intent for genuine community leadership and partnership, including in-kind support.

There are six deliverables of the 'Living our ways' research program:

- Establish a genuine model of co-production in disability research which is driven by Aboriginal and Torres Strait Islander people with disability.
- Improve the interpretation of quantitative data collected through the NATSISS, Survey of Disability Ageing and Carers (SDAC) and related instruments through a complementary qualitative knowledge base.
- Produce a national research agenda for prioritising the future Aboriginal and Torres Strait Islander Disability Research Project.
- Incorporate community-based capacity building for greater participation by Aboriginal and Torres Strait Islander disability research.
- Invite groups of Aboriginal researchers to build their capacity in disability studies.
- Summarise the analysis in a report for NATSISS, SDAC and Research and Data Working Group.

The research proposal included three core principles for conducting the research:

- The first principle referred to an intersectional approach to reflect the uniqueness of Aboriginal and Torres Strait Islander disability rights and research.
- The second principle referred to an authentically grounded approach to reflect the perspectives of Aboriginal and Torres Strait Islander people with lived experience of disability.
- The third principle referred to establishing a genuine community-directed model of co-production in Aboriginal and Torres Strait Islander disability research.

As the research progressed, these principles formed into a distinctive First Peoples disability research philosophy, which culminates in the presentation of a First Peoples disability research agenda that is sourced directly from the voices of Aboriginal and Torres Strait Islander people with disability.



The purpose of the research program reported here is to understand the issues affecting Aboriginal and Torres Strait Islander people from their viewpoint.



2

KEY TERMS AND CONCEPTS



KEY TERMS AND CONCEPTS

2.1 THE DEVELOPMENT OF CONCEPTS AND TERMS

The purpose of this chapter is to outline the key terms and concepts that appear in this research, providing definitions of the key ideas and concepts developed and used throughout. These concepts have been categorised as follows:

- i. Aboriginal and Torres Strait Islander people with disability and their community;
- ii. defining disability and functional impairment;
- iii. the processes of research production; and
- iv. the multiple forms of discrimination experienced by Aboriginal and Torres Strait Islander people with disability.

As disability within Aboriginal Torres Strait Islander communities incorporates clinical, social, cultural and human rights dimensions, its language and terminology can be imprecise and often contested when used in multiple contexts:

- In some cases a single word can have different meaning in different contexts. An example in this research is the word 'Community'.
- In other cases there are multiple words or phrases used to describe a single context, the choice of which reflects the user's knowledge, preferences or values. An example here is the interchangeability between 'Aboriginal and Torres Strait Islander people' and 'First Peoples'.
- In some cases, a concept has been explained in one way within an existing body of research, but has been extended within this research to explain findings in a different setting. An example here is the concept of 'overshadowing' applied in this project in a new way.
- In some case, new concepts have been devised to explain phenomena which could not adequately be explained by terminology presently in use. An example here is the explanation of 'apprehended discrimination' to describe the absolute breakdown of trust that occurs when a person is continually exposed to discrimination.

The relationship of language to the stigmatisation of Aboriginal and Torres Strait Islander people, and people with disability means that the choice and use of terms and phrases is made with great care relative to the context of this research in which these terms and concepts are used.

2.2 CONCEPTS RELATED TO THE FIRST PEOPLES DISABILITY COMMUNITY

'Community'

In the broadest sense, a 'community' is a group of people with shared beliefs, values and experiences.

The shared experiences of Aboriginal and Torres Strait Islander people mean the 'community' has a special connotation for them. It is not only a term that describes physical connection of a group of people, but also a spiritual sense of belonging.

In Aboriginal and Torres Strait Islander affairs, there are a variety of contexts in which 'community' can be used. Two prevalent examples of contrasting contexts in the use of 'community' are:

- **Spatial references to 'community':** In this context, 'community' is used to locate a person's sense of belonging which is place-based or geographical. For example, people may identify as belonging to an Aboriginal nation, and/or a town or locality.
- **Non-spatial references to 'community':** In this context 'community' is used independent of geographical markers and used to locate a person's sense of belonging based on their shared experiences with other people. In this sense, Aboriginal and Torres Strait Islander people with disability may be viewed as a 'community' based on shared experiences of disability, that transcends geographically based markers.

Notably, an individual may have multiple affiliations with different communities. For example, an Aboriginal or Torres Strait Islander person with disability may identify as a member of the disability community as well as a member of an Aboriginal nation.

On another point of clarification, 'First Peoples disability community' is used to refer to the group of Aboriginal or Torres Strait Islander people with a shared experience of disability; whereas the 'First Peoples Disability Network' is used to specifically refer to the community-based representative organisation established by the First Peoples disability community.

For the purposes of this project:

- 'Community' is used to refer to the First Peoples disability community. This is to convey the focus of the project, which is to narrate the shared experiences of Aboriginal and Torres Strait Islander people with disability.
- To avoid confusion within this report, place-based names are referred to as 'research sites'.

'Aboriginal and Torres Strait Islander people' and 'First Peoples'

'Aboriginal and Torres Strait Islander people' and 'First Peoples' are used interchangeably in the document, and reflects varying preferences based on the context. For example, the Australian Bureau of Statistics (ABS) incorporates the identifier 'Aboriginal and Torres Strait Islander' in the description of the NATSISS, which is a primary dataset used for statistical analysis; whereas the First Peoples Disability Network, a national community disability organisation, prefers the terminology of 'First Peoples' when referring to its community. Ultimately, they are different identifying terms used to refer to the same population group.

For the purposes of the inclusion criteria as an Aboriginal and Torres Strait Islander person, the research applies the criteria of self-identification. This is consistent with the 'Standard Indigenous Question' used by the ABS in its data collection and many other government agencies, which states that "An Aboriginal or Torres Strait Islander is a person of Aboriginal and Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander and is accepted as such by the community in which he or she lives."⁴⁰

⁴⁰ Department of Aboriginal Affairs (1981). Report on a review of the administration of the working definition of Aboriginal and Torres Strait Islander, Canberra: Commonwealth of Australia. Department of the Parliamentary Library, 2003. Defining Aboriginality in Australia, Canberra. Commonwealth of Australia.



2.3 CONCEPTS RELATED TO DISABILITY AND IMPAIRMENT

Medical, social and cultural presentations of disability

'Disability' is an overarching term which is subject to various interpretive models which explain its nature and effect. The two dominant models of disability covered extensively within the research literature are the 'medical model' of disability and the 'social model' of disability.

Medical model of disability: The medical model of disability is characterised by clinical diagnoses of impairment. Within a medical model, a focus is one of curing disability, and a disability diagnosis serves as a trigger for biomedical supports for an individual.

Social model of disability: A social model of disability emerged in the late 1970's as a reaction to the limitations of a medical model in addressing disability as a human right issue⁴¹. In contrast to the medical model, a social model of disability views disability as a social construct, in which disability is created by barriers in the physical environment and negative social attitudes and low expectations of those who have impairments. In the social model of disability, the focus is on accommodating people who experience an impairment by removing their barriers to access and social participation.

Despite the differences in their perspective, both the medical and social models have been framed from a western belief system of disability as a deficit in human functioning, either caused by a biomedical condition (the medical model), or a deficit in the social and physical environment (the social model). For Aboriginal and Torres Strait Islander people whose cultural practices are based on inclusion, these concepts of disability as a deficit are a foreign concept. Having 'no word for disability', the language of disability, including all the diagnostic labelling, is a language that Aboriginal and Torres Strait Islander people have had to learn out of necessity so they can negotiate the western disability systems intended to support them and improve their quality of life.

As the western concepts of disability differ from Aboriginal and Torres Strait Islander ontological understandings of human capability, this research explores a third model of disability – a 'cultural model of inclusion' – which is more consistent with the culture and beliefs of First Peoples. It further explores how in a post-colonial nation, the western models of disability can come together with culture within a single individual who can exhibit an integrated medical, social and cultural presentation of disability.

A working definition for 'disability' and 'functional limitation'

The World Health Organisation's International Classification of Functioning, Disability and Health (ICF) sets a standardised framework for disability terminology which integrates the biophysical and social factors affecting a person. In the framework, 'disability' refers to a specific condition or impairment related against their health, whereas functioning relates to the capacity to undertake a task as a consequence of having an impairment:

"Disability is an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between a person's health condition(s) and that individual's contextual factors (environmental and personal factors)."

Functioning is an umbrella term for body function, body structures, activities and participation. It denotes the positive or neutral aspects of the interaction between a person's health condition(s) and that individual's contextual factors (environmental and personal factors)."⁴²

The ICF framework frames disability and human functioning within a limited concept of health, which means that other factors which may inhibit social participation, such as racial discrimination, are outside its scope⁴³. This limitation in scope presents another gap in its application to what are significant disabling factors affecting Aboriginal and Torres Strait Islander people.

The ABS adopts the ICF Framework within its statistical dataset, and describes disability in terms of severity of the functional limitation. It categorises four levels of severity in functional limitation:

Profound – the person is unable to do, or always needs help with, a core activity task.

Severe – the person sometimes needs help with a core activity task, and/or has difficulty understanding or being understood by family or friends, and/or can communicate more easily using sign language or other non-spoken forms of communication.

Moderate – the person needs no help, but has difficulty with a core activity task.

Mild – the person needs no help and has no difficulty with any of the core activity tasks, uses aids and equipment and has difficulty in general mobility.⁴⁴

The ABS datasets used for the research adopt a self-identification method in identifying the severity of functioning limitation.

For the purposes of the research, the inclusion criteria is based on a self-identification process in which the participant self-identifies with the First Peoples disability community. This maintains consistency with the self-identification of Aboriginal and/or Torres Strait Islander status, and the self-identification approaches used by the ABS in the dataset used in the statistical analysis.

⁴¹ Shakespeare, T. (2010) 'The Social Model of Disability'. In Davis, L.J. (Ed.) The Disability Studies Reader. New York:Routledge. 266-273.

⁴² World Health Organization (2001) The International Classification of Functioning, Disability and Health (ICF). Geneva: WHO.
⁴³ World Health Organization (2001) Ibid.
⁴⁴ Australian Bureau of Statistics (2016) Disability, Ageing and Carers, Australia: Summary of Findings, 2015. Rel. 4430.0. Glossary. At: <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4429.0Main+Features!00232009>

2.4 CONCEPTS RELATED TO RESEARCH PRODUCTION

'Narrative'

"Narrative" is an overarching term meaning the use of story-telling in messaging. Narrative inquiry is a recognised approach within disability research through which the voices of people with disability are made central in shaping an understanding of the issues that affect them individually and socially.⁴⁵

Within this research, the 'narrative' of First People with disability has come together by combining three elements:

Testimony

The research collected first-hand oral testimony from Aboriginal and Torres Strait Islander people with disability on their life experiences of disability. The testimony was obtained through:

- i. Personal interviews with 47 people with disability; and
- ii. Participation at a forum of Elders.

The testimony was given orally, or in the case of Deaf Aboriginal people via a verbal translation from Auslan, and recorded digitally. The oral testimony was then transcribed verbatim into text form for analysis. The testimony is presented as verbatim quotes used to provide context and illustration in the thematic analysis.

Statistical data

The research was conducted on secondary analysis of statistical data collected independently by the ABS. The two principal data sources used for obtaining quantitative data were the National Aboriginal and Torres Strait Islander Social Survey (NATSISS) and Survey of Disability Ageing and Carers (SDAC). The processes for analysing and presenting the quantitative data within the model of co-production developed for the research is described further in Chapter 3.

45 Smith-Chandler, N. and Estelle Swart (2014) 'In Their Own Voices: Methodological Considerations in Narrative Disability Research' *Qualitative Health Research*, Vol. 24(3) 420–430.



Drawing on the researcher's field notes from the interviews, these 'yarning pieces' aim to provide a vignette on the life of an Aboriginal and Torres Strait Islander person with disability.

'Yarning pieces'

Whilst the presentation of testimony with statistical data together provided both scope and context in the analysis of thematic issues covered by the research, these two elements of the narrative could not provide a complete picture in isolation. What was missing from the verbatim transcription of the testimony was the human experience, particularly how many of the issues come together in the life of each person. To complete the narrative, a concept of 'yarning pieces' was created to connect themes as they presented within the life of each person.

Whilst testimony and statistical data can be generated and analysed using westernised methodologies for qualitative and quantitative research, the yarning pieces draw upon the Aboriginal concept of 'yarning' through which oral histories are transmitted in harmony with time and place.^{46,47} This is achieved by asking people: "What is your story?", and allowing them to recount it at their own pace, on their own terms, and within their own safe space. No judgment was made, nor boundaries placed upon what they could or could not say. The yarning pieces are not adjuncts that complement the testimony or statistical data, they are the mechanism through which otherwise disparate themes are drawn together in a cohesive narrative.

Drawing on the researcher's field notes from the interviews, these 'yarning pieces' aim to provide a vignette on the life of an Aboriginal and Torres Strait Islander person with disability. They are designed and written in a way that aims to place the reader in the chair of the interviewer, watching and listening to the person's story as it unfolds, and encompassing experiences beyond the spoken word.

46 Rogers, J. (2017). 'Photoyarn: Aboriginal and Maori Girls Researching Boarding Experiences.' *Australian Aboriginal Studies Journal*, Vol 1, pp. 4–14.

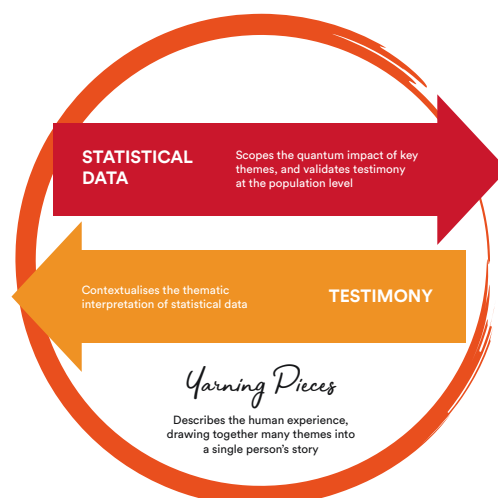
47 Bessarab, D. & Ng'andu, B. (2010), 'Yarning about Yarning as a Legitimate Method in Indigenous Research', *International Journal of Critical Indigenous Studies*, vol. 3, no. 1, pp. 37–50.



KEY TERMS AND CONCEPTS

The synergies between testimony, data and a culturally grounded analytic has taken the research from an exercise in statistical analysis to an immersive process of 'data whispering'. The data speaks a story, has patterns and flows, much like dots on a painting speak to an artist, the topography of the landscape speaks to a tracker, or stars to a night-time navigator. Together with the spoken word, the statistics and the stories have fused to deliver a dynamic narrative of disability in Aboriginal and Torres Strait Islander communities.

Chart 2.3 (1): Elements of the Narrative



A community-directed model of 'research co-production'

The promotion of the rights of the Aboriginal and Torres Strait Islander disability community is the rationale for doing this research and the inherent value underpinning its design. Core to the rights-based foundation of the research is the right to self-determination for the Aboriginal and Torres Strait Islander disability community, as it applies within the research domain. The right to self-determination is expressed by the United Nations Declaration on the Right Of Indigenous Peoples "the right to freely pursue their form of economic, social, and cultural development".⁴⁸

This research applies the right of self-determination as a participatory principle, a distinction to its conventional use as a political or legal construct. As a participatory principle, self-determination is compatible with the philosophies of emancipatory disability research^{49, 50}, with the added dimension of providing cultural surety over and above the active participation of marginalised populations.

There are implications in promoting self-determination as a participatory right with models of research co-production. By logical inference, the right of self-determination can only be optimised when research that affects the economic, social and cultural development of Aboriginal and Torres Strait Islander people with disability is led by their community. This puts the Aboriginal and Torres Strait Islander community in a position of sovereignty over the research, its aims, methods and translation. By contrast, Aboriginal and disability researchers who are highly regarded within Australia and internationally, act as technical advisors providing their expertise on academic quality to community. The effect of establishing community as the ultimate decision-making authority over the research inverts the "unequal power relationships between researchers and researched"⁵¹ that emerge when research is institutionally led.

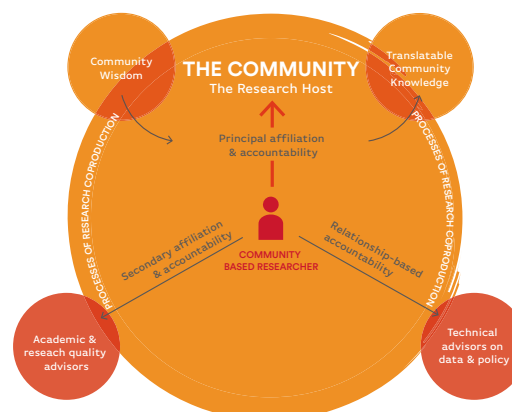
48 United Nations (2007) United Nations Declaration on the Rights of Indigenous Peoples, Article 3.
49 Barnes, C. (2003) 'What a difference a decade makes: Reflections on doing 'emancipatory disability research'. Disability in Society 18 (1).
50 Albert, B (ed) (2006) In or out of mainstream? Lesson from research on disability and development cooperation. The Disability Press, Leeds.
51 Hanley B. (2005) Research as Empowerment? Toronto Seminar Group.



Influenced by decolonising research methodologies⁵² and an Indigenous relationship approach to 'research is ceremony'⁵³, this research is a nexus with self-determination through several touch points:

- **First Peoples disability community as 'researcher' and host:** At the highest conceptual level, it addresses the power imbalances that can occur in co-production between 'researcher' and 'community'⁵⁴ by fusing these roles into one. In other words, 'community' is the 'researcher'. This is operationalised in this research by the First Peoples Disability Network adopting the role of host organisation for the research, and designating a member of its community as lead researcher.
- **Participants as owners:** 'participants' are more than just subjects of research, they are fully acknowledged as participant-owners of the research and its outcomes. This safeguards the cultural and intellectual property on behalf of the research and minimises the leakage of property rights outside the community.
- **The researcher as a 'message stick' for community wisdom:** the researcher has a custodial role over the testimony that is shared by the participants. Community wisdom stays with the community, and cannot be appropriated by the researcher, even in its conversion into formal forms of knowledge. During the research, the researcher acted as an agent of the participants, or a 'message stick' upon which the participants could write their story. The researcher acted with the assent from within the First Peoples disability community, and hence was accountable to community structures of authority as well as academically based research ethics. Having a lead researcher that was based within the First Peoples disability community was pivotal to ensuring that all stages of the research co-production proceeded in harmony with community values.
- **Consent as a form of ceremonial form of permission:** The roles and relationship of the participant and individual researchers alters the nature of obtaining consent to participate. By contrast, consent takes on a role in which consent designates the passing of permission from the participant to share their wisdom and their testimony, to the research as a trusted custodian who accepts a responsibility to care for the testimonies as artefacts of the cultural history of Aboriginal and Torres Strait Islander people with disability.
- **Academics and knowledge translators are trusted technical advisors:** Within this model academics are advisers to community on technical matters of research methods, data management, academic rigour and quality and knowledge translation. They work respectfully within a model of community-directed research and the inherent principle of self-determination, and do not over-reach by asserting a decision-making authority. They give expert guidance.

Diagram 2.3 (2): Community directed model of research co-production



52 Tuhiwai Smith, L. (2012) Decolonizing Methodologies: Research and Indigenous Peoples. 2nd Ed. Zed Books: London and New York.
53 Wilson, S. (2008) Research is Ceremony: Indigenous Research Methods. Fernwood Publishing: Halifax and Winnipeg.
54 Filipe A, Renedo A, Marston C. (2017) The co-production of what? Knowledge, values, and social relations in health care. PLoS Biol 15(5): e2001403



Intersectional discrimination is not a point-in-time concept. The detrimental consequences of intersectional discrimination at one point in life can be life-long, as it increases the likelihood of being exposed to future experiences of exclusion and discrimination.

2.5 CONCEPTS RELATED TO DISCRIMINATION AND INEQUALITY

'Inequality' in social outcomes

Chapter 6 uses statistical data to illustrate 'inequality' in social, health and wellbeing outcomes experienced by Aboriginal and Torres Strait Islander people with severe and profound disability compared to Aboriginal and Torres Strait Islander people with disability. 'Inequality' in this usage refers to the variation in the outcomes comparing the two sub-groups that can be objectively measured and shown to be not equal.

It should be noted that the statistical data is used empirically, and no statistical tests were used to determine where any variation was statistically significant. It should be further noted that a statistical analysis in and of itself does not imply correlation or causation on its own. For this expanded analysis, the statistical data on inequality, and the patterns in the data, combine with the testimony and yarning pieces to form a more complete narrative on the experiences of Aboriginal and Torres Strait Islander people, as described above.

'Intersectionality'

'Intersectionality' is an explanatory framework that explains how relativities in the empowerment and disempowerment of Aboriginal and Torres Strait Islander people with disability generate and maintain inequalities for people who intersect two (or more) marginalised population groups.

'Intersectionality' was devised by critical race theorist Kimberlé Crenshaw⁵⁵ to explain the effect of race and gender upon the incidence and impact of family violence against African American women. Crenshaw's observations of intersectionality showed that an explanation of race or gender in isolation from each other did not fully describe the experiences of African American women in their exposure to violence, and instead they constituted a marginalised group within a marginalised population. Intersectionality explores the dynamics in the power relations that exist between and within marginalised populations⁵⁶, and explains how inequalities in the power relationship between groups can create and sustain inequality⁵⁷. As a foundational framework for the research, intersectionality shows that to fully understand the unique experiences of Aboriginal and Torres Strait Islander people with disability, the research must recognise that they are a discrete group at an intersection of two marginalised populations.

- 55 Crenshaw K. (1991) 'Mapping the Margins: Intersectionality, Identity Politics, and Violence Against Women of Color' 43. Stanford Law. Review. 1241 1990-1991.
- 56 Cho S., Crenshaw K.W., McCall L. (2013) 'Towards a Field of Intersectionality Studies: Theory Application and Praxis' Signs: Journal of Women in Culture and Society 38, No 4: 785-810.
- 57 Choo H.Y. and Ferree M.M. (2010) 'Practicing Intersectionality in Sociological Research: A Critical Analysis of Inclusions, Interactions, and Institutions in the Study of Inequalities' Sociological Theory 28:2.

'Racism', 'Ableism' and 'Intersectional discrimination'

The theory of 'intersectionality' can be applied to explain the social experiences and life outcomes for people who are both Aboriginal and Torres Strait Islander and have disability. Crenshaw's explanation of intersectionality is consistent with Bostock's observation of "double disadvantage"⁵⁸, in which she drew upon her personal experiences as an Aboriginal leader and disability scholar and addressed the issue of multi-faceted discrimination that affects Aboriginal people who also have a disability. In pointing to a hierarchy in access and social equality, Bostock stated that Aboriginal people with disability were "at the lowest rung on the service ladder"⁵⁹.

Bostock's concept of double disadvantage aligns with the theory of intersectionality. As people with identities traversing two marginalised groups, Aboriginal and Torres Strait Islander people with disability experience both racially based discrimination ('racism') and disability related discrimination ('ableism'). The prevalence of racism and its adverse impact upon health and wellbeing of Aboriginal and Torres Strait Islander people is well documented.^{60 61 62}

In addition to racism and ableism as discrete forms of discrimination, the research detected a third experience – 'intersectional discrimination' – which is a unique interaction of race and disability-related discrimination experienced by people who are both Aboriginal and/or Torres Strait Islander and have disability. An example from the testimony is an account of an Aboriginal man with cognitive impairment who is harassed at a shopping centre by security guards who assume he is drunk. In this example, the physical presentation of a person with cognitive impairment interacts with populist prejudices about Aboriginal people and drinking which exposes a person who is Aboriginal and has cognitive impairment to a heightened vulnerability not adequately explained by racism or ableism alone. These three forms of discrimination are represented in Diagram 2.4.1

Diagram 2.4 (1): Racism, ableism and intersectional discrimination for people at the intersection of two marginalised populations



'Intersectionality' across the life trajectory: A 'matriculation pathway into prison'

Intersectional discrimination is not a point-in-time concept. The detrimental consequences of intersectional discrimination at one point in life can be life-long, as it increases the likelihood of being exposed to future experiences of exclusion and discrimination. The following table shows how inequality experienced by Aboriginal and Torres Strait Islander people with disability accumulates over the course of their lives. Even before they are born, the social circumstances into which Aboriginal and Torres Strait Islander people are born can add to the burden of disability. The impact of undetected and unsupported disability in their early childhood carries forward into the schooling years. This compounds into greater inequalities in later life, effectively placing them on

a 'matriculation pathway into prison'⁶³, as opposed to further education and employment. Whilst an intersectional analysis of the life trajectory presents a bleak picture of the opportunities that Aboriginal and Torres Strait people with disability are currently presented with, it can be transposed for positive impact. In addition to an explanatory model for understanding the impact of accumulated disadvantage, it can be further developed using knowledge translation strategies to identify the pivot points which can alter the life trajectory by providing timely supports to their disability.

- 58 Bostock (1991), *ibid*, at p.7
- 59 Bostock (1991), *ibid* at p.6.
- 60 Larson, A.; Gillies, M.; Howard P.J.; and Coffin J., (2007) 'It's enough to make you sick: the impact of racism on the health of Aboriginal Australians' Australian and New Zealand Journal of Public Health Vol. 31, Issue 4, pp 322–329.
- 61 Priest N.; Perry R.; Ferdinand A.; Paradies Y.; Kelaher M. (2014) 'Experiences of racism, racial/ethnic attitudes, motivated fairness and mental health outcomes among primary and secondary school students', *Journal of Youth and Adolescence*, 43(10):1672–87.
- 62 Ferdinand, A., Paradies, Y. & Kelaher, M. (2012) Mental Health Impacts of Racial Discrimination in Victorian Aboriginal Communities: The Localities Embracing and Accepting Diversity (LEAD) Experiences of Racism Survey, The Lowitja Institute, Melbourne.

- 63 Avery S. (2016) 'The life trajectory for an Aboriginal and Torres Strait Person with disability'. In: Aboriginal and Torres Strait Islander Perspectives on the Recurrent and Indefinite Detention of People with Cognitive and Psychiatric Impairment. First Peoples Disability Network.



Even before they are born, the social circumstances into which Aboriginal and Torres Strait Islander people are born can add to the burden of disability.

Scott Avery

KEY TERMS AND CONCEPTS

Table 2.4 (1): Intersectionality across the life trajectory of an Aboriginal or Torres Strait Islander person with disability⁶⁴

							
LIFE-STAGE ASPECT	Peri-Natal	Early childhood	Schooling years	Young people	Justice	Health	Ageing
Aboriginal and Torres Strait Islander	Low awareness of disability Environmental factors, increased likelihood of low birth-weight	Low awareness of disability Exposure to trauma Increased likelihood of OOH – off country, unstable home setting	Low awareness of disability “Bad black kid syndrome” – punitive schooling over supported disability	Less likely to secure employment Increased likelihood of police contact	Denial of rights – over incarceration	Subconscious bias – institutional racism	Reduced life expectancy Disability happens earlier in life and with more co-morbidities.
Disability	Low birth weight and environmental factors in developmental disability	Disability assessments aren’t carried out to the extent that they need to be	Undiagnosed and unsupported disability	Less likely to secure employment Communication impairments, reduced capacity to negotiate conflict	Denial of rights – indefinite detention and fitness to plea for people with cognitive and psychiatric disability	Subconscious bias – diagnostic over shadowing	Inadequate public infrastructure especially in remote communities.

64 Avery S. (2016) ‘The life trajectory for an Aboriginal and Torres Strait Persons with disability’. In: Aboriginal and Torres Strait Islander Perspectives on the Recurrent and Indefinite Detention of People with Cognitive and Psychiatric Impairment. First Peoples Disability Network

'Apprehended discrimination'

Participants in the study revealed exposures to racism, ableism and intersectional forms of discrimination. The frequency of their exposure across multiple forms of discrimination was so great that one of the discoveries of this research is that a pattern in the psychological responses to the threat of discrimination can be determined. In particular, the participants demonstrated a sequence of psychological responses to discrimination across a continuum. This continuum begins as an intuitive fear of discrimination, and develops into an increasingly rational understanding of discrimination that is acquired through increasingly frequent personal exposures to discrimination. This pathway from fear of discrimination to avoidance could not be adequately explained within existing terminology and concepts. To overcome the limitations in existing terminology, a concept of 'apprehended discrimination' has been devised to describe the rational fear of discrimination, which can ultimately lead to an avoidance of social situations in which a person could expect to be discriminated against.

The concept of 'apprehended discrimination' expands upon other research that signifies 'trust' and 'engagement' as vital components in the effective service delivery to Aboriginal and Torres Strait Islander people⁶⁵. In understanding apprehended discrimination as a continuum or pathway in the psychological responses to discrimination, there are a number of phases through which the participants progressed in describing the impact of discrimination in their testimony.

⁶⁵ Dew, A., McEntyre, E., Vaughan, P., Coony, E., Dillon Savage, I., & Dowse, L. (2018). *No More Waiting: A Guide For Organisations to Plan with Aboriginal People with Disability*. UNSW: Sydney. At p

FEAR OF DISCRIMINATION: The pathway commences with an intuitive understanding of discrimination. In the early stages of understanding, discrimination is externalised, in that the participants are drawing from a perceived understanding of discrimination which happens to others, distinct from their own personal exposures to discrimination.

APPREHENDED DISCRIMINATION: As they become more personally exposed to discrimination, their understanding of discrimination transitions from an intangible judgment to an increasingly rational thought process, in the sense that every incident adds weight of evidence to their rational judgment of discrimination, its frequency and its impact upon them. Apprehended discrimination is the 'a-ha' moment when they realise that their perception of discrimination has become their reality, a psychological realisation that invokes an unpleasant physiological reaction.

AVOIDANCE OF DISCRIMINATION: There comes a threshold point at which the accumulated exposure to discrimination is so great that the participant expects to be discriminated against, as distinct from being assessed as a chance encounter. Their response is self-exclusion, that is, to avoid situations in which they can be exposed to any further discrimination. The psychological response of avoidance is a rational choice, to avoid further harm by being further exposed to discrimination.



Illustrations of apprehended discrimination drawn from the testimony are provided in Chapter 5.2 in relation to everyday encounters of discrimination experienced by Aboriginal and Torres Strait Islander people with disability, and in Chapter 6.5 which provides a focussed discussion of apprehended discrimination in job-seeking and employment programs.

As an explanatory concept in describing avoidance as a psychological response to a rational fear of discrimination, 'apprehended discrimination' could also help other situations in which a fear of being discriminated against outweighs the potential benefit of seeking help. Such contexts might include:

- The mother of a child with Foetal Alcohol Spectrum Disorder, considering whether she should reach out seek support;
- The reason some Aboriginal and Torres Strait Islander people do not fill in the Census and other statistical reporting; and
- Whether the Aboriginal and Torres Strait Islander women are less likely to report incidents of family violence to the police, out of a fear that they themselves will instead will be picked up for minor infringements.



3 A COMMUNITY-DIRECTED RESEARCH METHODOLOGY

3.1 OVERARCHING DESIGN

This research is an exploratory scoping study and was primarily designed to promote the voices of Aboriginal and Torres Strait Islander people with disability in setting the agenda for future research. Its purpose was to canvass issues and generate ideas using an authentically grounded approach, using a research question that was distilled into four words: 'What is your story?' In keeping with the participatory aims of the research, Aboriginal and Torres Strait Islander people with a lived experience of disability were deemed the people most qualified to answer this question.

The grounded approach drew upon both the well-established grounded theory⁶⁶ approach to research following the grounded theory and sampling guidelines. The research commenced with firmly set values about how the research would be conducted as a community-directed approach to disability research, but without a pre-determined theoretical framework or hard-wired set of methods. Whilst influenced by the purposive, convenience sampling techniques of grounded theory, it is noted that these concepts were developed from a Westernised approach to research, and that these concepts would need to be adapted and extended for the research to be authentically grounded within the Aboriginal and Torres Strait Islander disability community.

The authentically grounded approach was operationalised into research practice through a number of design principles:

Principle 1: The research is philosophically, methodologically and operationally aligned to the control and direction of the First Peoples disability community.

Principle 2: The research continues the rights-based movement of the First Peoples Disability Network to advance the rights of Aboriginal and Torres Strait Islander people with disability.

Principle 3: The research is inclusive of all people who wish to participate, subject only to their self-identification as a member of the First Peoples disability community.

Principle 4: The research is discrimination and trauma informed, acknowledging the unique sensitivities of conducting research that includes people who are both Aboriginal and/or Torres Strait Islander and have disability.

Principle 5: The research meets both (i) international standards of ethical research practice and quality, and (ii) ethical standard for conducting research in Aboriginal and Torres Strait Islander communities.

66 Charmaz, K. (2006) Constructing Grounded Theory: A Practical Guide through Qualitative Analysis. SAGE Publications. London.

3.2 SCOPE AND CONTEXT

Before progressing to a detailed discussion of how the research was conducted and its findings, it's important to highlight what the research was not designed to do.

Firstly, as an exploratory scoping study aimed at generating issues and ideas, it is not intended or designed to be an evaluation of any specific disability services or support programs. This is a particularly important note for how the research should be interpreted when referencing specific disability support systems, such as the chapter on the National Disability Insurance Scheme. The aim of this research was to solely identify issues for further exploration, and in doing so highlights some focused areas of concern in relation to the equity and quality with which support programs are provided to Aboriginal and Torres Strait Islander people with disability. However, no definitive conclusions about program or service evaluation can be drawn from this research, other than to demonstrate a need for further focused evaluation on the issues of concern that have been identified.

Secondly, the testimonial data has the capacity to report on the quality of the personal experience. There was insufficient sample size in the qualitative survey to provide any inference on the prevalence of issues from the testimonial data alone. The research has attempted to overcome this limitation by using a mixed methods approach⁶⁷ in which the statistical data interacts with testimonial data to generate the cohesive 'narrative' addressing quality and prevalence.

Thirdly, the inclusion criterion for all data was self-identification as an Aboriginal and Torres Strait Islander person with disability. The research was promoted through the First Peoples disability community as inclusive of all disability types. By adopting an 'inclusive of all' approach the research was conducted consistent with the values of Aboriginal and Torres Strait Islander culture, segregation by disability types or clinical diagnoses of disability in the inclusion criterion and analysis was not relevant to the research.

Finally, this research has started a process of activating participation by Aboriginal and Torres Strait Islander people in research, and has been successful in reaching people who have never had an opportunity to speak on issues that affect them. Nonetheless, it should not be presumed that this process has comprehensively captured all the views of the dispossessed and marginalised. There are particular gaps within the Aboriginal and Torres Strait Islander disability community whose views appear to be underrepresented. These groups include the views of children and young people; people who are in detention; people who are homeless and sleeping rough. In this respect, this research is a starting point for further exploratory studies on the narrative of the even 'harder to reach', not merely to incorporate their story as a perspective within research, but in positioning it as central to the purpose for conducting social impact research in the first place.

67 Leech N, Onwuegbuzie A, (2008) A typology of mixed methods research designs, Quality and Quantity, 43(2), March, pp. 265-275.

3.3 SETTING UP STRUCTURES AND RELATIONSHIPS FOR RESEARCH CO-PRODUCTION

Academic Advisory Panel

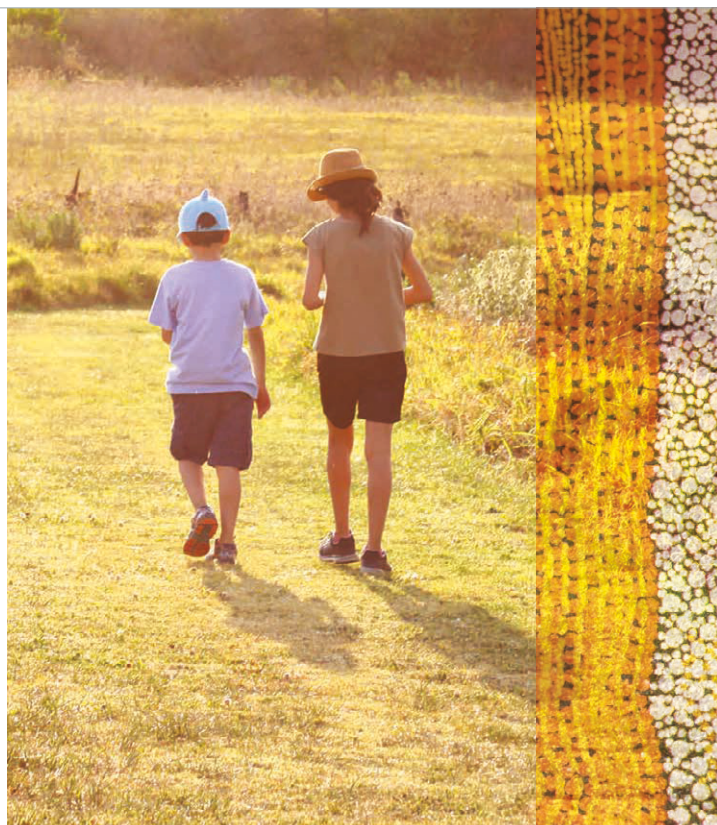
The 'Living our ways project' established an Academic Advisory Panel (AAP) comprising Aboriginal and disability researchers from two universities. The AAP is the core structure through which co-production of this research project occurs. That is, the research progresses through the connection between First Peoples Disability Network and the academic community, through the AAP.

The AAP interacts with the community-based researchers at regular review meetings, and through weekly communication with the lead academic researchers. The AAP established a community-led structure in that FPND sets the AAP's agenda aligned to the 'Living our ways' research aims and objectives. These aims and objectives were set by the First Peoples disability community in the design of the research. The AAP contributes its governance expertise and advice to ensure the highest standard of academic rigour is met and that the research aims are achievable. In its advisory capacity, the AAP provides support and advice in decisions about participant recruitment, data analysis, and the ethical conduct of the research, including direct participation in interactions with Aboriginal Research Ethics Committees.

Relationship strategies with the Australian Bureau of Statistics: A model of constructive engagement between Community and Government

The absence of disaggregated data has been a long-standing impediment to understanding the specific needs of Aboriginal and Torres Strait Islander people with disability. At the commencement of the project, even the number of Aboriginal and Torres Strait Islander people with severe and profound disability was contested, due to the lack of direct access to the data and rigour in estimation practices.

The First Peoples Disability Network recognised access to disaggregated Aboriginal and Torres Strait Islander disability data as a driver of social change and prioritised a strategic partnership with the ABS. This provided the third angle to the triangular model of research co-production referred to above. A strategic partnership for research was a natural extension of the long-standing interactions that First Peoples Disability Network had as contributors to expert advisory groups convened by the ABS, with the lead researcher personally appointed to Expert Advisory Groups for the NATSISS, the SDAC, and National Aboriginal and Torres Strait Islander Health Survey.





The aim of the partnership was to complete a narrative on the profile of disability in Aboriginal and Torres Strait Islander communities as told through the data. This required a mixed methods approach to the research in which:

- The qualitative data generated through the interviews contextualises the quantitative data, and reciprocally;
- The independence of the quantitative dataset provides scope to the issues raised by participants of the research in the qualitative interviews.

The source of the quantitative data used is the NATSISS and SDAC. Whilst the data for the two survey instruments is publicly available, the technical expertise provided by the ABS assisted the disaggregation of Aboriginal and Torres Strait Islander disability specific data from the responsive whole of population datasets. Ongoing advice and review also ensured that the community-based researchers at First Peoples Disability Network interpreted the data with integrity to the collection methodologies and limitations of both surveys.

A COMMUNITY-DIRECTED RESEARCH METHODOLOGY

The relational approach between a government data collection agency and a community organisation has produced data driven analysis on the social inequalities experienced by Aboriginal and Torres Strait Islander people with disability with unprecedented scope. The first output of the strategic partnership was the publication of an occasional paper entitled Social and Economic Wellbeing of Aboriginal and Torres Strait Islander People with Disability⁶⁸ in which the ABS acknowledged its partnership with and the contribution of First Peoples Disability Network. The presentation of narrative and the numbers side by side in this report builds on this collaborative approach.

There are several attributes to the strategic partnership which have contributed to its success as a model of cooperation between a community organisation and a government agency:

- It is fundamentally a relational approach in which goodwill and respect accumulates over continued engagement and interaction.
- Both share a vision for social change. The First Peoples Disability Network has an expressed desire to use data and evidence to improve the social circumstance of Aboriginal and Torres Strait Islander people with disability, and the ABS has an expressed desire to get data into the hands of people who strive to make a difference.
- The strategic relationship is a 'whole of organisation' approach with breadth of support in each organisation and access to structures within the ABS for the collection of Aboriginal and Torres Strait Islander data and disability data.
- The whole of organisation commitment is reinforced by strong interpersonal relationships

between a number of staff at First Peoples Disability Network and within the ABS, providing continuity.

- Each organisation acknowledged the other's particular expertise. The ABS is recognised for its expertise on the access and interpretation of quantitative data through its statistical collection. First Peoples Disability Network is recognised for its expertise on the access and interpretation of qualitative data through the collection of testimony from community. This has facilitated privileged access to the other's data and expertise.
- Once established the goodwill allowed for trust-building discussion. It is a notional concept of 'safe space' in which any issues around the access and interpretation of sensitive data could be addressed and worked through with mutual respect.
- The strategic relationship extended beyond initial aspirations to 'listen to the voices of Aboriginal people' because it provides a tangible contribution to a project that has been prioritised by community.
- There is a common language to communicate, which in this partnership is the language of data.

68 Australian Bureau of Statistics (2017) Social and Economic Wellbeing of Aboriginal and Torres Strait Islander people with disability. National Aboriginal and Torres Strait Islander Social Survey 2014–2015. (Feature article) Rel. 4714.0.

A COMMUNITY-DIRECTED RESEARCH METHODOLOGY

3.4 A PLAYBOOK FOR COMMUNITY DIRECTED RESEARCH

STAGE 1: PREPARATION AND CONCEPT DEVELOPMENT (January 2015–December 2015)

Research activity: Developed the concept of a community-directed approach to disability research and the core principles for its implementation

Reason for the approach chosen

The essential purpose of the research was to elevate and promote the voices of Aboriginal and Torres Strait Islander people with disability, but it needed in principle support. As an innovation in social impact research, there was no precedent to guide how this would be done. Hence there needed to be a firm set of principles which would direct how the research would progress which kept integrity with its intent.

How this was implemented in the research

The FPDN Board of directors formally endorsed a community-directed approach to research as part of its Strategic Directions in December 2015. This positioned FPDN as the lead organisation for the research activity, guided by a set of principles through which the community-directed model of research would be conducted.

Research activity: Established a research team to reflect the community directed model of co-production.

Reason for the approach chosen

FPDN's core strength is its connection and access to the disability community, but it required access to technical expertise on academic research and technical advice of statistical data. FPDN had long-standing but informal relationships with key Aboriginal and disability researchers, and the ABS. This research applied a project focus to these relationships.

How this was implemented in the research

A research team was established comprising:

- **Community:** represented by FPDN, who designated the researcher from its community to lead the research.
- **Research:** represented by an Academic Advisory Panel comprising leading Aboriginal and disability researchers to provide research and academic oversight to the project.
- **Policy:** Represented in this model by the ABS, who facilitated access and provided technical advice on statistical data.

Research activity: Secure the resources to undertake the project

Reason for the approach chosen

The research reflected a bold ambition for change coming from the First Peoples disability community. It needed a sufficiently secure base of core funding to continue.

How this was implemented in the research

Core two-year funding was received from the Australian Government's National Disability Research Development Scheme. The process of securing funding commenced in January 2015 with a formal Expression of Interest, proceeded through a Request for Tender stage, and was finalised with the signing of a funding agreement in November 2015.

Core funding was complemented by expertise-in-kind support from its academic partners at UTS and UNSW, and the ABS.

The lead researcher also received additional support from the Lowitja Institute as part of a PhD project related to this research to enable him to undertake knowledge translation activities that were not funded through the core funding.

Research activity: A data strategy was developed utilising a mixed methods approach

Reason for the approach chosen

The research foresaw that the impact of the participants' testimony might be diminished on the basis of an insufficient sample size.

Therefore it was recognised that qualitative data would be required to contextualise the quantitative data that affects Aboriginal and Torres Strait Islander people, to complement the personal insights garnered through interviews.

How this was implemented in the research

A data strategy was developed to obtain:

- **Quantitative data:** Through the NATSISS and the SDAC
 - **Qualitative data:** generated through interviews with Aboriginal and Strait Islander people with disability.
- Field notes of the interview process were also kept by the lead researcher as an interpretive guide during later stage analysis.

STAGE 2: PROJECT DESIGN (July 2015–March 2016)

Research activity: Developed a relationship strategy with the ABS to facilitate access to qualitative data and obtain technical advice on its interpretation.

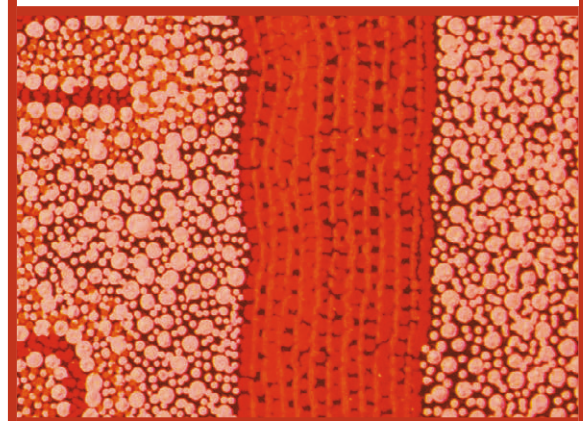
Reason for the approach chosen

As Aboriginal and Torres Strait Islander disability data was available but fragmented across various data sets, it was determined that the most qualified agency to assist in sourcing the data and accurately interpreting it was the source agency that collected it.

How this was implemented in the research

The lead researcher was invited by the ABS to join Expert Advisory Groups for the NATSISS and the SDAC. This facilitated access to both data as well as technical experts on the various datasets within the ABS.

In addition to participating on Expert Advisory Groups, the research and the ABS met on numerous occasions during the course of the project.



Research activity: Community consent was obtained from local Aboriginal communities in which the qualitative component of the research would be conducted.

Reason for the approach chosen

A convenience sampling method was used for the selection of research sites and individual participants due to the exploratory nature of the research combined with the limited resources available relative to its scope and purpose.

Community consent started with the lead researcher's existing community network, then expanded to FPDN's established network, then, as the research built a track record with community, expanded again into FPDN's emerging networks.

Within the convenience sampling approach, the research nonetheless aimed to obtain participation from a cross section of metropolitan, regional and remote areas. This was needed to enable some exploration of the comparative experiences of Aboriginal and Torres Strait Islander people living in urban, regional and remote locations.

How this was implemented in the research

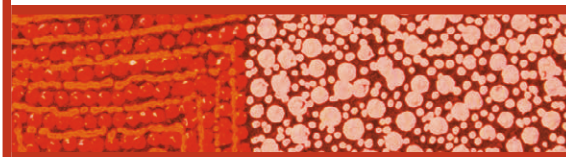
The community consent pathway was leveraged from FPDN's existing community engagement activities, in that the research was considered an extension of the rights and disability awareness activities conducted in Aboriginal communities.

Community consent- Deadly Deaf Mob (Commencing site): The first cohort providing their consent to participate was the Deadly Deaf Mob, a social network of Deaf Aboriginal people. This came about when one of the conveners of the Deadly Deaf Mob learned about the research, and asked the lead researcher who is also a Deaf Aboriginal man whether the Deadly Deaf Mob could participate.

Community Consent - Disability community NSW: Community consent was then secured through members of the Aboriginal Disability Network (NSW).

Community consent- Barkly Shire, including Tennant Creek and Utopia: The research then followed the community engagement activities of FPDN into the Barkly Shire in the Northern Territory. Noting that the research was a non-sequential, staggered process, the community consent in the Barkly Shire was happening concurrently with interviews in NSW.

Community consent - Deadly Deaf Mob (second site): The convener of the Deadly Deaf Mob subsequently invited the lead researchers to continue interviews with the Deaf community at a second research site. During the course of the project, the process of obtaining community consent commenced in Northern Australia and regional South Australia, but these were discontinued due to the resource constraints of both the project and the community organisations approached to facilitate access to research sites.



Research activity: Create an interview style and protocol that was based upon deep listening and sensitive to trauma.

Reason for the approach chosen

The interview protocol was designed to create a 'safe space' in which Aboriginal and Torres Strait Islander people with disability could give their testimony on their terms and in their own time.

How this was implemented in the research

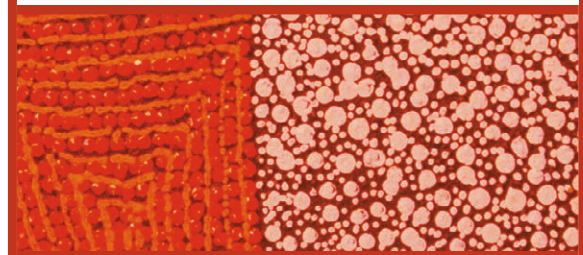
Interview style: An unstructured interview technique was utilised to enable participants to tell their story on their terms and at their own pace.

Discussion prompts: As opposed to questions, five discussion prompts were woven into the interview to facilitate the telling of testimony. It commenced by asking a general question: "What is your story?", designed to situate the participant at the centre of the interview from the outset, rather than the researcher. It then proceeded to prompt discussion of barriers, strengths and sources of personal support. It then concludes with a question around what matters to them in regard to their future.

Discussion prompts:

1. What is your story?
2. What barriers and obstacles have you faced in getting the help you need?
3. Who do you turn to when you need help?
4. What are some of the good things you have been able to do?
5. What matters to you regarding your future?

The discussion prompts did not contain any reference to 'disability'. Other than introducing the researcher as from the First Peoples Disability Network, which set the general domain for discussion, references to 'disability' were otherwise avoided unless introduced into the discussion by the participant. This was consistent with one of the aims of the study that was to understand how Aboriginal and Torres Strait Islander people with disability intuitively identify with their disability.



Research activity: A study protocol around the collection of testimonial data

Reason for the approach chosen

The study protocol maintained the aim of promoting the voices of Aboriginal and Torres Strait Islander people living with disability. International standards for research quality and ethical protocols for research in Aboriginal and Torres Strait Islander communities were used as a minimum standard point, and democratised to facilitate the inclusion of First Peoples with disability.

The use of the term 'inclusion criteria' to determine participation is a choice to reflect the participatory aims of the research, and to distinguish it from a 'selection criteria' which may be taken as limiting.

How this was implemented in the research

An 'Inclusion criteria': The inclusion criteria for participant was:

- Self-identification as an Aboriginal and/or Torres Strait Islander person; and
- Self-identification as a person living with disability.

As the research was introduced as an extension of FPDN's community engagement activities, the inclusion criteria in practice became self-identification with the First Peoples disability community.

Consistent with the aim of promoting the voices of Aboriginal and Torres Strait Islander people living with disability, service providers and other people operating in a professional capacity were not considered within the inclusion criteria (although on occasions, some were present during the interviews in a role of support person to the participant).

Participant information and consent form: A two-page (one single sheet, double sided) was drafted from scratch in the personal presence of an Aboriginal person with disability as a representative of the participant group, and separately reviewed by another Aboriginal person with disability. The final version of the participant's information and consent form incorporated the following advice provided during the drafting:

They found comfort in knowing the research was being led by an Aboriginal non-government organisation, rather than Government or a University, although this was not an immediate realisation. This was reinforced by including FPDN's logo on the form.

- They wanted an iron-clad assurance that their personal story would not be handed to a Government agency.
- They found lengthy, technically worded consent forms intimidating, and would be reluctant to sign them.

Data Management: The research conformed to ethical guidelines for secure data management and the presentation of the participants' confidentiality. This included the identification of raw testimony during its transcription into text form, and secure storage of data in electronic format.

Safety protocols: Protocols were established to encourage awareness of signs that the participant was affected by trauma. These protocols included:

- stopping the interview if the safety of the participant was of concern, and
- making sure a support person was available at all times.



STAGE 3: ETHICS (January 2016–June 2017)

Research activity: Ethics approval was sought and obtained from the Aboriginal Health Research Ethics communities with jurisdiction over each research site.

Reason for the approach chosen

As an Aboriginal community controlled organisation, FPDN respects and promotes the role of the Aboriginal Research Ethics Committees as an independent barometer of ethical conduct in Aboriginal communities. An iterative process which enabled research to commence in sites where community consent was readily obtainable, whilst allowing more time to obtain community consent in other sites.

How this was implemented in the research
As with the community consent process, the ethics approval was variable, reflecting slightly different approaches and requirements from each of the Aboriginal Health Research Ethics Committees in each of the regions where the research was conducted:

- The New South Wales Aboriginal Health and Medical Research Council (Approved April 2016, with annual renewal). This was prioritised as FPDN's domicile state, and where the community consent process was most advanced.
- Central Australian Human Research Ethics Committee (Approved April 2017, with end of year renewal): This covered the Barkly region in the Northern Territory and the Elders forum in Alice Springs
- South Australian Aboriginal Health Research Ethics Committee (Approved June 2017):

A separate ethics process also commenced for potential research sites in the northern regions of Northern Territory. However, this process coincided with the timing of the Royal Commission into the Protection and Detention of Children, and sensitive to the resource constraints that would be placed upon supporting community controlled organisations at this time, it was decided not to proceed.

Research activity: Meet with Elders and FPDN Board for their endorsement to proceed with the research.

Reason for the approach chosen

In addition to obtaining ethics approval from the relevant people the research obtained 'spiritual assent' from Elders of the First People disability community and the FPDN Board before proceeding with any interviews.

How this was implemented in the research

Assent of Elders: The research was presented to Elders from the First Peoples disability community and FPDN's Board in March 2016, who endorsed the research approach and recommended that the research begin.

STAGE 4: DATA COLLECTION

Research activity: Secure access to disaggregated statistical data on disability in Aboriginal and Torres Strait Islander communities.

Reason for the approach chosen

Statistical data was needed to:

Scope the population-wide prevalence and profile of disability in Aboriginal and Torres Strait Islander communities, and

- Interrogate intersectionality as a foundational assumption in the social, health and wellbeing outcomes experienced by Aboriginal and Torres Strait Islander people with disability compared to others in the population.
- As there was no single data source containing a discrete population, it was anticipated that the statistical analysis would require polyangulation of data across multiple data sets.

How this was implemented in the research

Prevalence and Profile: Statistical data on the prevalence and profile of disability amongst the Aboriginal and Torres Strait Islander population was sourced from;

- The NATSISS, disaggregated by people self-identifying as having disability;
- The SDAC, disaggregated by people who self-identify as Aboriginal and / or Torres Strait Islander.

This data is reported in Chapter 4.

Social, health and wellbeing inequality: Statistical data which compared the social, health and wellbeing outcomes of Aboriginal and Torres Strait Islander people with severe and profound disability to Aboriginal and Torres Strait Islander people without disability was sourced exclusively from the NATSISS. This data is reported in:

- Chapter 6 with respect to social health and wellbeing inquiries;
- Chapter 8 in respect to trauma and mental health; and
- Chapter 9 in respect to cultural participation.

All statistical data sourced from the ABS was collected by the ABS independently of this research project and is available on their public website. ABS staff from the National Centre for Aboriginal and Torres Strait Islander Statistics and Disability, Ageing and Carers Section provided technical advice and assistance on the extraction of data from publically available data tables, and on the correct interpretation of the data with reference to the limitations on the survey instruments used to collect the data.

Research activity: A 'rock-up recruitment' approach to facilitate participation that worked within the communication channels preferred within each research site.

Reason for the approach chosen

To bridge the communication gap in which the language of research discourse was seen as alienating within community, the researcher coined the phrase 'rock-up recruitment' to convey a flexible, non-threatening manner in which the researcher would 'rock up' to community, sit with the people, understand and then utilise the community communication structures to communicate the purposes and objectives of the research. The objective was to position the researcher within communities as available to take people's testimony, but not so obtrusive as to be seen as pressuring people to participate.

How this was implemented in the research

'Rock-up recruitment': The flexible recruitment approach generated participation through a variety of means including:

- direct referrals of participants from community members;
- unsolicited request by participants who had heard about the research through the Koori grapevine (word of mouth);
- promotion on the Deadly Deaf Mob social media sites;
- guest speaking spots on community radio;
- community barbecues;
- an invitation by a Men's group; and
- attendance at Aboriginal gatherings and community meetings to which the researcher was invited.

Research activity: Conducted interviews with participants to collect testimonial data

Reason for the approach chosen

The interview schedule was staggered, which was a consequence of the staggering of the community consent and ethics reviews processes.

There was a secondary purpose of staggering in that it enabled testimonial data to be collected in FPDN's home state of NSW whilst community consent and ethical review was taking place in sites outside NSW.

This strategy generated some testimonial data as runs on the board for a community directed model of research as safeguard in the event that resources were suddenly withdrawn for whatever reason.

Interviews continued until the qualitative data reached saturation point using the purposive convenience sampling techniques.

How this was implemented in the research

All interviews were conducted by the lead researcher. This maintained a consistency in the style of interview throughout.

All testimonies were given verbally and digitally recorded. Interviews with the Deadly Deaf Mob were conducted with the assistance of an Auslan interpreter, in which the verbal response from the interpreter was recorded. As an additional precaution for the Deadly Deaf Mob interviews conducted in Auslan, the signed responses of the participant were also video recorded in case they were needed for verification during the transcription of the interview, although this proved to be unnecessary.

The interviews generated a participant profile shown in Table 3.3.1.

Research activity: Elders Forum

Reason for the approach chosen

The purpose of the Elders forum was twofold:

- First, it provided an opportunity for Elders to speak on their own behalf on their views of how disability is seen within their communities through recorded testimony.
- Second, it provided their assent to how the research was conducted during the interviews, before it proceeded to analysis and reporting

How this was implemented in the research

There were 11 participants at the Elders Forum, which was conducted at Alice Springs, Northern Territory in September 2017.

STAGE 5: DATA MANAGEMENT

Research activity: Testimonial data was de-identified and securely stored

Reason for the approach chosen

Data management practices for the de-identification of raw text and storage of data were put in place to comply with best practice ethical standards for protecting participants' confidentiality and the secure storage data.

How this was implemented in the research

De-identification: Once an interview was completed, the audio recording was transcribed verbatim into text form. The lead researcher then screened the raw text and removed any identifying attributes including references to names (whilst retaining a gender reference), city or town name (whilst retaining a reference to urban, regional or remote setting) or specific names of organisations that provided them with support. The exception to this rule was the retention of references to Aboriginal nations, as it is improbable that a person could be identified by that attribute alone, and it is an important data in understanding how Aboriginal and Torres Strait Islander people choose to identify themselves.

An additional screening for attributes or quotes that could potentially identify participants was also conducted during the writing and review stages of the draft (see stage 7).

Storage: The de-identified narrative texts were then stored on a secure server at First Peoples Disability Network's office, after which the audio and video recordings were permanently destroyed.

STAGE 6: ANALYSIS

Research activity: De-identified testimonial data was imported into NVivo software for a two-staged categorical and thematic analysis.

Reason for the approach chosen

The use of Nvivo software enabled an iterative analysis of the testimonial data, involving:

- a categorical screening of all testimonial data
- a deeper thematic analysis; and
- capacity for key word searching

How this was implemented in the research

Categorical screening: As an initial stage, all de-identified texts were screened by the researcher to identify key themes

Thematic analysis: once key themes were identified, texts relating to a particular theme were collated from all texts for an analysis of key messages and issues.

Research activity: Single testimonies were integrated with field notes to generate 'yarning pieces'

Reason for the approach chosen

During the writing of the analysis using statistical and verbatim quotes from the testimonial data, it was clear that those two types of data alone could not fully convey a comprehensive narrative.

How this was implemented in the research

Creation of yarning pieces: At the conclusion of the categorical and thematic analysis, the researcher revisited the field notes from some of the interviews, which when combined with verbatim quotes from testimony, morphed into the yarning pieces.

STAGE 7: COMMUNITY AND ACADEMIC REVIEW

Research activity: The research was subjected to a multi-layered process of community and academic review prior to its publication.

Reason for the approach chosen

A review process by both the First Peoples disability community and leading academics was built into the project governance, so the end product satisfied the dual requirements of being community and culturally compatible research, and of high academic quality.

In addition to internally established review processes, a final draft of the research was submitted to the Aboriginal Health and Medical Research Council in compliance with the conditions of ethics approval; and the providers of research funding, in compliance with the research funding agreement.

How this was implemented in the research

Community and academic review: Prior to final publication, the research has been reviewed by:

- Representatives from the First Peoples disability community, as affirmed by a resolution of the Board of Directors at FPDN;
- The Academic Advisory Panel;
- Representatives of the ABS (exclusively relating to the technical accuracy of the presentation of statistical data);
- The Aboriginal Health and Medical Research Council, as affirmed by their formal approval to publish.
- The Research Data Working Group as administrators of the National Disability Development Research Scheme through which research funding was provided.

STAGE 8: RESEARCH TRANSLATION**Real time translation****Reason for the approach chosen**

As the researcher was a first-hand witness to acute inequality and unnecessary suffering, there was a duty of care to draw attention to issues as they arose, rather than wait until the completion of the research project. The real-time translation also helped build the research as a rights-based movement, which in turn encouraged greater participation of Aboriginal and Torres Strait Islander people, supporting a key deliverable of this project.

How this was implemented in the research

Real-time translation into policy advice: The findings of the research were incrementally infused into the policy advice and advocacy work of the lead researcher and FPDN in meeting their obligations as systemic advocates on behalf of community. This advice was unfunded and provided on call to:

- Community members,
- Aboriginal and Torres Strait Islander organisations,
- University and research institutions, and
- A number of Government agencies at the Commonwealth, State and Territory levels.
- Working groups and roundtables on the Closing the Gap framework, the Indigenous Advancement Strategy, National Disability Strategy and a number of state-based programs.

Create a publication which can act as a resource for planning, training and teaching**Reason for the approach chosen**

There is need for a comprehensive resource to support community organisations seeking to set up services and train a workforce to meet the needs of Aboriginal and Torres Strait Islander people with disability.

The publication needs to be able to reach a broad range of people. It needs to be in a style and format accessible to those in the Aboriginal and Torres Strait Islander sector who want to know more about the disability sector who want to know more about Aboriginal and Torres Strait Islander people.

How this was implemented in the research

'Culture is inclusion' is the first publication from this research.

Table 3.3.1 Participant Profile

Total number of participants	
47	
Total Number of interviews	
41	
Average time per interview	
31.01 minutes	
Participants by gender	
Female	25 (53.2%)
Male	22 (46.8%)
Participants by cohort	
Deadly Deaf Mob (two sites)	11
Urban – NSW	11
Non-urban – NSW (regional and remote)	15
Non-urban – Northern Territory	10
Elders Forum	
Number of Participants	11
Areas represented	NSW
	Remote Northern Territory
	Barkly Shire, Northern Territory
	Torres Strait Islands
	Queensland
	South Australia
	North-west Australia



One of the highlights of the day was when a number of participants gathered around an Aboriginal map of Australia pointing and finger-spelling which Aboriginal nation they were from.

Case Cohort: Deadly Deaf Mob

The Deadly Deaf Mob is the name of a social network of Deaf and hearing impaired Aboriginal and Torres Strait Islander people. FDPN and its lead researcher have an extensive history of supporting the Deadly Deaf Mob, who reciprocally view this research as an opportunity to document their experiences in a research context – a form of participation they have not previously had the opportunity to be involved in.

The Deadly Deaf Mob research project was initiated by a cohort of Deaf Aboriginal people. In February 2015, the lead researcher of the 'living our ways' project was invited by three members of the Deaf Aboriginal community, connected through social media as 'the Deadly Deaf Mob' to assist them in preparing a grant application under the 'My Choice Matters' grant scheme. The funding application was being prepared under each of the individual's names, which would be consolidated to convene a gathering of Deaf and hearing impaired Aboriginal people. The grant application was successful, and the Deadly Deaf Mob convened a gathering in Western Sydney from 30 September to 1 October 2015. The conveners then invited the lead researcher to prepare a video on the research which was shown at the Conference, and this was later placed on the Deadly Deaf Mob Facebook page. One of the conveners of the Deadly Deaf Mob provided a letter of support for the purposes of obtaining ethic approval.

The first round of interviews with the Deadly Deaf Mob were conducted at FDPN's Head Office in Redfern NSW on 16 September 2016. The interviews were conducted in Auslan, and a number of the participants stayed after their interview to keep yarning as a group. One of the highlights of the day was when a number of participants gathered around an Aboriginal map of Australia pointing and finger-spelling which Aboriginal nation they were from.

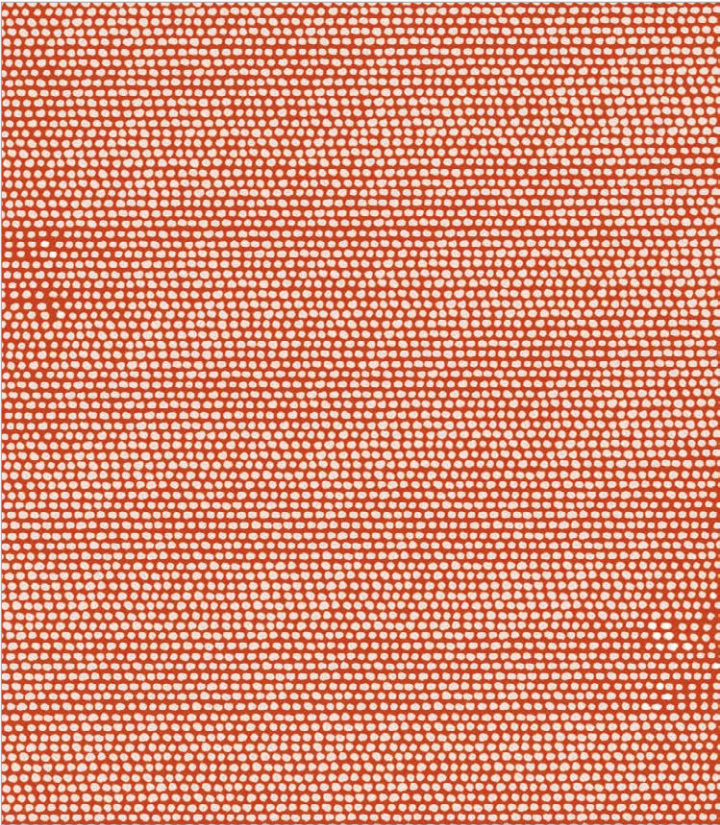
After the Redfern interviews, a few members of the Deadly Deaf Mob moved interstate. They spoke positively of their experience with others from the Deaf community in their area, which resulted in an invitation to visit and conduct some further interviews. Again, these interviews were conducted in Auslan, but with a difference. A last-minute withdrawal of the interpreter who had been booked to attend the second day meant that arrangements were made for two interpreters who were based interstate to do the interpretation via Skype using the researcher's laptop.⁶⁹



69 Photo taken with express permission.



4
PREVALENCE AND
PROFILE OF DISABILITY
AMONGST THE
ABORIGINAL AND
TORRES STRAIT
ISLANDER POPULATION



KEY FINDINGS:

- Prevalence and profile:** Disability in Aboriginal and Torres Strait Islander communities is twice as prevalent, more complex in terms of co-occurring disabilities, and compressed within a shorter life expectancy compared to other Australians.
- Severe and profound disability:** The number of Aboriginal and Torres Strait Islander people with severe and profound disability, using the best available data, is estimated to exceed 60,000 people.
- Disability diagnoses:** The high reporting of unspecified disability indicates that disability diagnoses are either not available or not known by the individuals, which can act as a barrier to them accessing adequate support for their disability.
- Overshadowing of co-occurring disabilities:** For people who experience multiple disabilities, a focus on supporting just one disability may overshadow the adequate recognition and support for other co-occurring disabilities.
- Gender and remoteness:** There are variations in the prevalence of severe and profound disability within Aboriginal and Torres Strait Islander communities when prevalence data is disaggregated further by gender and remoteness.

4.1 DATA SOURCES AND LIMITATIONS IN ESTIMATING THE PREVALENCE AND PROFILE OF DISABILITY IN ABORIGINAL AND TORRES STRAIT ISLANDER COMMUNITIES

There is no focussed population-based instrument to capture prevalence, profile and outcomes for Aboriginal and Torres Strait Islander people with disability.

Two primary sources of population data collected by the Australian Bureau of Statistics which allow a depth of analysis of disability amongst Aboriginal and Torres Strait Islander people are:

- i. The NATSISS, a sample survey of Aboriginal and Torres Strait Islander people which includes disability questions; and
- ii. The SDAC, which is a sample survey of people with disability and their carers which includes an identifying question for Aboriginal and Torres Strait Islander people who complete the survey.

There is also the National Aboriginal and Torres Strait Islander Health Survey (NATSIHS)⁷⁰ which collects data on disability. However, the NATSISS is more appropriate for exploring some of the social components of Aboriginal and Torres Strait Islander people's experiences with disability that are relevant to this project and its qualitative findings. The Australian Census does not expressly collect data on disability, but does so indirectly through a general question on a person's 'need for assistance'. Unlike the NATSISS and the SDAC, both of which collect data from a sample of their target populations, the Census aims to collect data for the entire Australian population.

Whilst both surveys include Aboriginal and Torres Strait Islander disability, subtle differences in the methodological approach used make it difficult to make a direct reconciliation, a point that is acknowledged by the ABS.⁷¹ Both surveys generate data that provides useful insights, yet each survey has relative strengths and limitations as a scientific tool compared to the other.⁷²

A comparison of the methodologies and their structural limitations is outlined in Table 4.3.1 as an aid to interpreting the data. Notably, both the NATSISS and the SDAC collect data from Aboriginal and Torres Strait Islander people with disability living in private dwellings. In other words, neither survey collects data on people living in institutional settings, such as prisons or in out of home care. Neither collects data on people who are currently homeless, or 'living rough'. There is otherwise of dearth of data to estimate the homelessness rate of Aboriginal and Torres Strait Islander people with cognitive impairment.⁷³ This population cohort represent some of the most isolated and excluded people in society, and due to the nature of their social isolation, accurate data on the disability prevalence amongst this group does not exist. In an absence of data, the understanding of intersectionality makes it reasonable to assume that the prevalence of disability amongst Aboriginal

and Torres Strait Islander people not living in private dwellings is significantly higher than those living in private dwellings.

In addition to limitations due to the design features in each survey, there are underlying cultural factors to consider when interpreting the data. Chapter 1 of this report, 'No word for disability', highlighted a belief system of Aboriginal and Torres Strait Islander people in which disability is normalised, and in which disability discourses and diagnostic terminology are not always understood or accepted, and hence there is a dispensation to under-disclose disability on cultural grounds. Similarly, if Aboriginal and Torres Strait Islander people do not trust the way data is used, or fear that they may be discriminated against by disclosing a disability, then this may also lead to an Aboriginal and Torres Strait Islander person not disclosing disability. Taken together, the design, cultural and social limitations in collecting data on disability from Aboriginal and Torres Strait Islander people means that, whilst data is improving, under-reporting of disability in Aboriginal and Torres Strait Islander communities in the official statistics is likely.



71 See 'Technical note.' Australian Bureau of Statistics (2017) Aboriginal and Torres Strait Islander People with a Disability, (SDAC) 2012. Rel. 4433.0.55.005.

72 Biddle, N., Al-Yama, F., Gourley, M., Gray, M., Bray, J.R., Brady, B., Pham, L.A., Williams, E., & Montaigne, M. (2012). Indigenous Australians and the National Disability Insurance Scheme: The extent and nature of disability, measurement issues and service delivery models. Commonwealth of Australia: Canberra. At p.34.

73 Townsend C., White P., Cullen J., Wright C., & Zeeman, H. (2017). 'Making every Australian count: Challenges for the NDIS and the equal inclusion of homeless Aboriginal and Torres Strait Islander Peoples with neurocognitive disability', Australian Health Review, Mar 30.

70 Australian Bureau of Statistics (2013) Australian Aboriginal and Torres Strait Islander Health Survey: First Results, Australia, 2012-13 Rel. 4727.0.55.001.



According to the NATSISS data, 45% of Aboriginal and Torres Strait Islander people report living with a disability or long term health condition, which compares to 23% of Aboriginal and Torres Strait Islander people reporting living with a disability in the SDAC.

4.2 NUMBER OF ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE WITH DISABILITY

Differences emerge between the NATSISS and SDAC in estimating the prevalence of disability amongst Aboriginal and Torres Strait Islander people. Using the NATSISS data, 45% of Aboriginal and Torres Strait Islander people report living with a disability or long term health condition, which compares to 23% of Aboriginal and Torres Strait Islander people reporting living with a disability in the SDAC. The principal point of difference between the two surveys is the recording of 'long term health conditions' in the NATSISS, but not in the SDAC.

However, the differences in the scope of statistical data collected does not in itself explain the discrepancy between the two surveys, and there is still an amount of unexplained difference. Possible factors in the discrepancy in the disclosure of disability by Aboriginal and Torres Strait Islander people in the survey may include the way the questions are framed, with respect to the cultural and systemic factors affecting how an Aboriginal or Torres Strait Islander person might interpret the question; and the level of involvement that Aboriginal and Torres Strait Islander people had in collecting the data.



4.3 PREVALENCE OF SEVERE AND PROFOUND DISABILITY

Importance of statistical data on severe and profound disability

Both the NATSISS and SDAC enable further analysis on the prevalence of disability by the severity of functional impairment that is self-assessed by the respondents to the surveys. People with severe and profound disability are included in the total population of Aboriginal and Torres Strait Islander people with disability. The rationale for further disaggregating disability data by severity recognises that disability exists on a spectrum, and how severity of disability can contribute to a higher determination of need.

Quantifying the prevalence of severe and profound disability among Aboriginal and Torres Strait Islander people is critical to modelling the support requirements to meet the need.

The number of Aboriginal and Torres Strait Islander people with severe and profound disability has particular relevance to the implementation of the National Disability Insurance Scheme (NDIS) in Aboriginal and Torres Strait Islander communities. The NDIS provides support packages to people with a severe and profound disability that meet the Scheme's disability requirements⁷⁴ including, but not limited to:

- Having a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments, or to one or more impairments attributable to a psychiatric condition;⁷⁵
- is, or is likely to be, permanent;⁷⁶
- results in a substantially reduced functional capacity to undertake, or psychosocial functioning across a number or areas.⁷⁷

⁷⁴ Commonwealth of Australia (2013) National Disability Insurance Act: Section 24

⁷⁵ Ibid, (section 24(1)(a))

⁷⁶ Ibid, (section 24(1)(b))

⁷⁷ Ibid, (section 24(1)(c))

Whilst the NDIS eligibility criteria does not expressly reference 'severe and profound' in relation to the disability requirements for accessing a support package, estimates of Aboriginal and Torres Strait Islander severe and profound disability using the ABS datasets serve as an independent population-based measure from which to model access to the NDIS by Aboriginal and Torres Strait Islander people.

As highlighted by the data presented in the following chapters, Aboriginal and Torres Strait Islander people with severe and profound disability have unmet needs for support across a range of sectors which is over and above their access to the NDIS. An emergent workforce of Aboriginal and Torres Strait Islander disability professionals will require improved data which better describes the unique and complex support requirements of Aboriginal and Torres Strait Islander people with disability, both in number and its nature.

Accurately estimating the number of Aboriginal and Torres Strait Islander people with severe and profound disability is critical to defining the size of the sector and the market for support services, from which further modelling can be built.

Estimates on the prevalence of severe and profound disability amongst Aboriginal and Torres Strait Islander people

There is convergence on the estimated rate of severe and profound disability amongst the Aboriginal and Torres Strait Islander population that is recorded through the NATSISS and the SDAC. The NATSISS found that 7.7% of Aboriginal and Torres Strait Islander people reported having severe and profound disability. This result compares to a prevalence rate of severe and profound disability of 7.3% of the Aboriginal and Torres Strait Islander population using SDAC data. Using age-adjusted comparators, the SDAC and the NATSISS respectively estimate that the prevalence of disability is between 1.8 and 2.1 times the prevalence rate of severe and profound disability in the non-Indigenous Australian population. These relativities in the prevalence of disability for the Aboriginal and Torres Strait Islander population and non-Indigenous population have been age adjusted by the ABS to consider differences in the age composition of the two populations. This is illustrated by the material differences in the life expectancy between Aboriginal and Torres Strait Islander people and the rest of the Australian population. Aboriginal and Torres Strait Islander men experiencing 10.6 years lower life expectancy compared to other Australian men and Aboriginal and Torres Strait Islander women experiencing 9.5 years lower life expectancy compared to other Australian women⁷⁸. The significance of this is that not only is disability more prevalent amongst Aboriginal and Torres Strait Islander people, the economic burden of disability is compressed into a shorter life.

⁷⁸ Australian Bureau of Statistics (2013) Life Tables for Aboriginal and Torres Strait Islander Australians, 2010–2012. Rel. 3302.0.55.003

In the absence of a focussed census of disability in the Aboriginal and Torres Strait Islander population, extrapolating the prevalence rates of severe and profound disability in the Aboriginal and Torres Strait Islander population estimates provides an expected value on the number of Aboriginal and Torres Strait Islander people with severe and profound disability. The expected value is calculated using the following formula:

$$Ex (S\&P) = a (S\&P) \times Population$$

Where:

- *Ex(S&P) is the expected number of Aboriginal and Torres Strait Islander people with severe and profound disability;*
- *a (S&P) is the estimated prevalence rate (probability) of severe and profound disability; and*
- *'Population' is the estimated Aboriginal and Torres Strait Islander population.*

The estimated Aboriginal and Torres Strait Islander population as at 2018 is 781,091 people. This is sourced from the post-enumeration projections of the Aboriginal and Torres Strait Islander population from the 2011 Census⁷⁹. Population projection from the 2011 Census are used as they include statistical adjustments for an undercount in the number of Aboriginal and Torres Strait Islander people who complete the Census, which is needed to accurately project the Aboriginal and Torres Strait Islander population. This differs from the Aboriginal and Torres Strait Islander population data from the 2016 Census which was released in June 2017, as the 2016 Census data count only records people who have identified as Aboriginal and Torres Strait Islander and completed the census (649,200 people)⁸⁰. The statistical adjustment for an expected undercount in the 2016 Census had not been completed at the time of this report, and as the Census count alone could under-estimate the number of Aboriginal and Torres Strait Islander people with disability by as much as 15% to 20%, it is not used in this estimation.

Based on the current Aboriginal and Torres Strait Islander population estimates, the best available estimate of Aboriginal and Torres Strait Islander people with disability is 60,144 people using the prevalence rate derived from the NATSISS, and 57,019 using the prevalence rate derived from the SDAC.

⁷⁹ Australian Bureau of Statistics (2014) Estimates and Projections, Aboriginal and Torres Strait Islander Australians, 2001 to 2026. Rel. 3258.0.

⁸⁰ Australian Bureau of Statistics (2017) 'Census: Aboriginal and Torres Strait Islander population.' Media Release, 07/5/2017

Table 4.3.1: Estimates of the prevalence of disability amongst Aboriginal and Torres Strait Islander people with disability, comparing the NATSISS to the SDAC.

	NATSISS	SDAC
Scope and methodology		
Date of latest survey data	2014-2015	2015
Survey approach.	Self-reported quantitative sample survey.	Self-reported quantitative sample survey.
Designed to be completed by.	Aboriginal and Torres Strait Islander people.	People with disability and their carers.
Question set used.	The NATSISS uses Short Disability Module which applies the same criteria as the SDAC to identify people with disability and determine their severity of restriction. However, it uses only a short question set and a series of prompt cards to establishes the presence of effects of any long-term health conditions, limitations or restrictions, and then ascertains the extent to which these require the person to be assisted to carry out various core activities.	The SDAC contains over 140 questions designed to identify disability and underlying impairments causing disability. The SDAC includes a set of 39 questions that are designed to exclude people if their need for assistance is not the direct result of disability.
How Aboriginal and Torres Strait Islander disability is identified within the data collection.	Disability questions are included within the survey and asked of people aged 15 years and over ⁴ .	The survey contains an Aboriginal and Torres Strait Islander identifier.
Inclusion criteria for survey respondents.	Aboriginal and Torres Strait Islander people living in private dwellings.	People with disability, ~ all ages living in private households.
Geographical limitations.	Some coverage of remote Aboriginal and Torres Strait Islander communities.	The SDAC does not include those living in very remote and discrete communities.

	NATSISS	SDAC
Data on the prevalence of disability		
Percentage of Aboriginal and Torres Strait Islander population reporting as living with disability and/or long term health condition.	45%	
Percentage of Aboriginal and Torres Strait Islander population reporting as having some disability (without including long term health conditions).		23.9%
Data on the prevalence of severe and profound disability		
Percentage of Aboriginal and Torres Strait Islander population reporting as having severe and profound disability.	7.7%	7.3%
Comparator: Percentage of people reporting as living with severe and profound disability in the Australian population.	4.6%	5.8%
Age adjusted ratio: Likelihood of severe and profound disability occurring in Aboriginal and Torres Strait Islander people compared to other Australians.	2.1 times	1.8 times
Estimated number of people with severe and profound disability when prevalence rate is extrapolated to Aboriginal and Torres Strait Islander population (using 2018 population projections).	60,144	57,019



The most common category of disability reported by Aboriginal and Torres Strait Islander people is physical disability, which includes mobility impairments, experienced by 6.2% of the population.

4.4 PROFILE OF DISABILITY BY DISABILITY TYPE

Table 4.3.1 highlights the prevalence of disability types that have been self-reported by Aboriginal and Torres Strait Islander people through the NATSISS. Restating the limitations of the survey methods, this data presents an indicative profile of disability by type in Aboriginal and Torres Strait Islander communities, from which a number of insights can be drawn for further focussed investigation.

The most common category of disability reported by Aboriginal and Torres Strait Islander people is physical disability, which includes mobility impairments, experienced by 6.2% of the population. The second most commonly reported disability category was sensory impairment, reported by 3.6 % of the population. The sensory category of disability includes sight, hearing and speech impairments. Third on the list of most prevalent disability categories for people with severe and profound disability is psychological disability, reported by 2.5% of the Aboriginal and Torres Strait Islander population. The reported prevalence of severe and profound physiological disability equates to approximately one in three of all Aboriginal and Torres Strait Islander people with severe and profound disability. The effects of trauma generated by multiple exposures to social isolation that accumulate over the life a person who is both Aboriginal and/or Torres Strait Islander and has disability are explored further in Chapter 8.

4.5 UNSPECIFIED DISABILITY AND THE UNAVAILABILITY OF DISABILITY DIAGNOSES

In addition to specific disability categories, 3.6% of the Aboriginal and Torres Strait Islander population have been included in the category 'Other not specified'. To place the size of the 'other' category in context, it is equal to the second highest category of severe and profound disability by type. That people are reporting an unspecified disability indicates that the impact of complex disability is well understood within Aboriginal and Torres Strait Islander communities, even if disability cannot be expressed using diagnostic labels.

The testimony from the research showed that people with disability are not clear on the role that having a specific diagnosis has in being able to access supports for disability. The distinction between 'disability' and 'diagnosis' is not clear to Aboriginal and Torres Strait Islander people within the communications and practices of disability services providers. Having a disability diagnosis is understood to be vital in driving the systems of support for disability, and further, people with disability are concerned that those that need support but do not have a diagnosis will fall through the cracks. This concern is expressed by a support person who attended an interview with one of the participants who did not have a diagnosis for her disability:

"The doctor hasn't given her a diagnosis....They're not even doing the tests. So, I wouldn't know how to, myself, to get the help. You know, to get [her] diagnosed without costing a lot of money"

Accessing a diagnosis is further complicated by living in a remote community, as pointed out by one of the participants, a mother speaking about her long battle to obtain a diagnosis for her daughter who is non-verbal, uses a wheelchair, and has profound disability:

"We was going to [the city, from a remote community] but I had to change because we was down there for about four years, travelling down there, and we been down there and they couldn't tell me what she was diagnosed with. And so, all that time we were back and forward they couldn't find right genes for her. And, so when we went to [a hospital a in a different city] and then we made a big change. So, there was a bit of trouble getting a diagnosis in the start. They just didn't know or they had it wrong. Well, she got all the tests done that many times in [the city] and every time we go back they couldn't find anything. And, they switching her, like, changing medication and so went to [the city] and then she had scan done on her brain and changed her medication and slowed her seizures right down.

[INTERVIEWER]: So, you've got a diagnosis now. Is that right?
Yeah. But, I don't know what [it is] – but I leave it all up to Doctor"



FOR FURTHER RESEARCH:
What modifications are required to the processes of diagnosing and supporting disability, to mitigate the risk of under-disclosure due to cultural and social factors?

4.6 THE OVERSHADOWING OF CO-OCCURRING DISABILITIES

Co-occurring disability refers to a person with disability experiencing more than one disability type. In other words, a person with a disability affecting their mobility may also have a sensory disability such as hearing or vision impairment, and/or have a cognitive disability, and/or a psychological disability.

Amongst Aboriginal and Torres Strait Islander people with severe and profound disability, the rate of co-occurring disability is on average 2.5 disability types per person with disability, as shown in Table 4. This means that every person experiencing one disability type will most likely have at least an additional one or two other disability types.

Co-occurring disability is an important consideration in ensuring that support for people experiencing multiple disability types is adequate. If the focus of support is exclusively based upon a primary presenting disability, there is a risk that it may 'overshadow' the presence of a co-occurring disability. This is a variant of 'diagnostic overshadowing',^{81 82 83} a term used to describe an under-diagnosis of health needs because symptoms are attributed to a person's disability rather than a serious illness, which is discussed further in Chapter 6.6. In this extension to the concept of 'over-shadowing', the comprehensive needs of people with disability are under-diagnosed because a focus on one disability obscures the support requirements for other disabilities. Given the issues that Aboriginal and Torres Strait Islander people face in accessing even a primary disability diagnosis, there is a risk that co-occurring disability will remain invisible in their assessment of need. As such, 'overshadowing' warrants further focussed exploration beyond what could be achieved through this research, with particular attention to the practices of assessing needs by disability specialists and service providers.

- 81 Jones, S., Howard L., and Thornicroft, G. (2008) 'Diagnostic overshadowing': Worse physical health care for people with mental illness.' *Acta Psychiatrica Scandinavica*, 118: 169–171.
 82 Mason, J., and Scior, K. (2004) 'Diagnostic Overshadowing' Amongst Clinicians Working with People with Intellectual Disabilities in the UK.' *Journal of Applied Research in Intellectual Disabilities*, Vol 17.2: 85–90.
 83 Katteri, R. and Bywood P. (2011) 'Primary Health Care for People With Intellectual Disability'. PHCRIS Research Roundup, Issue 17.

FOR FURTHER RESEARCH:

What are the compounding effects of the over-shadowing of co-occurring disability upon the health and wellbeing of people with disability?

How can the risk and detrimental impact of over-shadowing be mitigated through improvements to the diagnostic practices of disability specialists, health care professionals and service providers?

Table 4.6.1: Incidence of disability by type, and rate of co-occurring disability amongst Aboriginal and Torres Strait Islander people with severe and profound disability (NATSISS, 2014–2015)

Disability type (Severe and profound disability)	Numbers (Australia)	% of Aboriginal and Torres Strait Islander population
Physical	27,800	6.2%
Sensory (sight, hearing, speech)	16,100	3.6%
Physiological	11,300	2.5%
Intellectual	11,200	2.5%
Head injury, stroke	3,400	0.8%
Other not specified	16,200	3.6%
Number of disability types per person with severe and profound disability	2.5	

4.7 INTERSECTING GENDER, REMOTENESS AND THE PROVISION OF 'ON-COUNTRY' SUPPORT

The prevalence of disability is higher among Aboriginal and Torres Strait Islander women (47.0% reported living with disability, with 8.4% experiencing severe and profound disability) than Aboriginal and Torres Strait Islander men (42.9% reported living with disability, with 7.1% experiencing severe and profound disability).⁸⁴

There are also differences in the reported prevalence by remoteness. 45.4% of all Aboriginal and Torres Strait Islander people living in non-remote areas (metropolitan and regional) reported having some disability, and 7.8% reported having severe and profound disability. The prevalence of disability in remote areas is comparatively lower, with the prevalence of some disability 44.0% and severe and profound disability 7.5% among Aboriginal and Torres Strait Islander people living in remote locations.

Aboriginal and Torres Strait Islander disability is further disaggregated by gender and remoteness in Table 4.7.1 below:

Table 4.7.1: Prevalence of Aboriginal and Torres Strait Islander disability by gender and remoteness (as a percentage of the total Aboriginal and Torres Strait Islander population), NATSISS 2014–15⁸⁵

By Gender		By Remoteness		Total
Female	Male	Non-remote	Remote	
Living with disability or restrictive long term health condition				
47.00%	42.9%	45.4%	44.0%	45.1
Severe or profound disability:				
8.4%	7.1%	7.8%	7.5%	7.7%

An interesting observation is the relative prevalence when looking at the combined effect of gender and remoteness. Among Aboriginal and Torres Strait Islander women living in remote communities, the reported prevalence of severe and profound disability is 6.1%. The reported prevalence for Aboriginal and Torres Strait Islander men is 9.2%, or 1.5 times the prevalence rate amongst women. However, when looking at the same statistics for non-remote areas, the result is the reversed. The reported prevalence of severe and profound disability among Aboriginal and Torres Strait Islander men living in non-remote areas is 6.4% of that population cohort, where the reported prevalence for Aboriginal and Torres Strait Islander women in non-remote areas is 8.9%, or 1.4 times the prevalence rate amongst men in non-remote areas.

- 84 Australian Bureau of Statistics (2016) NATSISS, Rel 4714. See Table 11.2
 85 Australian Bureau of Statistics (2016) NATSISS, Rel 4714. See Table 12.3 'Health and Disability'

Table 4.7.2: Prevalence of severe and profound disability

Intersecting gender and remoteness (as a percentage of the total Aboriginal and Torres Strait Islander population), NATSISS 2014–2015

	Remote	Non-remote
Female	6.1 %	8.9 %
Male	9.2%	6.4%



4.8 HIERARCHIES IN THE SEGMENTATION OF THE ABORIGINAL AND TORRES STRAIT ISLANDER DISABILITY MARKET

Who gets what they need in a market approach to disability services?

The prevalence of disability detailed in the chapter contests an emerging description of the Aboriginal and Torres Strait Islander disability market as a 'thin market'. The 'thin market' description has emerged from a Productivity Commission report, in the context of its report on National Disability Insurance Scheme (NDIS) Costs (Productivity Commission, 2017),⁸⁶ and is increasingly used to describe the market conditions for Aboriginal and Torres Strait Islander people with disability⁸⁷. The Productivity Commission report does not provide a working definition for what constitutes a 'thin market'. In the jargon of financial markets, where the term originated, a thin market is a market where there are few buying options and low demand, and is characterised by low trading volume, and high volatility.⁸⁸

A 'thin market' analysis and its assumptions cannot be applied to the context of Aboriginal and Torres Strait Islander disability without critical review, as the data on the prevalence of disability show that a number of assumptions inherent in a 'thin market' description do not apply. First, a 'thin market' description appears to conflate issues affecting the delivery of disability services and supports to people living in remote communities with issues affecting the delivery of services to Aboriginal and Torres Strait Islander people as a whole. In breaking down the population prevalence by remoteness, 78.7% of all Aboriginal and Torres Strait Islander people with a disability and restrictive long term health conditions live in non-remote areas, compared to 21.3% who live in remote areas⁸⁹. This profile of disability does not match the assumptions within a 'thin market' analysis.

By equating issues affecting services to Aboriginal and Torres Strait Islander people solely with remoteness, 'thin market' analysis effectively excludes the substantial component of people living in non-remote areas from the view of policy and service design. As outlined in Chapter 1, large swathes of Aboriginal and Torres Strait Islander people who have needed support for their disability have been historically marginalised from accessing the various disability support schemes that have existed in the past. From an economic viewpoint, a market demand curve that draws a straight line from what has occurred in the past as the basis for future demand projections will continue to isolate the 'buyers' that have been hidden from the market due to institutionalised access barriers. From a social viewpoint, a 'thin market' description carries forward into policy the implicit biases which reinforce an historical legacy of unmet demand. In this sense, language matters.

⁸⁶ Productivity Commission (2017) National Disability Insurance Scheme (NDIS) Costs, Study Report, Canberra.

⁸⁷ Productivity Commission report has categorised Aboriginal and Torres Strait Islander people disability supports as a 'thin market', alongside other defined demographic cohorts, including: people who live in outer remote or very remote areas; have complex, specialised or high intensity needs; or very challenging behaviours; are from culturally and linguistically diverse backgrounds; and have acute and immediate need. *Ibid.*, at p. 37.

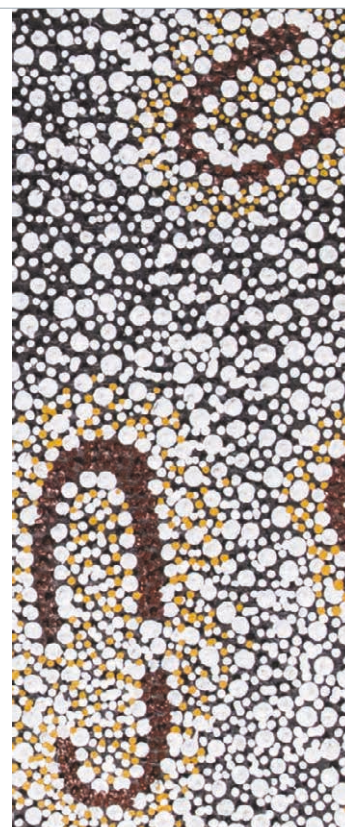
⁸⁸ Rostek, R. and Werekta, M. (2008). 'Thin Markets'. In: Durlauf, S.N. and Lawrence E. Blume L.E. (eds). The New Palgrave Dictionary of Economics. Palgrave Macmillan.

⁸⁹ ABS (2016) NATSISS. See Table 12.1 Table 12.1 'Health and disability, by sex and remoteness'.

The data and analysis highlights the fact that the Aboriginal and Torres Strait Islander disability market is larger than has generally been accepted in public disability policy, and therefore warrants significant investment to build a comprehensive large scale market infrastructure. While the Aboriginal and Torres Strait Islander disability market is made more complex by the geographical disparities of where people live, the main issue that needs to be confronted is the high level of unmet demand for disability support. Responding to the prevalence and profile of Aboriginal and Torres Strait Islander people with disability will require a service model which is realistic to issues in remote service delivery, where there may be a small number of people with disability living in any given remote community, but also characterised by a cultural model of disability support which can benefit all Aboriginal and Torres Strait Islander people with disability regardless of where they live.

FOR FUTURE RESEARCH:

What are the design principles of a core cultural model of disability support that can be applied to benefit all Aboriginal and Torres Strait Islander people with disability regardless of where they live?



Having to leave Country and community to access services is a dilemma faced by many Aboriginal and Torres Strait Islander people, who have to trade off better access to services in a metropolitan location with the detrimental health and wellbeing consequences of leaving Country and community.

PREVALENCE AND PROFILE OF DISABILITY AMONGST THE ABORIGINAL AND TORRES STRAIT ISLANDER POPULATION

The provision of 'On Country' disability support

An interesting interpretation of the gender and remoteness data is that women with severe and profound disability living in remote communities have a greater likelihood of leaving their Country and community and moving to a metropolitan area to access disability support services whilst men in remote communities are more likely to stay in community, as women undertake traditional carer roles that compensate for the limited access to structured disability support services in remote communities.

Furthermore, men who acquire a disability, say through accident or injury, whilst living away from their Country are able to return to their Country, as Aboriginal and Torres Strait Islander women assume carer duties, even if informal and without systemic support. Women, on the other hand, do not benefit from informal carers roles provided by men to the same extent that they provide them to men, and hence they may be forced to leave their communities to access the degree of service required to support their disability. What prevails is an inherent gender inequity in which the burden of compensating for the lack of services of remote communities falls predominantly upon Aboriginal and Torres Strait Islander women, either: in the quantum of care they provide to others; or in being forced to leave their Country when they themselves require access to disability support services.

Having to leave Country and community to access services is a dilemma faced by many Aboriginal and Torres Strait Islander people, who have to trade off better access to services in a metropolitan location with the detrimental health and wellbeing consequences of leaving Country and community. This data shows that if you are also an Aboriginal or Torres Strait Islander woman with disability from a remote community, this dilemma becomes more acute. Whilst this might be intuitively understood by many Aboriginal and Torres Strait Islander people in remote communities, the significance of the data is that the gravity of the inequality experienced by Aboriginal

women can be acknowledged, quantitatively measured, and ultimately addressed.

There is a positive, however that Aboriginal and Torres Strait Islander men choose to return to Country and receive informal care through their community rather than access systemically supported services in non-remote areas. This points to the inherent competitive strength of culturally competent community care, even if it is not fostered through structured support. The strengths of Aboriginal and Torres Strait Islander community care should be explored further through sector development and research.

In terms of building upon a conceptual model that explains the compounding inequalities in health and social outcomes experienced by people who are both Aboriginal and Torres Strait Islander and have disability, this finding that the theory of 'intersectionality' continues to hold true once gender and remoteness are added.

FOR FURTHER RESEARCH:

How does gender inequality compound inequalities experienced by Aboriginal and Torres Strait Islander women with disability?

How can disability service models be sensitised to address these inequalities, especially for people living in remote communities?



5
DISCRIMINATION
EXPERIENCED BY
ABORIGINAL AND
TORRES STRAIT
ISLANDER PEOPLE
WITH DISABILITY

Scott Avery

KEY FINDINGS:

Aboriginal and Torres Strait Islander people with disability frequently experience discrimination in multiple forms:

- Racism, related to being an Aboriginal and/or Torres Strait Islander person;
- Ableism, related to being a person living with disability; and
- A unique form of 'intersectional discrimination' that is an interaction of discrimination, that is both Aboriginal and Torres Straits Islander and disability related.

Frequent exposures to discrimination throughout the life of an Aboriginal and Torres Strait Islander person can have cumulative impact which manifests into 'apprehended discrimination'. This is a pathway in which a fear of discrimination transforms into a rational expectation of discrimination. An effect of apprehended discrimination is that it can lead to a person avoiding social situations where they could be exposed to possible discrimination.



Frequent exposures to discrimination throughout the life of an Aboriginal and Torres Strait Islander person can have cumulative impact which manifests into 'apprehended discrimination'.

5.1 EVERYDAY EXPERIENCES OF RACISM, ABLEISM AND INTERSECTIONAL DISCRIMINATION

As people intersecting two marginalised population groups, Aboriginal and Torres Strait Islander people with disability can experience discrimination that is both race and disability related. Chapter 2 discussed in conceptual terms how racism and ableism can occur of their own accord, but also interact which each other to generate a unique experience of discrimination which is referred to in this research as 'intersectional discrimination'. This chapter builds upon the concepts described in Chapter 2 by presenting how multiple forms of discrimination appeared in the testimony of the Aboriginal and Torres Strait Islander people who were interviewed for the research.

In reviewing the testimonial data on discrimination, it should be noted that participants were not directly asked during the interview if they had been discriminated against. Instead, the participants' recounting of their experiences of discrimination came as a result of this more general discussion prompt on what barriers they faced in their lives.

Below are two examples drawn from the testimony that illustrate the 'everyday' nature of discrimination as it appears in the lives of Aboriginal and Torres Strait Islander people with disability. The first example comes from a group of participants who live in an Aboriginal Housing complex on the outskirts of a regional centre. This example highlights how one form of structural discrimination (in this example, a lack of access to transport), can compound with other personally directed forms of discrimination (in this example, racial vilification). The participant lives in a community group of about thirty people, all are Aboriginal, none with access to transport. The centre of town is a few kilometres away and buses don't come out their way, so he says that he walks into town when he needs something. He says that he sees a counsellor for an hour or so every few weeks for a mental health condition, "as I am supposed to". He then mentions that on the walk back from seeing his counsellor, he is often racially abused by people in the street and driving past, instantly undoing any benefit of his therapy.

A second example highlights how race and disability can interact to accentuate the risk of discrimination for people who are Aboriginal and Torres Strait Islander and have disability. The testimony comes from an outer metropolitan area, involving an Aboriginal woman with a cognitive disability and possible undiagnosed hearing impairment, and her son, an Aboriginal man who also has an intellectual disability. The support person, attending with the participant, said that he works at a local disability place. "He's a supervisor now. He's been there a long time," and she comments that "as he is getting older, he's losing his, you know, his fine motor skills", which causes him to lose his balance and fall. She recalls an incident during a shopping trip:

"Because he's, you know, his balance is off. And, the other day – we'll put this on the issue, is that [the participant and her son] went to go shopping. And, the security guard at the Shopping Centre... stopped [the son] and said, "No. We don't like – you can't come in because you're intoxicated." And, he wasn't intoxicated. That's just how he is.

And, they told Woolworths not to let him in. And, I was there. I ripped them. I said, "If you can't tell between a person living with a disability and a person that's intoxicated." I said, "You shouldn't be working here." I said to the security guard. And, I said, "As for you, [speaking about the Shopping Centre], you can't discriminate. Can't discriminate against people living with a disability." So, then they let him do the shopping. And, then they came and apologised to [the mother]. I said, "Don't apologise to her. You need to apologise to that young man." I said, "Because you stopped him."

She mentioned that this type of incident happens regularly. The participant said that when she goes to the club.

"They say, 'That's enough. You've had enough to drink.' [But] I don't drink."

The support person follows up

"And, they put her out."



Direct references to discrimination contained within the participants' testimony spanned a range of ordinary day activities

Whilst these two testimonies highlight how racism and ableism interact to generate a unique form of intersectional discrimination, the participants consistently relayed experiences that could be directly attributed to either racism, ableism or an intersectional form of discrimination in response to the prompt, "What barriers have you faced?" Their testimony included exposures of to a range of discriminatory behaviours, which included:

- being subjected to prejudicial assumptions about what they could or could not do because they were Aboriginal or Torres Strait Islander and/or have a disability;
- not being believed, because their life experiences were seen as contradictory what professionally trained people were taught;
- being viewed as a burden when they had asked for accommodations to be made to enable them to participate in a social activity; and,
- being called a racist or ableist name out of frustration by the person that they were speaking with at the time of the incident.

The type of daily routines that the participants were undertaking at the time they encountered this highlights how their day to day lives are constantly interrupted by casual exposure to discrimination. Direct references to discrimination contained within the participant's testimony spanned a range of ordinary activities such as:

going to the doctor;

going shopping;

going out for a meal;

taking a phone call at work;

catching a plane;

asking to attend or participate in a community group meeting; and

applying for a job.

5.2 'APPREHENDED DISCRIMINATION' AND THE PATHWAY TO AVOIDANCE

'Apprehended discrimination' was introduced as a concept in Chapter 2 to describe a pathway in which repetitive exposures to discrimination transforms an intuitive fear of discrimination into a rational expectation of discrimination, which in turn leads to an avoidance of situations where discrimination could possibly occur. The concept of 'apprehended discrimination' is illustrated through three examples drawn from the testimony.

The first example is a single construction of the sequential pathway from a fear of discrimination to a personal avoidance of discrimination. It involves an Elder with a physical disability, whose status in community meant that he was regularly invited to meetings to talk on Aboriginal issues and culture:

Phase 1 Fear of discrimination: His initial reference to a fear of discrimination is described intuitively and is externalised: "Most of the [meeting] organisers don't have a disability, ...so they make the bookings on their own ability."

Phase 2 'Apprehended discrimination': The next sequence in his testimony describes his personal experiences of being unable to access buildings because of disability, which helps form his rational thinking on the likely threat of discrimination: "When I get to the meeting, it's not accessible or the lifts are out."

Phase 3 Avoidance: The third sequence describes his response which pre-empted an expectation of discrimination: "So, that's why I don't bother to go to a lot of meetings."

A second example shows how multiple exposures to discrimination accumulate and lead to avoidance, as exhibited through a single person's testimony. The participant in this example is an Aboriginal woman living in a remote location who has a son with a cognitive disability:

Phase 1 Fear of discrimination: She initially speaks of a historical legacy of distrust of police by the local Aboriginal community. She speaks of past injustices which have framed her intuitive thinking on discrimination: "[The] police hung someone here before. The police killed a black person, they hung him in jail here." She then makes reference to a recent incident where an Aboriginal man from her community was assaulted by police, and then makes a direct connection to her son: "[My son] has a disability and I'm scared for my son."

Phase 2 'Apprehended discrimination': The testimony progresses along the continuum when she raises that she had approached the Department of Education and the police to get help for her son who had been "interfered with" at school. This request for help went unheeded, and the undercurrent of her testimony is that it is because they are Aboriginal.

Phase 3 Avoidance: The apprehension of discrimination has progressed into avoidance – she has withdrawn her son from school for fear for his personal safety, and he is currently not receiving formal education.

A third example relates to the employment of people with disability, which is discussed in connection to employment inequality in Chapter 6. This is a construction of apprehended discrimination and involves piecing together various components of narrative across a single issue:

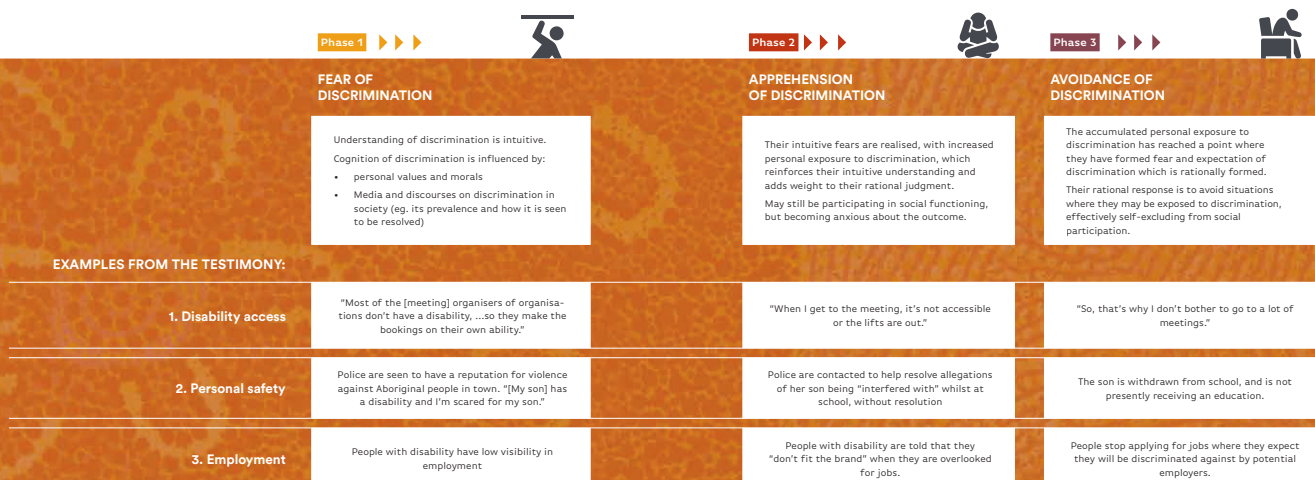
Phase 1 Fear of discrimination: First, the statistical data demonstrates that there is inequality in employment outcomes experienced by Aboriginal and Torres Strait Islander people with disability compared to the rest of the population, setting a data-based foundation for fear of discrimination.

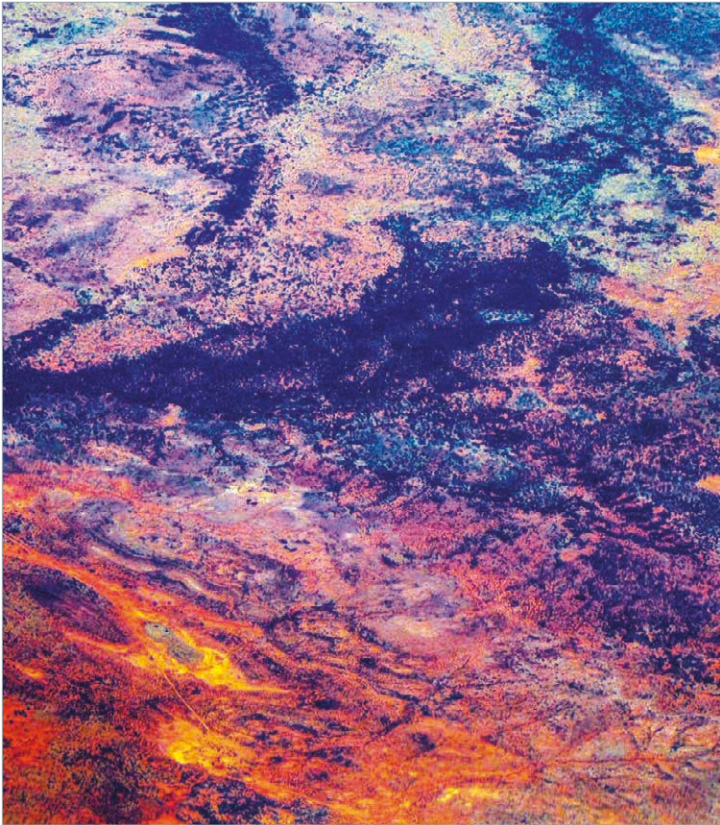
Phase 2 'Apprehended discrimination': Within the testimonies, the participants who referenced discrimination in employment had progressed the intuitive fear of discrimination, and spoke extensively of their personal exposure to discrimination in employment, including a yarnning piece in which a young woman with disability says that she is told that she is unable to secure causal employment with high profile corporations as she "does not fit the brand".

Phase 3 Avoidance: The pathway from apprehended discrimination progresses to avoidance, illustrated by an example when a vision-impaired person says that he no longer applies for jobs that have holding a driver's license in the selection criteria. He puts his reasoning down to an expectation that not meeting this criteria, which is a function of having disability, would be used to reject his application without any further consideration, regardless of his merit in meeting all other aspects of the selection criteria.

The personal experiences from participants are used to expand the concept of 'apprehended discrimination' in the following diagram.

Diagram 5.2.1: Apprehended discrimination: A pathway from fear of discrimination to avoidance





6 INTERSECTIONAL INEQUALITY: THE NUMBERS AND NARRATIVES

KEY FINDINGS

Intersectional inequality: The statistical and testimonial data shows that as a group intersecting two marginalised groups, Aboriginal and Torres Strait Islander people with disability experience greater social, health and wellbeing inequalities relative to other population cohorts. The inequality that they experience is greater than the inequalities that Aboriginal and Torres Strait Islander people, and people with disability, experience as discrete population groups.

Acute and pervasive inequalities: The intersectional inequalities that Aboriginal and Torres Strait Islander people with disability experience are acute and pervasive across all the systems which are intended to support disability; including the provision of disability services, health, education, employment, housing, and transport.

Barriers to inclusive communities: Aboriginal and Torres Strait Islander people, particularly those living in remote and regional communities, are susceptible to living in inaccessible housing and physical environments unsuitable for people with disability. The inaccessibility in the living environment is compounded by a lack of accessible transport, which is vital to a person with disability's self-esteem and independence. This has the effect of reducing their capacity for social interaction in their communities, and in extreme cases becoming prisoners in their own houses.

Education: Aspirations for further education are high, including a strong appetite for further cultural education, but these aspirations are often unfulfilled due to systemic barriers in the education pathway. Limited access to Auslan interpreters creates a specific educational barrier for Deaf Aboriginal people due to access.

Employment: Prejudicial attitudes towards people with disability by prospective employers curtail the employment opportunities for people with disability. Sustained exposure to discrimination in the job market increases the prospect of apprehended discrimination leading to people with disability ceasing to seek employment.

Health: Aboriginal and Torres Strait Islander people with disability experience stark inequalities in their access to health care compared to other population groups. Institutionalised ableism and racism in the health systems, overshadows their clinical and health care requirements, which leads to suboptimal health care and a heightened risk of adverse health care events.

6.1 PATTERNS IN THE DATA

The NATSISS produces population-wide data on social, health and wellbeing outcomes for Aboriginal and Torres Strait Islander people, which can be disaggregated by disability status. To enable a comparison to the social, health and wellbeing of other Australians, select indicators are compared to responses to ABS's General Social Survey⁹⁰ which is a sample survey of the whole Australian population.

In Table 6.1.1 overleaf, there are five population groups where the selected social, health and wellbeing indicators are compared:

- The general population that does not have disability (which may include Aboriginal and Torres Strait Islander people with disability within the data collection source);
- People with disability (which may include Aboriginal and Torres Strait Islander people with disability within the data collection source);
- Aboriginal and Torres Strait Islander people that do not have disability;
- People who are both Aboriginal and/or Torres Strait Islander and living with disability that is not severe and profound; and
- People who are both Aboriginal and/or Torres Strait Islander and living with severe and profound disability.

TABLE 6.1.1: Percentage of population experiencing selected social, health and economic outcomes, by population group (General Social Survey⁹¹ and NATSISS⁹²)

INDICATOR	(i) General population	(ii) People living with disability	(iii) Aboriginal and Torres Strait Islander people with no disability	(iv) Aboriginal and Torres Strait Islander people living with disability that is not severe and profound	(v) Aboriginal and Torres Strait Islander people living with severe & profound disability
Self-assessed health as excellent/very good	69.0%	32.0%	53.4%	22.9%	13.9%
Had problems accessing health care services	2.8%	11.4%	11.3%	19.5%	27.0%
Total experienced one or more stressors	59.2%	69.8%	62.6%	75.3%	82.7%
Feelings of safety walking alone in local area after dark	55.9%	43.9%	58.6%	47.5%	37.5%
Participation in the labour force	83.0%	53.0%	68.1%	51.8%	31.1%

91 The General Social Survey is used as the data source for: (i) General population; and (ii) People with disability.

92 The NATSISS is used as the data source for: (iii) Aboriginal and Torres Strait Islander people with no disability; and (iv) Aboriginal and Torres Strait Islander people living with disability; and (v) Aboriginal and Torres Strait Islander people and with severe & profound disability.

90 Australian Bureau of Statistics (2014) General Social Survey: Summary Results, Australia. Rel. 4159.0. Table 11: 'Disability'.

There is a pattern in the data that illustrates intersectional inequality across the indicators:

- Aboriginal and Torres Strait Islander people experience greater inequality in their social and health outcomes compared to other Australians.
- Aboriginal and Torres Strait Islander people who also live with disability experience greater inequality when compared to:
 - Aboriginal and Torres Strait Islander people without disability, and
 - non-Indigenous people with disability;
- Aboriginal and Torres Strait Islander people with severe and profound disability experience greater inequality in social, health and economic outcomes than Aboriginal and Torres Strait Islander people with disability that is not severe and profound.

Relating this to the concepts of intersectionality and intersectional discrimination introduced in Chapter 2, the data can be used to categorise social inequality into three types:

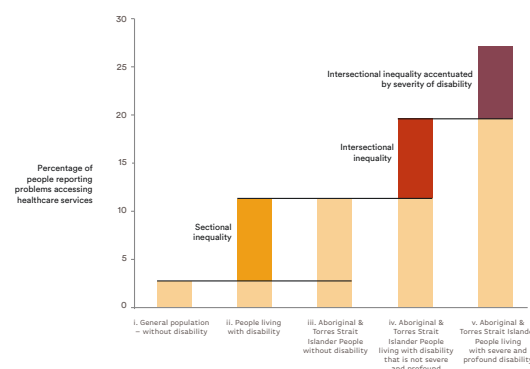
Sectional inequality This is inequality that affects the one marginalised group as a discrete population, ie. the population of people living with disability (group ii), and Aboriginal and Torres Strait Islander people without disability (group iii). This is referred to as 'sectional inequality' to provide a point of contrast to 'intersectional inequality'.

'Intersectional inequality' This is the compounding of inequality that affects those people who are members of two or more marginalised groups, ie. Aboriginal and Torres Strait Islander and live with disability (group iv).

'Intersectional inequality' accentuated by severity of disability Separating populations who report having any disability (group iv) and people reporting severe and profound disability (group v) recognises that disability exists on a spectrum, and hence highlight how the severity of disability can further accentuate intersectional inequality.

The clearest example of intersectional inequality presented in table 6.1 relates to problems in accessing health services. This is represented diagrammatically in Figure 6.1.1 below:

Figure 6.1.1: Sectional and intersectional inequality in accessing healthcare services. (General Social Survey 2014, NATSISS 2014–15)



The remainder of the chapter explores inequalities that exist within the Aboriginal and Torres Strait Islander population using a more detailed investigation of thematic issues. It uses the NATSISS as the source for statistical data, which is brought together with testimony and yarning pieces in order to align it to policy priorities.

To facilitate the translation of this research into policy, the data is organised to align with the priority areas outlined in the National Plan to Improve Outcomes for Aboriginal and Torres Strait Islander People with Disability.⁹³

93 Commonwealth of Australia – Department of Social Services (2017) Australian Government Plan to Improve Outcomes for Aboriginal and Torres Strait Islander People with Disability.



There was a broad range of topics raised within the theme of inaccessible housing: from disability access, to housing affordability and experiences in accessing social housing.

6.2 INCLUSIVE COMMUNITIES

Reference to the Australian Government's Plan to Improve the Outcomes of Aboriginal and Torres Strait Islander People Living with Disability:

Area 1: Aboriginal and Torres Strait Islander people with disability have access to appropriately designed shelter and live in accessible, well designed communities that are fully inclusive of all their residents.

The data collected through the NATSSIS and the SDAC are limited in scope and do not record the environment Aboriginal and Torres Strait Islander people with disability are living in or public infrastructure. For example, the NATSSIS asks whether a person has daily face to face contact with family and friends, but has no capacity to assess if geographic location is a factor. The SDAC asks questions like "do you have trouble climbing stairs?", but does not address whether the stairs should be there in the first place.

Disability accessible housing:

Neither the NATSSIS nor the SDAC can provide insights into rates of homelessness amongst Aboriginal and Torres Strait Islander people with disability, as they only survey people living in private dwellings. The NATSSIS does collect data on previous experiences of homelessness. This shows an intersectional effect: Aboriginal and Torres Strait Islander people with severe and profound disability have experienced homelessness at 1.9 times the rate of Aboriginal and Torres Strait Islander people without disability (41% compared to 22%).

Accessible housing was raised as a major issue for participants in the interviews, with 10 of the 47 participants referencing it as an issue. There was a broad range of topics raised within the theme of inaccessible housing: from disability access, to housing affordability and experiences in and accessing social housing. This was particularly the case in the remote sites visited, where according to participants housing providers included disability accessibility at best as an afterthought, and at a worst case a wilful oversight:

"It's disgusting how... our housing company is treating these disability people in their homes. You've got her son can't get no help, you've got another man who -, he's got to walk up steps and he's nervous because there's no rail for him to get into his house, there's no rails for him to hang onto in the bathroom"

Scott Avery

The picture below⁹⁴ illustrates the issues of disability accessible housing in remote communities. Taken in a very remote community, it shows the entrance to a house which had recently been built as part of a remote housing project. The occupants had been on a waiting list for seven years before the house was built, and were not consulted during its construction. What is shown below is a steel ledge, approximately five centimetres high, at the main entrance to the house. The occupants said that when people with disability come over, they have to lift them over the ledge so they can come into the house.



Another of the participants at the Elders forum is a wheelchair user living in an apartment with standard height shelves which she could not reach. There was also a raised ledge at the entrance which made it difficult for her to enter. She had been asking for some time for modifications with the NDIS, but had not heard back from them at the time of the interview.

A few participants spoke of experiencing homelessness or a direct threat of homelessness, although they did not necessarily describe it using those terms. One participant, a deaf Aboriginal woman, spoke of difficulties in finding housing when she moved to a city area to better access other services:

"In [other cities], there's lots of Aboriginal organisations whereas in [the city I live in] the access is limited. When I came here, I couldn't get a house here, because here the [Housing organisation] have merged with - like, single mothers or abused mothers, deaf, disability, it's all in one. So, there's a ten-year waiting list to get a home. I had nowhere to stay. So, [my female friend] she's bought her home, so luckily she allowed me to stay with her, and she doesn't mind me living with her until I can get a home."

Another participant from a remote area described his current living situation as "living rough" in a town camp, unable to secure any form of housing:

"We tried [talking with someone about getting housing]. We tried. Nothing happened. It's just overcrowding what existing houses are there. There was some houses bought, [a person from the Government] bought those houses, didn't they? But, they never connected them up. They're just sitting there in a paddock."

There is an apparent hierarchy to the provision of housing support:

1. The first-tier issue is provision of any housing at all;
2. The second tier is the issue of incorporating disability accessibility into the design and construction of new housing; and
3. The third tier is the modification of existing housing to make it accessible. The evidence from the site visits to remote communities indicates the issue of providing core housing is seen as so great in magnitude, that disability access and home modifications are at the end of a very long queue.

Over and above the functional aspect of houses providing shelter, there is a psychosocial dimension of living in a place you can call your own. When a person who is living rough was asked what having a house would mean to him, he replied:

"I want to go home. That's all."



94 Taken with express permission from the community.

'Fit for purpose' disability aids:

A second core issue contributing to the (non) inclusiveness of people with disability in communities is the suitability of the disability aids that they are provided with in the physical environment. The deterioration and lack of suitability of available wheelchairs in remote communities was observed consistently.

This issue is illustrated in the following photograph. This photo was taken in one of the research sites during the initial stages of the research. It shows a standard issue foldable wheelchair, which in an urban environment where there are footpaths, would be considered light and portable because it can be folded up and put into a car boot. The same wheelchair, when put into a different physical environment, may cease to be suitable. The wheelchair in this photo's rubber wheels have melted off because of the extreme heat, making it completely unusable.



95 Photo taken with express permission from community.

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The photo below left⁹⁶ was not an isolated observation. One of the participants at the Elders forum travelled from a regional centre to Alice Springs with a manual wheelchair. It was broken at the seat support which made it rub against the wheel, requiring such physical exertion to make the wheelchair function that people had to take turns to push her. At another regional centre, a participant mentioned living only few streets from the Town Centre, said that they rarely went into town or too far from home, as if their wheelchair broke down, they would be stranded.

Indeed, it was rare for the researchers to see a fully functioning wheelchair in any remote communities visited, and this made a distinct impression upon their social visibility within communities. In some of the remote communities, a graveyard of discarded wheelchairs was the only outwardly visible sign of people with mobility impairment living in that community. For people who rely on wheelchairs, the lack of suitable and well maintained chairs could leave them isolated within their own homes.

Transport:

A third core obstacle to inclusive communities is a lack of access to transport. This has a particular impact on inclusion, as a lack of access to transport creates knock-on access problems, such as getting to school, getting to a job interview, or getting to medical appointments:

"Transport is another failure because there's no transport to get to hospital and appointments, because if you go to your local doctor and you get a referral to go to the Women's and Children's. I had my grandson, nobody could transport me, so I had to get up at four o'clock in the morning, catch a bus to Women's and Children's to have an MRI, you know."

One participant living in a regional centre said that transport was a major problem, and that there was only one disability access taxi in the region where she lived:

"Well, there isn't much transport here. There's only one taxi. And, it's only going till like, morning, till six o'clock in the afternoon. Which, isn't really right at all. You know? Like, other people that walk everywhere or push themselves, yeah."

When asked how she gets around, she captured a lifetime's experience in three words:

"I push everywhere."

Much like housing, transport has both a functional dimension and a psychosocial dimension. Whilst there is a practical requirement for people with disability to get from point A to point B, the ability to do so without being made to feel a burden is a vital aspect of a person with disability's sense of independence. This is where promoting and providing inclusive transport can be as significant as the logistical aspects of transport, and the testimony pointed to Australian airlines as poor performers in this regard:

"So, with some of the barriers that I've met would be with just, say, one to tick off would be transport and a couple of years ago I flew with [an airline]. And, they – their whole disability policy, that which my wife went through to make sure that we knew what steps were in place. Then we went through the whole system of going to the airport... that was blown out of the water. Nothing was in place. There was no transfer equipment. The people didn't know how to use it properly."

They took apart my chair completely when it hadn't ever been taken apart before, and when I got to [the destination] had to put the whole thing back together. And, just the whole experience with the crew on board was negative and – and especially then when we came back to [the city] and had a really rude altercation with one of the [airline] staff because we couldn't find my wheelchair and the lady was going off at my wife, which brought [her] to tears. And, we ended up eventually finding my wheelchair that was, not in pieces, but it wasn't right. So, we had to sort of put it back together."

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The structural limitations of a personal agency approach to social change:

The issues of housing, disability aids and transport highlight the impact that the structural limitations in the physical environment place upon a personal responsibility approach to improving someone's social, health and wellbeing status.

Simply put, people with disability can't go to school and can't go to work if they can't get there. The barriers created by inaccessibility are also relevant in the coming sections on the inequalities experienced by Aboriginal and Torres Strait Islander people in education, employment and in health.

There are practical consequences when public disability policy is devoid of the impact of structure on personal agency. A case in point is the implementation of the National Disability Insurance Scheme, which is discussed further in Chapter 7. This is a model of disability support in which the design principles are exclusively about fostering personal agency. Whilst it might not be within the remit of a National Disability Insurance Scheme to fix the public infrastructure problems that exist in remote communities, inclusion strategies that are dependent upon a personal agency model will fall short of their optimal effectiveness if the structural limitations cannot be accommodated within public policy that aims to be inclusive of disability.

6.3 JUSTICE

Reference to the Australian Government's Plan to Improve the Outcomes of Aboriginal and Torres Strait Islander People Living with Disability:

Area 2: Aboriginal and Torres Strait Islander people with disability have the right to be free from racism and discrimination, have their rights promoted, and a disability-inclusive justice system.

Exposure to threatened or actual violence

Exposure to violence or a traumatic death of a close family member or friend was referenced by participants in 9 of the 41 interviews (22%). The types of violent and traumatic episodes referred to included: references to close family members who had been murdered or 'lost'; women alluding to seeking respite from gender based violence; being subjected to a violent attacks with a weapon; deaths by suicide; a young child dying because of medical neglect; and an extensive and detailed account of being exploited by a human trafficking ring.⁹⁶ There is a clear gender bias in the responses, at least with respect to the person making the disclosures, with 7 of the 9 recounts of violence made by women.

It is worth remembering at this point that participants were not directly asked whether they had been exposed to violence. These incidents were voluntarily disclosed by the participants in response to a general invitation to share their life story.

The quantitative data collected by the NATSISS suggests an intersectional effect, with the data showing that Aboriginal and Torres Strait Islander people with severe and profound disability are approximately twice as likely as Aboriginal and Torres Strait Islander people without disability to have been either threatened with or exposed to violence within the past year.

INDICATOR	Aboriginal and Torres Strait Islander people		
	With severe and profound disability	Without disability	Rate (x times likely)
Experienced threatened violence in past year	25%	14%	1.8
Experienced physical violence in past year	19%	11%	1.7
Felt safe at home	71%	87%	0.8

96 The details of these events have been redacted as a measure of privacy to the participants, and to reduce the risk of excessively trauma to Aboriginal and Torres Strait Islander people who might read this report.

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Imprisonment of Aboriginal and Torres Strait Islander with disability

Intersectional, quantitative data on Aboriginal and Torres Strait Islander people with disability in detention is not available from the data sources used in this study. The NATSISS is a survey that is confined to private households so it excludes people who are currently in detention or other forms of institutional care from its inclusion criteria.

The ABS publishes data from the National Prisoner Census which includes data demographic and legal characteristics of prisoners such as age, sex, country of birth, Indigenous status, legal status, prior imprisonment, most serious offence/charge and length of sentence being served. The most recent report, Prisoners in Australia (2017)⁹⁷ shows that incarceration rate for Aboriginal and Torres Strait Islander people was 2,434 prisoners per 100,000 of the Aboriginal and Torres Strait Islander population. By comparison the imprisonment rate for other Australians was 160 prisoners per 100,000 non-Indigenous population. As data on disability is not reported, it is not possible to quantify the intersectional impact if disability upon the rate of imprisonment of Aboriginal and Torres Strait Islander people using the national data set.

However, jurisdictional data from New South Wales on the health and wellbeing status of people in the juvenile justice system shows that the prevalence of complex disability and multi-faceted disadvantage is higher amongst Aboriginal young people compared to other young people⁹⁸. It paints a bleak picture of who ends up in juvenile detention:

54% 54% of young people in juvenile detention are Aboriginal or Torres Strait Islander.

23.8% Of young Aboriginal people, 23.8% scored extremely low and 39.6% were borderline on the tests used to assess intellectual ability.⁹⁹

87% 87% of young Aboriginal people met the threshold criteria for at least one psychological disorder, and 69% met the criteria for two or more.¹⁰⁰

25% 25% of young people had a past head injury resulting in loss of consciousness, with females more likely than males to have sustained a head injury (52.6% vs. 22.5%)

68.2% 68.2% of young people in juvenile detention reported experiencing at least one form of childhood abuse or neglect, with more than one-quarter (28.1%) experiencing some form of severe abuse or neglect.

97 Australian Bureau of Statistics (2017) Prisoners in Australia. Rel. 4517.0

98 Justice Health & Forensic Mental Health Network and Juvenile Justice NSW (2017) 2015 Young People in Custody Health Survey: Full Report. NSW Government.

99 This is using a FSIQ Indicator. Ibid, at Table 148, p 81. (Note that this is not an assessments of cognitive impairment)

100 Ibid, at Table 117 page 65

Within this study, one participant referred to being placed in detention, and another participant mentioned a family member who had spent time in prison. As there was insufficient data drawn from the qualitative research, it is not possible to draw any definitive conclusions on the experiences of people with disability in the justice system, nor reasons for its omission from the narrative. However, it is reasonable to expect that Aboriginal and Torres Strait Islander people with disability are imprisoned at higher rates than other people with disability and at higher rates than Aboriginal and Torres Strait Islander people without disability and have poorer experiences and outcomes when interacting with the justice system, as identified in other research.

Outside this study, a 2015 report by University of New South Wales report entitled 'A predictable and preventable path: Aboriginal people with mental and cognitive disabilities in the criminal justice system'¹⁰¹ provides a comprehensive account of Aboriginal and Torres Strait Islander people with cognitive impairment in the criminal justice system. Another investigation by international human rights agency Human Rights Watch in 2018 has also chronicled an account of abuse and neglect of prisoners within the Australian prison system¹⁰².

101 Baldry, E., McCausland, R., Dowse, L. and McEntyre, E. (2015) A predictable and preventable path: Aboriginal people with mental and cognitive disabilities in the criminal justice system. UNSW, Sydney

102 Humans Rights Watch (2018) I Needed Help, Instead I Was Punished: Abuse and Neglect of Prisoners with Disabilities in Australia.



6.4 EDUCATION

Reference to the Australian Government's Plan to Improve the Outcomes of Aboriginal and Torres Strait Islander People Living with Disability:

Area 3: Aboriginal and Torres Strait Islander people with disability achieve their full potential through participation in an inclusive high quality education system that is responsive to their needs. People with disability have opportunities for lifelong learning

Unfulfilled aspirations for education

Aboriginal and Torres Strait Islander people volunteered high aspirations for their personal advancement through education:

"There's one thing I want to do before I leave this earth is to have my degree in human rights law and then I'll be happy with that."

"I'm studying social welfare and psychology at [University] and my main goal is to go on and do neuroscience and be able to become a neuroplastician and work in that field."

Education was an important factor in the life journey of the participants in the research, with 36 of the 41 interviews (88%) including some reference to 'school'. Further, 23 of the interviews (56%) indicated some current or previous experience with the higher education system, with 14 making some reference to 'University' education (34%), and 16 making some reference to 'College' or 'TAFE' (39%). These reflected high levels of participation in the education system by the participant group. Whilst noting the difficulties in making a direct correlation between the statistical data and the testimonial data used for the study, references to undertaking higher education from the participant group interviewed appear substantially higher than the rates of participation in education for Aboriginal and Torres Strait Islander people within the NATSISS (see Table 6.4.1 below). This suggests the possibility of a positive education bias amongst the participants in the study.

Whilst Aboriginal and Torres Strait Islander people with disability express high aspirations for education, statistical data on education outcomes show that these aspirations remain unfulfilled. Population wide, Aboriginal and Torres Strait Islander people with disability attain educational outcomes at half the rate of Aboriginal and Torres Strait Islander people without disability.

Table 6.4.1: Education Indicators, Aboriginal and Torres Strait Islander people – by disability status, NATSISS 2014–15.

INDICATOR	Aboriginal and Torres Strait Islander people		
	With severe and profound disability	Without disability	Rate (x times likely)
EDUCATIONAL ATTAINMENT			
Currently studying	14%	25%	0.6
Certificate III qualification or higher	19%	34%	0.6
Educational attainment below Yr 10	42%	18%	2.3



"It's all about the boxes"

Note that school age children were not interviewed as they were outside the selection criteria. As the voices of school age children are not present in the research, there is likely some understatement of the issues around education. Based on this limitation alone, it is recommended that there is more focused education research that encompasses the voices of children and young people.

However, there were some interviews with parents of Aboriginal children with disability. One participant drew attention to the compartmentalised approach to education where programs for Aboriginal and Torres Strait Islander children run independently of programs for children with disability; as opposed to flexible, coordinated programs which are both culturally inclusive and disability inclusive. In this case, the mother of an Aboriginal child with Autism described being compelled to choose which aspect of support to prioritise through a selection of boxes to tick (which is assumed to drive school funding support). Reduced to its core facts, the case study reads as a farce:

"And, you know, I was filling out the school form and it came to the, "Do you identify as an Aboriginal Torres Strait Islander person? Please tick this box. "Does your child have any special needs?" And, I thought, well, this is going to go two ways. I'm going to tick that Aboriginal box and they're going to focus on that. And, I'm going to tick that Autism box and then going to focus on that. Which one are they going to prioritise?"

I made the decision that I would prioritise [my son's] Autism and – do you know what I mean? Like, that was a really hard decision for me. Because, I've always identified [as being Aboriginal] and, you know, that's our heritage.

I had to pick a box... I just felt if I focus on this they're going to focus on that and then he's going to become a statistic and at the exclusion of the other. So, if I pick this box and not that box they'll focus on the autism and not the other part. And, if I did it the other way that's all they would focus on.

So, I made that choice. And, it was probably the wrong choice at the time. But, you know, I was so scared for him to go into school in general and my experience with the education system down the track is that Aboriginal students are, you know, sort of, put into a group and, sort of, excluded and, you know, the way they manage it is they might not even have an achievement. But, every week they go to the principal with some sort of work that they've done and they're removed from the class and put in a special group and that's how they're treated.

And, the question came up with Aboriginality again when [my daughter] enrolled. Because, of course I ticked the box for her. I'm, like, yes, that's who we are. Tick the box. Don't even think twice about it.

And, then [the school] questioned [my son's] parentage. Whether there was the same father. You know, how they were related. If he was not Aboriginal and she was Aboriginal. So, then I was called up to the school and I had to give an explanation... So, I explained to them and I said, "Look, this is why I did it." So, the box got ticked again and everybody was happy. Because, if there's a box to tick everybody's happy.

It's all about the boxes. See, if there's no box to tick everything falls apart."



Interrupted pathways in further education

The participants tended to describe an interrupted pathway, in which they built their education in piecemeal blocks, rather than as a continuous pathway of matriculation. This observation relates to the excess demands of managing their disability (such as transportation issues, campus access, interpreters, and health issues) concurrently with the demands of study.

One of the people interviewed mentioned that they aimed to complete a succession of certificate level qualifications, as that could be managed within the physical and logistical demands of his disability. Another participant said:

"I've always started courses. I never finish them. No, I didn't finish the first course I was doing".

Later in the interview, the person revealed that the reason she did not complete her first course at University was that she suddenly acquired a disability mid-way through completing her degree. The combined physical and psychological trauma caused her to withdraw from her studies. Having had the flow of her educational pathway interrupted by acquiring a disability, her subsequent attempts to re-enter the University system have faltered.

INTERSECTIONAL INEQUALITY: THE NUMBERS AND NARRATIVES

Many University and higher learning institutions have equity strategies to promote inclusion of both Aboriginal and Torres Strait Islander students, and students with disability. These narratives say that the presence of social factors for both groups of students make educational journeys unpredictable, and do not always conform with the lock-step curricula in many educational institutions. Whilst highly motivated and capable, there are groups of students who have not been able to navigate their way into higher education system, and their actual attainment is lower than what is possible. This knowledge would not be readily available to higher education institutions, as this prospective cohort of students are currently sitting outside the system, but the lived experience knowledge could be tapped to improve the quality and effectiveness of educational equity strategies.

Customised support for individual learning requirements

There were good models of learning support which were provided by the participants who had undertaken further study. As the nature of disabilities and hence needs for learning support are diverse, the key to effective support to establish clear lines of communication between a dedicated support unit and the student to establish their specific support needs, and have the support in place prior to the first lesson:

"So, education has been really good because I did my Cert 4 and I had scribes put in place which was really helpful. I've only got limited wrist control but I can read a text book but I'm really slow at opening the pages. So, I'd have a scribe in place going through text books, opening up the books, highlighting passages, when the teacher's going through the notes. And, that's in TAFE. It's supposed to be a lot harder in university, I've been told, to obtain scribes."

Whilst it might appear obvious that having support in place prior to the commencement will improve outcomes, it is not always the case that Aboriginal and Torres Strait Islander students with disability know who to go to for their cultural support and disability support. This is a particular barrier for students commencing study at large complex institutions. This can cause them to fall behind in their academic work from their commencement, and may lead to their withdrawal from studies.

One gap in support that emerged through the testimony is support for students with mental health conditions. Whilst it was mentioned that access for students with physical disabilities was a focal point of disability support units in educational institutions, issues of access for students with psychosocial disability have not been fully integrated. One participant spoke of the impact a mental health condition, which is episodic and requires periods of hospitalisation, has had on her capacity to complete her academic studies and the unavailability of support within the institution:

"Staying at university has been really hard for me, in terms of keeping up with assignments and, in the beginning, there was lack of support at the uni, in terms of mental health support. Like, I find that they have a disability centre, but it's not really catered to people with mental illness."

Additional educational barriers experienced by Deaf Aboriginal and Torres Strait Islander people

The Deadly Deaf Mob interviews generated rich and extensive data on the specific educational issues for Deaf Aboriginal and Torres Strait Islander people, which is summarised in this section. Education was far and away the dominant issue raised by the Deadly Deaf Mob participants, with all participants citing their experiences being a Deaf person learning in a hearing world.

Three core issues emerged from the Deadly Deaf Mob educational experiences. The first issue is the transitory nature of accessing education, with people having to shift around from school to school, and often going from one school with a Deaf pedagogy which promoted sign language to the next school with different pedagogy that favoured verbal education. Difficulties in accessing specific Deaf education, particularly (but not limited to) in non-metropolitan area meant whole families had to move:

"Mum moved to [the city] because of my education, because of the barriers that I had out in the country, because there were no resources out there that were available."

The second issue was access to Auslan interpreters. Access to interpreters is not universal, yet as the two contrasting experiences show, is pivotal to the educational experience of Deaf students:

"I had a hard time in my education because I was in a mainstream school and in that period I didn't have any interpreters available for my education. I didn't have a support worker. So, my – my English – my written English is okay, but it's not the best, you know, it's not at that standard that it should be at."

"I had a good experience, I didn't miss out on anything, I had an interpreter. The teachers were hearing and I had an interpreter, so I had a really positive experience."

As is the case with many other needs of people with disability, it is family and community who bear the load of compensating for a lack of interpreter services through systems:

"I've got a brother and a sister and my eldest brother who was always my interpreter, I grew up with him, he's four years older than me, he always interpreted to me."

The third theme from the Deadly Deaf Mob is their strong desire to learn more about their own Aboriginal cultural heritage. They described an approach to their education which was dedicated to making them proficient learners in a western hearing world. However, a general lack of access to Auslan within Aboriginal and Torres Strait Islander communities has left them isolated from the depth of cultural knowledge that is taught to hearing Aboriginal and Torres Strait Islander people. This has left them with a sense of longing for further cultural learning.



6.5 ECONOMIC SECURITY AND EMPLOYMENT

Reference to the Australian Government's Plan to Improve the Outcomes of Aboriginal and Torres Strait Islander People Living with Disability:

Area 4: Aboriginal and Torres Strait Islander people with disability, their families and carers have opportunities to gain economic security through employment and business ownership, enabling them to plan for the future and exercise choice and control over their lives

Undervaluing the contribution of Aboriginal and Torres Strait Islander people with disability through employment

Table 6.4.1 shows that Aboriginal and Torres Strait Islander people with severe and profound disability are almost twice as likely as Aboriginal and Torres Strait Islander people without disability to be unemployed (1.8 times), and half as likely to participate in employment (0.5 times).

Table 6.4.1: Education Indicators, Aboriginal and Torres Strait Islander people – by disability status, NATSISS 2014–15.

INDICATOR	Aboriginal and Torres Strait Islander people		
	With severe and profound disability	Without disability	Rate (x times likely)
EMPLOYMENT PARTICIPATION			
Participation rate	31%	68%	0.5
Employment rate	19%	55%	0.3
Unemployment rate	34%	19%	1.8

The testimony reflected the unfulfilled aspirations for employment held by the participant group. 24 of the 41 interviewees (58.5%) referenced 'jobs' during their interview, and the overwhelming majority of their testimony centred on their inability to get them. The issue of employment was particularly significant for Deaf Aboriginal people, with employment issues raised in every one of the interviews with the Deadly Deaf Mob.

Many participants had indicated that they had undertaken study or a training course to improve their employment prospects (refer 6.4), but this had not advanced their long-term employment prospects:

"So when I finished school I went to TAFE and study hairdressing. And that was a one year apprenticeship. And there were so many barriers. I thought it would be fantastic. But – no. The whole industry and the area was full of people who can hear. So I know how to cut and shampoo and do everything. But everyone was hearing and they all spoke, so we had to communicate through writing and paper...I did love that job but ended up leaving."

In most cases, the barriers and discrimination that the participants faced in their job-seeking experiences could be traced back to their disability, rather than being an Aboriginal or Torres Strait Islander person. However, some participants held an expectation that they would be discriminated against because they were Aboriginal and Torres Strait Islander, and this is the point 'apprehended discrimination' filtered into the testimony:

"It's difficult to get jobs. And, that's the main issue. And, it's difficult to get accepted in mainstream societies. And, a lot of people with – who are wheelchair bound have a – found it difficult to get into employment and they still can't – there's a lot of them still having problems with disabilities with employment. And, being accepted. Then the other disadvantage is if you're an Aboriginal person – well, my experience was that if you're an Aboriginal person you can't get a job... I was brought up during the old racist Australia days and the white Australia policy and all of that. And, that's another disadvantage. Trying to make your way in – in that world."



It's as much about the job giver as it is the job seeker

Improving employment prospects is a policy priority of both the Closing the Gap strategy and the National Disability Strategy. However, outcomes data on employment show that the intersectional impact of disability on outcomes for Aboriginal and Torres Strait Islander people have not been adequately addressed in either strategy. There is a dominance of employment programs, bundled under the euphemism, 'capacity-building' which target the upskilling of the job-seeker, on the assumption that 'capacity' is where the problem lies. By contrast, little consideration is given to problems with the job-giver.

Not fitting "The Brand"

I had met this person through a friend of a friend, in early 2016 not long after we had started the research program, and had not yet commenced interviews. When we first met, she told me that she couldn't get any of the "Westfield type jobs" as when she turned up for an interview, she would be told that she "didn't fit their brand". Hearing this, and the sheer arrogance that some big brand employers show people with disability leaves me with white-knuckled fury. I made a mental note to follow up down the track to ask whether she would be prepared to go on record and be interviewed for the research.

By the time of the interview, just over a year after we first met, I already knew much of her background. I know of her disability diagnosis, although she doesn't mention it once during the recorded interview. Growing up in an urban area, she is young, currently at University, and comes across as softly spoken, and highly intelligent. The thing that I notice most is how extremely polite she is.

"I grew up with a lot of, kind of, discrimination due to my disability, but not only that, within my high school, because I was of Torres Strait Islander descent, I actually got extra support. So the other student would get jealous in a sense that I would get extra support, and they would kind of discriminate against the group of us that were Indigenous."

During her high school years, being 'Indigenous' was more a label than an identity. Things started to change at University. "Up until then, I didn't understand why I was getting extra support. And, like, what it meant to be Indigenous. I didn't really understand until I actually got to Uni, actually did a subject on Indigenous studies... and I kind of got to connect with other people

that were Indigenous." She tells me that she entered University through a pathway scheme for Indigenous students, and that she has a private tutor which is sponsored by the Uni.

"With my disability, I obviously face a lot of barriers, especially with getting a job. That is a big one. The employment side of things is a big obstacle in the way that, like, I can't get a normal job at Macca's for example, because if I was to work at a check out they would need to do is put a chair there for me to sit on. But they don't like to make these alterations. So it is hard for me to get a job, and for people to look past, get to know the 'who I am', instead of looking at the disability."

The stigmas and false assumptions that other people hold around her and her disability is a constant source of frustration for her. In her case, it is the conflation of her physical disability with intellectual impairment. "Because I've got a physical disability, [people assume] that I must be intellectually impaired. So when I tell them, no, I actually go to University and actually work [in a policy research support role]... they actually get quite shocked." She gives an example of an

experience she has had the employment agency that has her on its books.

"I had an interview with this one agency and this was just to see if I was going to work with them or not. And the person that was actually interviewing me talked to my mum instead of me because she thought that I couldn't communicate. And mum was like 'She can talk. You don't need to talk to me. She's fully capable of communicating.'"

"Just a horrible experience", as she describes it, it is one example of many in her life. She is yet to meet an agency, or a person in an agency who has helped her find a job. It has soured her view on whether employment agencies will ever be able to help her. "They are amazing at helping you fill out a resume and all that sort of stuff. But when it actually come to finding you a job they can't do it."

Her education experience, at least at University, appears in contrast with her attempts at getting some work. Despite the occasional hiccups, usually due to a lack of communication, her education experiences "have actually been great". She gets a regular disability

service plan with exam adjustments, and has access to a participation assistant which helps out. She is doing two degrees, and her goal is to become a neuroplastician and become a researcher in neuroscience. I jot down a note to look up what a neuroplastician does when we're done with the interview.

The discussion comes back again to employment. The inability for "people to actually look past the disability" is clearly dispiriting for her. Her current casual job has irregular hours, and she would like to be able to get some extra money in. "I would just love to get a normal job, like a check out chick...All I would need is a chair. Like, just to put those little minor alterations in place so I could do the job...Just get to know me, instead of judging what is on the outside."

What keeps her strong is converting her lived experience of disability into resilience and a source of motivation. "What keeps me strong is knowing that I can use my personal experiences to make a difference to the world, to inspire others, no matter how small... Just use all my negative experiences and hardships and turn them into positive. That's what keeps me going".

She describes her greatest achievement as getting a casual job where the wisdom of her experiences are valued. "I was just over the moon when I was accepted to work, so empowered that I'm able to make a difference and educate people."

The disconnect between policy and the lived experience of seeking employment

Whilst the people involved in the study uniformly expressed their desire to participate in employment, they also conveyed the high expectations of them. In some instances, the high expectations were self-imposed, typically born from a previous bad experience in which their skills and qualifications were belittled. Regardless of whether the high expectations were internally or externally imposed, an undercurrent filtered through the narrative that people with disability are constantly having to prove themselves in the workplace in a way that is over and above what is required of people without disability.

"I thought to myself, you know, if I do something completely different, like, move to another city, go to school, you know, try and get a good job or whatever, you know, get involved in TAFE and study and finish year 12 and achieve those goals, and then people would you know, give me the credibility and say 'Wow, you can do it.'"

"I'm in my fourteenth job now since I've come to [the city]. And, I've always been successful in finding jobs and – and, now I – I'm doing a traineeship and I'm getting more and more confident, I'm learning more, I'm going out to do lots of courses and training and – and, especially events."

On one hand Aboriginal and Torres Strait Islander people are expressing their desire to advance themselves through education and employment, on the other they are subject to simplistic job seeker program and policy slogans around 'capacity building' and telling them to 'go to school and get a job'. The clear message coming from the research is that Aboriginal and Torres Strait Islander people with disability are willing and able to go to school and get a job, but they can't gain or sustain regular employment because of barriers which are both physical and attitudinal.

Herein lies the dangers in reductionist policy discourse. Policy messaging around 'capacity building' targets people in what behavioural change theorists might describe as the precontemplative stage of change.¹⁰³ They are short and sharp messages, aimed at motivating people who are currently unmotivated in changing their behaviour with a short, sharp call to action (ie. upskill yourself, go to school and get a job). The issue is that this assessment is not grounded in their lived reality of trying to find secure employment, completely misreading where people are at in the stage of change continuum. The people in this study have moved beyond the precontemplative stage and are motivated. In failing to acknowledge the core structural impediments in securing employment, motivational styled messaging paradoxically becomes acutely demotivational, as its exclusive contribution is to fuel the negative stigmatisation for those who can't secure employment.

Apprehended discrimination and the avoidance of participating in employment

Apprehended discrimination, or self-exclusion because of a rational fear of being discriminated against, can help explain the pathway in which people go from being motivated, to demotivated, and on to not participating in the employment market. The concept of apprehended discrimination as it applies in employment is practically illustrated with the following hypothetical: There are many client-stakeholder engagement styled jobs that are advertised on job seeker websites which include a driver's licence as an essential criterion. From a functional viewpoint, visiting clients and stakeholders might be an essential part of a job. What the requirement of a driver's licence as an essential criterion does is not only stipulate that you must visit stakeholders, it also prescribes how that function must happen (ie. self-drive in a car). As there are many people with disability unable to hold a driver's licence they are, as a consequence, locked out applying for that position because of one seemingly innocuous job stipulation. An Aboriginal and Torres person with disability might be qualified in every other aspect of the position, but sensitised to the multiple forms and detrimental health effects of discrimination that they have been routinely exposed to, choose not to even apply to avoid putting themselves in a position where they could be further discriminated against because of their disability. The fear of discrimination is enough to contribute to inequality in the outcomes.

Rather than subject themselves to the possibility of being discriminated against based on that one job criteria, they will not apply for the position, even if they see themselves as qualified in every other way.¹⁰⁴

When a person is constantly looked over for employment, the effect on personal confidence is debilitating. When someone has their heart set on a career and their life-long ambitions are cast aside because of their disability, it can be dream-shattering:

"I've applied for [a major Australian airline] as a [flight steward] and so I asked, you know – I got an interpreter in to help me fill out the forms and – so, we sent that off. And, it failed. And – because, I only had one issue and that was the – the inability to hear. So – and, that's the problem. You must be able to hear to work on the planes. And, it really pissed me off. You know, I can do that. I know – I know I can do that. I've travelled all over the place. I've been overseas continuously. I've travelled all over the world. And, I thought to myself, you know what? I would like to work for [the airline]. And, you know, that was my dream and that's what I wanted to do and I couldn't do it. It was only because I'm deaf and I couldn't hear.

So, you know what job I'm doing now? I'm working as a cleaner."

Multiply this single experience by many, and you have apprehended discrimination.

¹⁰³ Prochaska, J.O., and Velicer W.F. (1997) 'The Transtheoretical Model of Health Behavior Change'. Am J Health Promotion 1997;12(1):38-48.)

¹⁰⁴ This hypothetical is drawn directly from a real life experience of a vision impaired Aboriginal person, who had told the researcher that he no longer bothered applying for jobs which included having a driver's licence as a standard criteria, regardless of whether it was relevant to the job or not. As this experience was shared informally with the researcher at a break during a community forum, it is presented in this report as a hypothetical rather than a fully documented narrative interview. Nonetheless the researcher wishes to acknowledge the source of this hypothetical as coming from the Aboriginal and Torres Strait Islander disability community.



'Health' for Aboriginal and Torres Strait Islander people focuses not only on physical health but also encompasses spiritual, cultural, emotional and social wellbeing.

6.6 ACCESS TO HEALTH CARE SERVICES

Reference to the Australian Government's Plan to Improve the Outcomes of Aboriginal and Torres Strait Islander People Living with Disability:

Area 5: Aboriginal and Torres Strait Islander people with disability attain the highest possible health and wellbeing outcomes throughout their lives, enabled by all health and disability services having the capability to meet their needs.

Access and the psychosomatic dimensions of healthcare

There are multiple dimensions to Aboriginal and Torres Strait Islander health and wellbeing. 'Health' for Aboriginal and Torres Strait Islander people focuses not only on physical health but also encompasses spiritual, cultural, emotional and social wellbeing. Health is more than the absence of sickness; it is the relationship with family and community, providing a sense of belonging and a connectedness with the environment:

"Aboriginal [and Torres Strait Islander] health means not just the physical well-being of an individual but refers to the social, emotional and cultural well-being of the whole Community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total well-being of their Community. It is a whole-of-life view and includes the cyclical concept of life-death-life"¹⁰⁵.

"Health ... is a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity"¹⁰⁶.

All of the above aspects of health were raised through the testimony in one way, shape or form. Given the breadth of coverage, this section focuses on access to health services, particularly those related to the somatic aspects of health. Issues of trauma, mental health and psychosocial disability were so pervasive that they warranted a dedicated discussion in Chapter 8, which follows.

In many respects, health status is where the impact of discrimination and inequality in other aspects of life materialises. Life expectancy data for Aboriginal and Torres Strait Islander people is not disaggregated by disability status, so the statistics on self-assessed health status is the best available summary proxy for the overall quality of health experienced by Aboriginal and Torres Strait Islander people with disability. It is here in health that the inequalities experienced by Aboriginal and Torres Strait Islander people with disability are at their starkest.

105 National Aboriginal Health Strategy Working Party (1989) National Aboriginal and Torres Strait Islander Health Strategy.
106 World Health Organisation (September 1978), Declaration of Alma-Ata, International Conference on Primary Health Care, Alma-Ata, USSR

Scott Avery

Approximately one in seven Aboriginal and Torres Strait Islander people with severe and profound disability assess their health as excellent or very good (14%). By comparison, approximately one in two Aboriginal and Torres Strait Islander people without disability assess their health as excellent or very good (53%); and for people without disability the self-assessment rating of excellent or very good health is more than two in three (69%)¹⁰⁷. Based on this data, the likelihood that an Aboriginal and Torres Strait Islander person with severe and profound disability would assess their health as excellent or very good is one-fifth as likely as someone in the general population assessing themselves as having health which is excellent or very good.

Table 6.4.1: Health Status and Access Indicators, Aboriginal and Torres Strait Islander people – by disability status, NATSISS 2014

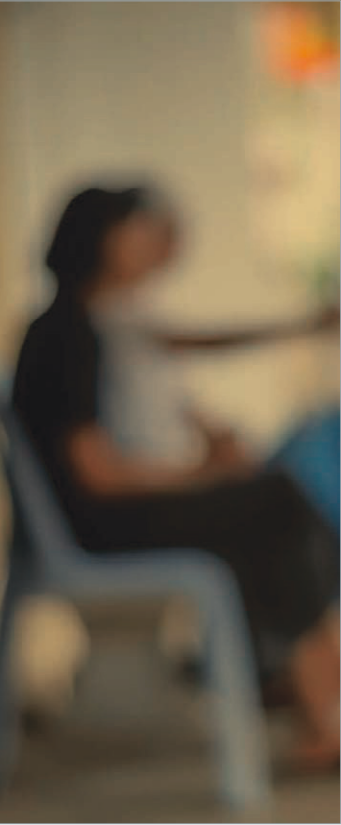
INDICATOR	Aboriginal and Torres Strait Islander people		
	With severe and profound disability	Without disability	Rate (x times likely)
HEALTH			
Self-assessed as excellent or very good	14%	53%	0.3
Difficulty in accessing health services	27%	11%	2.5
Trust in own doctor	76%	82%	0.9
Trust in hospital	54%	70%	0.8

The statistical data on accessing health care in Table 6.6.1 show that Aboriginal and Torres Strait Islander people with disability experience difficulty in accessing health care services at 2.5 times the rate of Aboriginal and Torres Strait Islander people without disability. It is not clear whether this is because of the high frequency of trips to a health care provider (ie. high frequency of health care visits means there are more opportunities for something to go wrong), or despite it (ie. whilst high frequency of visit means there are more opportunities to get things right there is some other significant factor which is an impediment to access).

Trust is the other psychosomatic variable in the provision of health care. Aboriginal and Torres Strait Islander people with disability have trust in their own doctor at a slightly lower rate than other Aboriginal and Torres Strait Islander people (76% compared to 82%), with a greater gap in the comparative levels of trust when it comes to hospitals (54% compared to 70%). On balance the participants in the research spoke about their relationship with their personal doctor casually, although there was one participant for whom a trusting relationship with her doctor was critical to their sense of personal empowerment:

"The doctor who prescribed me all this medication...but then at the age of 16 he said, "All right. You've got a choice". He said, "It's your choice now to get off the medication or continue with it". And, so I said that I'm getting off it. A few weeks after he asked to see me again just to see how I was going. He said it was the best decision I ever made.

So, I felt like finally I had a voice, you know, I feel like I could say what I wanted."



107 Australian Bureau of Statistics (2014) General Social Survey.

Diagnostic overshadowing and the intersection of institutional ableism and racism in health

Chapter 4.6 presented the body of research which has found that 'diagnostic overshadowing' can apply in the provision of health care services to people with disability when symptoms of an illness are attributed to a person's disability rather than the presenting undiagnosed condition. The disability 'over-shadows' or obscures the serious illness, and the serious illness remains undiagnosed. As a version of institutional ableism, it occurs when a treating healthcare practitioner's clinical judgement is subconsciously biased by preconceptions, prejudices and assumptions about disability. At a minimum, the quality of care to the patient with disability is compromised, but it also heightens the risk of a catastrophic health event.

The concept of 'diagnostic overshadowing' is extended by this research, which found that access to health care by Aboriginal and Torres Strait Islander people with disability is adversely affected by institutional racism as well as institutionalised ableism. One participant, a quadriplegic wheelchair user, spoke extensively on how the quality of healthcare had been compromised through diagnostic overshadowing, citing a series of incidents across a range of health care settings where practitioners did not demonstrate a working knowledge of how disability related to their area of clinical practice.

"I've had a lot of ups and downs with the health system. So, just a little interaction that I had a couple of weeks ago. Like, because a lot of people just presume, even within the health system, because I'm a quadriplegic. I can't feel from the chest down. And, I went to a podiatrist and, you know, he's

mucking around with my – with my toes and he's like, "You can't feel that. You can't" – and he's just presuming that's, you know, perception of people in wheelchairs. They can't feel from here down. But I can feel everything bar my right leg sensation wise...

And that's even in hospitals as well. Like, I've had interactions with nurses that say, "You can't feel this" or, "You can't do that." I'm like, "Hey, no. I can feel my left leg. I know what you're doing down there. Like, take it easy, all right?" "Just don't take the mickey and think you know?" So, I've had some good experiences but some bad ones as well, just because of what people presume and so forth."

Power relations between the clinician and the patient play a role. Intersectionality, which is framed in terms of power hierarchies between people in power and vulnerable population, is also relevant. The power relationship between a clinician and a patient with disability can be greater than between a clinician and a patient without disability. This narrative shows that systemically generated practice trumps patient experience in a westernised model of health care, and ultimately it is the believability of the person with disability that is contested. When institutional ableism intersects with institutional racism, as is the case with Aboriginal and Torres Strait Islander people with disability, the power differential between clinician and patient is greater again. An example of the intersection between ableism and racism, and the heightened risk of catastrophic health event, is an Aboriginal or Torres Strait Islander person with disability whose health concerns are dismissed as being alcohol related, when the clinical assessment of a health practitioner is biased because of the negative stereotyping of Aboriginal and Torres Strait Islander people and alcohol consumption.

During community consultations for this research, the researcher was informed of a critical incident involving a young Aboriginal man who required emergency treatment for severe dehydration and hypothermia. The man involved has Aboriginal tattoos and uses a motorised wheelchair, thus visibly projects his dual identity as an Aboriginal person and person with disability. He was returning home in his motorised wheelchair from an Aboriginal community meeting held outside on a hot day when his body started overheating. As his condition started to deteriorate, he made his way to a bottle shop attached to a pub, being the only place in the vicinity with ice and air conditioning. By the time the ambulance arrived, he was in a state of semi-consciousness, and whilst he could hear what was being said, he was immobile and unable to communicate with them. Even though there was no presence of alcohol in his system and a bottle of water on him that he could not open, he was under-triaged as suffering from excess

alcohol consumption, as opposed to dehydration. He recalls vividly perceiving "the looks of disgust from the paramedics, all the way through the hospital, the doctors and the nurses". It was not until he "started coming to" that the exact nature of his medical emergency was correctly diagnosed, and as soon as they realised that alcohol was not a factor, the medical staff "started backtracking".

Whilst the conditions of this case are a perfect storm for institutionalised ableism and racism, it does highlight the adverse health consequences of failing to follow through with diagnostic protocols in full when vulnerable patient groups are concerned. This is not an isolated incident. There is at least one coronial inquiry where a critical incident resulted in the death of a young Aboriginal woman, in which "premature diagnostic closure" by medical staff was found to have been present.¹⁰⁸



¹⁰⁸ This refers to the coronial inquest into the 2014 death in police custody of Ms Dhu, a young Aboriginal woman in Western Australia. Whilst the Coroner did not rule Ms Dhu's death as avoidable, the Coroner did find various errors and omissions in the diagnosis and treatment of her condition in her various presentations to a medical facility. Testimony was provided to the inquest that "premature diagnostic closure", the legal term used by the Coroner, had occurred after police told medical staff that the patient was "faking it". See: Coroner's Court of Western Australia (2016). Inquest into the Death of Ms Dhu.

Yarning piece

I want to go home... for my own blood family."

Towards the end of the morning, one of the community workers came in and asked whether one more of the men could come in and tell their story, as someone had been waiting a long time. "Of course".

In came an elderly man, with a walking stick. He was softly spoken with a gentle demeanour. He said he was sixty, but he looked considerably older. By my reckoning, he had waited about an hour and twenty minutes to speak with us whilst other men from the community centre had come in to tell their story.

Very early in the interview, I got the sense that he was lonely, and just wanted to talk to someone. He started his story by talking about how he worked on a station when he was younger, then came into town with his family. "That's where I got disability, down here", he said. He started to describe what happened, but talking about it was clearing making him uncomfortable. "It's hard to talk about. Yeah. Yeah.", he said. "Okay. That's fine. You don't need to talk about it."

We switched tack to talk about his family, then talk about some of the barriers he had faced in his life. At this point, he mentioned that he was sleeping rough. "I live at bush... Just around the town area. Just down – [pause] – we've got nowhere to sleep".

About ten minutes into the interview, the story drifts back to his health.

INTERVIEWER (I): Do you see a doctor about any health issues?

PARTICIPANT (P): Yeah. I went up there [to a regional hospital]. I've got to go – I've got to go back too. I've got this operation... I've got some pins down here.

At this point the man lifts his trouser, and points to his leg. There is a diagonal bulge covered by a scar which looks to be covering a pin, which is about an inch long and clearly visible. It was quite stark, reminding me of those flat-topped mountains that pop up out of nowhere you can see when you go driving in the outback.

I: Okay.

P: I've got a walking stick down here. That's why I can't work. Can't do anything.

I: So, you've had an operation recently. Okay. I can see the scar over your knee.

P: Yeah. Bit sore up here.

I: It's swollen. Is it sore now?

P: Just – I'm right to walk around.

I: Yeah. Yeah. Just got to take it easy. And, how long ago was that operation?

P: Well, that was one month back, with – what's the date today? That was last month.

I: And, were you in hospital for very long?

P: Yeah. Down at [the regional hospital].

I: And, how long were you actually in hospital for?

P: I've been there for two weeks...Just everything got healed up. They put – – They put pin down here.

I: Okay. I can see the size of the pin over your knee cap there. Have you got to keep going to see the doctor regularly to make sure it's all right?

P: Yeah. Yeah.

I: And, it's working good?

P: Yeah. Yep. They'll be – they'll be – they'll be calling me up here.

I: Do they come and see you or do you got to go into town?

P: No. I'm going to the big hospital, talk on these video links down to a doctor. Yeah. They'll be calling me maybe after this month. I'll be going back there to have another operation to take – take the pins out...in a month.

I: One month. All right. And, when do you go... does someone come and get you? Or – –

P: No. They put me on a bus.

Yarning piece

I: They put you on a bus. Okay.

I make a mental calculation that this would be about a six or seven hour bus ride.

I: From out there? From -- --

P: From the hospital.

I: Right. From the hospital. Okay. And, how do you get to -- from where you're sleeping at? Because, you said you were sleeping rough. Is that right?

P: Yeah.

I: How do you get there?

P: I walk.

I: You walk?

P: Yeah. Walk slowly.

I: And, how -- how many -- how long would that take you to walk?

P: Well, the hospital's a couple of blocks in. Yeah. Be about 500 metres.

At this point, I'm registering that an Australian health care system would discharge a sixty-ish year old man from hospital after a significant knee operation into a situation when he is on own his own and sleeping rough.

He then spoke of what it was like "living bush". He described it as safe, but it was cold and there was no bathroom or running water. He has to get water for himself with a bucket from the local rodeo ground, which is across the road from the camp site. Stating the obvious, I point out that this might be tough going with a crook knee, to which he laughs ironically and readily agrees.

He speaks of a common bond between him and others who live bush, and says that they all look out for each other. I ask what would happen if he needed urgent help, and he said that the people he lived with would call the ambulance to come and get him, as some of them have their own phones. He makes the point he is not the only one in his situation. "So, we need to tell the government that we've got men with a disability, living bush."

But despite sharing a common bond with his 'living bush' community, he speaks with a tinge of regret at his lack of personal space and the infringements upon his dignity. These are basic acts of living that many Australians might take for granted. He said "you can't get breakfast...because when you put it [fresh food] out there you've got to hang them up a tree and the crows come and eat, or dogs around there [if it is left on the ground]."

His family checks on him regularly and brings him food and fire wood. It is clear by his demeanour when he speaks of them that his family is his strength. But they live too far away. I ask him why he doesn't stay with them, and he replies "it's just overcrowded. There's too many people in kid's house, can't fit in". These are the words of a humble man who doesn't want to be a burden.

Despite being relatively young by Australian standards -- by my reckoning, he is some twenty five years younger than the national average life expectancy - there is already a sense of a final destiny creeping into his story. What matters to him in his future is simply a roof over his head and his family around him. When I asked are there things that he would like that would make things better for him, his response was a dignified request. "I want to go home. That's all. Yeah. Get -- get my family to come. For my own blood family. My daughters."

Scott Avery

Elevating the voice of Aboriginal and Torres Strait Islander people with disability in health care research

Healthcare research which centres the service provider as the exclusive source of knowledge cannot, by definition, detect the influence of subconscious bias upon the care provided to Aboriginal and Torres Strait Islander people with disability and other vulnerable groups. Whilst it may be suitable to centre practitioners in clinical research, the sociology of health can only be understood through promoting the voices of vulnerable patient groups as a check and balance to implicit biases that are taught, practiced and recreated through clinical education and training.

The National Aboriginal and Torres Strait Islander Health Plan provides an avenue through which the lived experience of the Aboriginal and Torres Strait Islander patient can be integrated into research, policy and practice. If it is to be held true to its vision of a health system free of racism, then by logical inference, it must hypothecate a place for Aboriginal and Torres Strait Islander people as a frame of reference for further health research, as only they are positioned to provide a critical reaction to the inherent biases built into the system that provides services to them.

The data, both quantitative and qualitative, present a compelling case that disability has a material impact on the health outcomes of Aboriginal and Torres Strait Islander people. The National Aboriginal and Torres Strait Islander Health Plan is considering the impact of racism in health, however it is completely silent on the impact of ableism. Indeed, the only activities relating to disability contained within the current implementation plan are cross references to the National Disability Strategy¹⁰⁹ and to the implementation of the NDIS¹¹⁰. This is not enough. Neither the disability sector nor the NDIS has responsibility for the provision of care within Australian health care systems. If anything, the significance of the NDIS in relation to health is as the future cost bearer of an increased and avoidable burden of disability that occurs because of institutionalised ableism, diagnostic overshadowing, and sub-optimal health care practices provided to Aboriginal and Torres Strait Islander (and other) people with disability. The current status quo can be addressed through an ongoing intersectional approach to health research for people with disability, emphasising Aboriginal and Torres Strait Islander people and other vulnerable groups.

The avoidance of suffering has an impact on quality of life and an economic benefit. The impact on quality of life is revealed in the narratives in this chapter. The economic impact will be realised in disability service provision and the full implementation of the NDIS if it becomes a cost bearer for failings in the health system

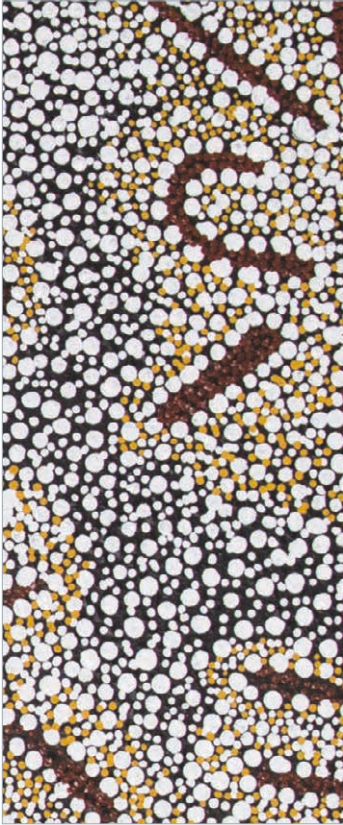
¹⁰⁹ Commonwealth of Australia -- Department of Health (2017) Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan 2013--2023. At p. 12

¹¹⁰ Ibid, at p14





7 ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE AND THE NATIONAL DISABILITY INSURANCE SCHEME



The National Disability Insurance Scheme was launched in July 2013 in a number of trial sites. One of the trial sites was the Barkly Shire, Northern Territory, which coincided with one site where research interviews were conducted. While acknowledging that it is still early days in the implementation of the NDIS, it was found to have had relatively little impact on the lives of the participants in the personal research interviews. The ‘NDIS’ or related words¹¹¹ were referenced in 11 of the 41 interviews (26.8%), for a total of 27 mentions by participants.

111 The text search included: ‘NDIS’, ‘insurance’, ‘scheme’, and ‘package’.

7.1 NARRATIVE DATA ON THE NDIS

In referencing the NDIS, not all participants mentioned having direct personal interaction with the Scheme. Two of the participants spoke about their anticipation of the Scheme’s contribution to a system-wide approach to communication and support for people with disability.

One participant expressed an aspiration that the NDIS would help them navigate ‘the system’ in positive terms:

“There’s no one to guide Deaf Aboriginals now into the wider community. And – and, really, that’s what the NDIS should be about and making sure that everybody is provided with the individual needs that are needed for them.”

Another expressed frustration that the NDIS would merely add to the systemic complexity, and highlighted a need for independent sources of communication and personal advocacy:

“Well, the system like it currently is, with NDIS. That’s another story. Another long story. It’s unbelievable.”

Other participants who referenced the NDIS did so with varying degrees of personal engagement, and varying experiences with the Scheme and its processes. Nonetheless, there was not a single participant from within the research cohort who had conveyed that they have completed, or that they understood, the process of getting a package, having a package activated, and being satisfied with the outcome.

One research participant from a metropolitan area attended the interview with a support person who acted as a personal advocate. At the time of the interview, she was not on a plan, and is best described as having just started the process. She did not have a formal disability diagnosis, and her support person was concerned that the absence of a diagnosis would be a barrier to accessing the Scheme:

“The doctor hasn’t given her a diagnosis of what’s wrong with [her]. And, I’m frightened that [she] is going to fall through the cracks and not going to be entitled to a package.”

The support worker was concerned that the participant did not fully understand the importance of the correspondence that came from the NDIS and that some letters sent to her directly may have been inadvertently thrown out.

During the interview, it emerged that there were two members of her immediate family living in the same household, with intellectual disability, neither of whom had been contacted by the NDIS, and that they too would fall through the cracks:

"I understand that the NDIS is individual. But, from what I hear, they can be flexible, as well. And, I honestly think that [she] and her two boys are going to fall through the cracks. And, they would need a package that kind of – I know they're individual, but link into each other. Because if anything happens to [her], what's going to happen to her boys? You know what I mean? They need something in their home. A structure."

Another research participant from a remote area, had secured a package for one of her sons who has a severe cognitive disability. In prefacing her discussion on the NDIS, she had spoken extensively of the difficulties that her son faced in getting an education, and due to a series of bad experiences including abuse, was not attending the only local school in the area. Despite securing a specific dollar package from the NDIS for her son, she remains highly distrustful that the package would be spent on her son and in a way that would benefit him:

"People with disability (don't) get the money that the NDIS or the government that sends them out here, you know....And, now my son missed out on an education. ... All I want is for someone to come up there, at least twice or three times a week and – and give my son an education, you know, just – well, he knows a lot but at least teach him some other things that he need to know. He's got a right to have a one-on-one teacher. I've been trying to fight for that for years."

When people get us funding there's only certain things they can use that funding for. I'm not allowed to even use that – their funding to take me and my son over there for that. I want – I want a big easel, I want some paintbrushes, I want some – all these paint things so my son can sit up there and do these things, that'll be good for his hands."

Other participants said that they were on plan that had helped them personally. Two participants had said that they met with NDIS representatives – "they've got my story there", said one – and had a plan. Whilst they felt that the NDIS had provided what they needed, they nonetheless appeared more as passive participants to a process that was happening around them, rather than being fully empowered and in control. With regard to navigating the NDIS processes, they turned to someone from within their community, not an NDIS employee for help:

"Then, I had that artificial leg for eight years, maybe. And then, 2008 I don't feel like using the artificial leg anymore. Yeah. I had to send it back to town and – and that – and, now I start – I didn't know about NDIS. I didn't know about it. Only in 2015 I know about NDIS. When I was walking around no – with the crutches now, for that many years. And, 2015, I got myself a new scooter now and I've got the scooter back home there. Yeah. About – about 2015. Then I – then I know – I realise – they told me about NDIS and that they help me out with – I get that new scooter. I didn't know – I didn't know about NDIS that many – that many years. Only 2015 and now. I didn't know – they told me – someone from NDIS want to see you. I'm thinking, who? I don't even know NDIS. This was 2015, I know NDIS."

...Sometimes I go next door here. I talk to [a male community worker]."

Another participant had said that she had had a planning meeting in relation to her two sons. She had said that she had just attended a community organisation's information session, and that was helpful:

"Where I'm – yeah. Yeah. I'm in a good place right now and I just want to move forward and hopefully

get everything I can out of the NDIS. That's going to be helpful for myself and the boys. But, mainly for them. I want them to live life like everyone else."

I've had I've had my plan done and, yeah. I have to hear – I'm – I'm thinking about, oh my god, I want a review ASAP. There's some things I want to change already in there. Just learnt some stuff that I can – oh, I didn't know I can do that."

Some participants reported extended time lapses between initial planning meetings and further communications from the NDIS, leaving them wondering what was going on with their case. One participant with a mobility impairment needing a wheelchair reported long delays in responding to modifications to her unit "not physically made for disability people but 'elderlies'" to make it more accessible. An Elder from a regional centre also said that they had had a meeting with the NDIS and asked for a new wheelchair. She was promised this, although she had not heard anything further in the month since the meeting had taken place.

Communications with local Aboriginal people are hit and miss. When one Elder was asked whether the NDIS people she had dealt with acknowledged and respected her role as Elder in the community, she replied "yes". Within the same place, another Elder was asked about disability support in the region, to which he replied "Nothing". When pressed on whether the NDIS had come to speak with him, he said, "No, they don't even speak to me. This the first time we have you mob here – [to talk disability]" (with reference to the FPDN community engagement team and researchers).



One Elder from a remote area in Central Australia said that there were people in their community who have received packages, some valued upwards of \$50,000, which they can't spend because there aren't any services in the community.

7.2 ELDERS' VOICES ON THE NDIS

Speaking on behalf of their communities, the participants at the Elders' Forum spoke more directly to their concerns about the implications of the roll-out of the NDIS in Aboriginal and Torres Strait Islander communities. At the heart of their narrative is a deep suspicion that the NDIS is yet another government stratagem that will only serve to undermine self-determining capacities within their communities.

It is not just the further infringements of self-determining capacity that concerns the Elders. They cited examples where the application of the market-based model of the NDIS is inconsiderate of the social circumstances of Aboriginal and Torres Strait Islander people with disability. These considerations do not include cultural ways of doing business, but also go to an understanding of the core living conditions that exist in some Aboriginal communities. As one example, an Elder from one remote community spoke of an absurd situation where people have been approved for substantial packages from the NDIS, but are starving and homeless. One Elder from a remote area in Central Australia said that there were people in their community who have received packages, some valued upwards of \$50,000, which they can't spend because there aren't any services in the community. But the families are going hungry, and need shelter, but they can't buy food and blankets because food and blankets are not seen as 'reasonable and necessary'.

"And the other thing that people ask for is really – we call it proper help, and proper help for our families is food – because sometimes we arrive out there, family's got no food, so we need to be able to get food for people, and that's something that the NDIS says is not a reasonable or necessary support. But if you arrive and that family's got no food, that's what you've got to deal with. You can't be talking about that physio that's coming out here in three months' time or – you've got to – it's totally counterintuitive not to respond to what's going on for that family that day..."

"Because the other thing [our Elders] pointed out to me is swags and blankets is something that our families ask for all the time, help with making sure that they've got somewhere warm and safe to sleep at night, and that's a really practical thing and we've done that for years. Like, I've been since 2004 providing swags and blankets to families, and now the NDIS is coming and they're saying, 'No, they're saying, 'We don't buy swags and blankets for people. That's' not reasonable or necessary'. But if you've got nowhere to sleep, of course swags and blankets are reasonable and necessary, so we're having – we've been having lots of arguments with NDIA and saying that they need to change the way that they do business. In Aboriginal communities, it's different, and they need to be able to respond to that difference, because otherwise, in five years' time we're all going to be sitting at a table saying, 'The NDIS didn't help much, did it?' and we don't want that. The NDIS is an opportunity and we want to make sure that Aboriginal people can access that opportunity and get the best out of it."

7.3 IMPLICATIONS

There are barriers to accessing the NDIS which even amongst the Aboriginal and Torres Strait Islander population can differ markedly. Whilst differing cultural practices are a consideration, the main difference observed during this research was lack of homogeneity in the communication and policy application by the NDIS. Communications on what the NDIS is and how it operates have been shown within this research as hit and miss. This has led to anomalies in accessing the NDIS, where in some regional areas, the difference between inclusion and exclusion could be as little as living one street further away from the town centre.

There is also evidence that the NDIS is being implemented as a transactional process, in which eligibility and supports are determined through a bureaucratic assessment using a dichotomous 'yes' or 'no' criterion. Whilst this may lead to more Aboriginal and Torres Strait Islander people receiving physical supports than they otherwise may have had access to, they are nonetheless being positioned as passive participants in the process, particularly in the absence of a strong and trusted local member of their community who can help them navigate the NDIS system. This could be alternatively described as the NDIS happening to Aboriginal and Torres Strait Islander people, which is falling short of the NDIS's promise of empowering people by giving them 'choice and control'.

At the community level, there appears to be some recognition of the status of Elders in communities within the implementation of the NDIS, although this level of recognition is not being received as universal. Elevating and promoting the status of Elders within the disability community is a strength-based pillar for the implementation of the NDIS which has positive benefits in promoting a community-wide version of choice and control. The testimony from Elders on how they have seen their role gradually eroded over time is a reminder that the NDIS is operating in an historical and policy context which has seen a diminution of control by Aboriginal and Torres Strait

Islander communities over affairs that affect them, and the erosion of their natural leadership structures.

The interpretation of what is 'reasonable and necessary support' in Aboriginal and Torres Strait Islander communities requires a much deeper interrogation. If people are starving, then food is necessary. If people are homeless, then shelter is necessary. These observations relate to the essential foundations of survival.

The observations emanating from the Elders Forum reiterate that without a basic public health infrastructure, the market-based model of the NDIS cannot operate. There needs to be a reconsideration of the assumptions that do not fit the reality, in order for the NDIS to make any sense for people with disability living in communities affected by poverty and a lack of basic utilities. Secondary implications of chronic hunger and homelessness on the future burden of disability, especially relating to childhood development, are not withstanding, and yet to appear on the NDIS's or other government agencies policy radar.

There needs to be a reconsideration of the assumptions that do not fit the reality, in order for the NDIS to make any sense for people with disability living in communities affected by poverty and a lack of basic utilities.

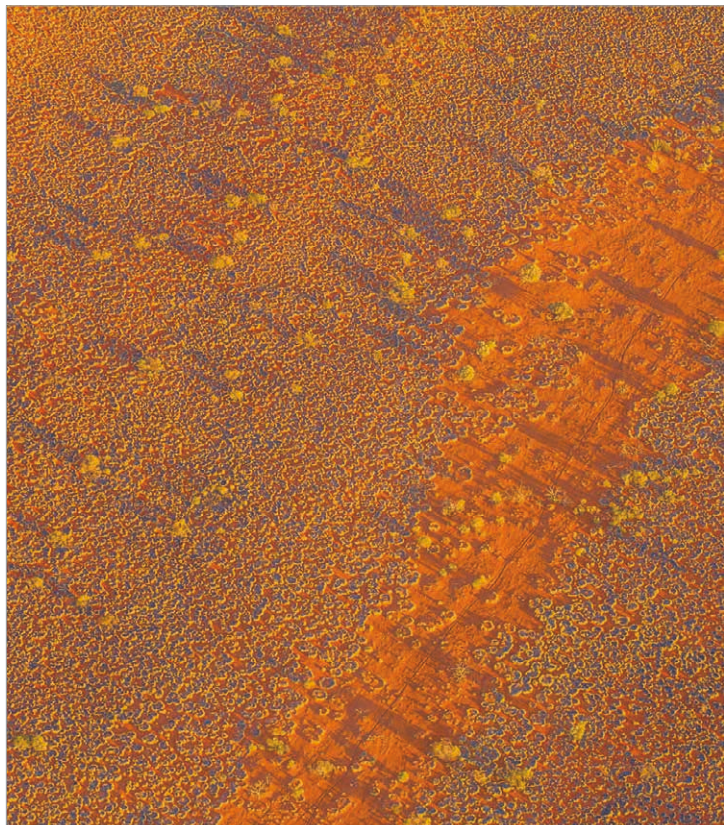
FUTURE RESEARCH:

What is the role of Elders as natural leaders of strategies for the greater inclusion of people with disability?

What aspects of a community version of choice and control are vital for personal choice and control to be operationalised in Aboriginal and Torres Strait Islander communities?

How should the concept of 'reasonable and necessary support' be interpreted in an Aboriginal and Torres Strait Islander disability context?

What will be the impact upon the future burden of disability borne by the NDIS attributable to chronic hunger, homelessness and poverty? What early mediation strategies can be put in place to reduce this burden, measured in terms of economic cost and social impact?



8 MENTAL HEALTH AND WELLBEING – TRAUMA AND HEALING



The walls of nineteenth century institutions designed to keep people with disability out of sight from the rest of society have been replaced by social walls.

Scott Avery

MENTAL HEALTH AND WELLBEING – TRAUMA AND HEALING

8.3 VARIANTS OF TRAUMA

Whilst social isolation through ‘othering’ is essentially a disability story, the nature of trauma experienced is unique to Aboriginal and Torres Strait Islander people.

Exposure to trauma presented itself in various ways in the participants’ testimony. First, there were citations that could be classified as intergenerational trauma, in which the historical hurt that has been inflicted on Aboriginal and Torres Strait Islander people has been passed down to subsequent generations. Second is personal exposure to traumatic events. Third are micro-retraumatisations, in which exposure to everyday discrimination triggers negative thoughts.

Intergenerational trauma is the historical legacy in a person’s narration of their own contemporary history. The two unresolved traumas, both associated with colonisation, and very current, which continue to loom large in the lives of Aboriginal and Torres Strait Islander people are the threats of incarceration and death in police custody, and the Stolen Generations and removal of children from their families by the State.

“That’s straight out because he’s Aboriginal and because the police are taking the law into their own hands here. The police hung someone here before. The police killed a black person, they hung him in jail here. Not only that, there was other unexplained deaths here.”

“I’m very proud of my great-grandmother. She was a part of the Stolen Generation, and she [has severe mental health issues].”

“You know, we’ve had bad experiences with the Stolen Generation where – you know, the white Australians came in and they took all our children and they took them to the Mission and that’s where my uncle was from. And, I remember once – you know, with the stolen generations one of my uncles had disappeared and I remember all the families being really upset during that time.”

“Like, and I’ve always gained, like, my confidence from, like, because my grandfather from the Stolen Generation and you know, he – the hardships that he went through when he grew up.”

“I did not know I was an Aboriginal descendant until I was 24. My dad was nearly a Stolen Generation. His mum died after their last sibling was born.... So, that was really, really scary when Dad told me. So, they tried to be as white as they possibly could.”

“So, basically, how to do I start? So, I’ll start with my mum, ‘cause it sort of stems from there. So, my mum was part of the Stolen Generation. And, she spent, from the age of four until she was 18 in the homes. So, growing up with my mum, sort of, impacted me, as a person.”

The second variant of trauma that was evident through the interviews is a personal exposure to traumatic events. As Chapter 6.3 highlighted, there is an extraordinarily high personal exposure to traumatic episodes amongst the participant group. More than one in five of the participants referenced a personally traumatic event in their life, which included people close to them being murdered; the unexplained death of a child; sexual assaults; and being subject to violent assaults with a weapon.

The ever-present threat of child removal provides a nexus between the intergenerational traumas of the past and the traumatic events of the present. One participant provided a detailed and frank account of raising two sons with autism and intellectual disability as a single mother. The pathway of this testimony incorporated the range of aspects previously mentioned in relation to social isolation that she encountered as a carer of two young men with disability: from communication barriers her boys experienced in their education; avoidance of public transport; trouble in getting suitable accommodation; inappropriate schooling; experiences of her sons’ fear of going to the doctor, or getting their hair cut; to wheelchair inaccessible housing.

This has manifested into mental health issues of her own, with periodic treatments in a rehabilitation facility. The escalation of her own distress, and in the telling of her testimony, came when the state based community services agency arrived without notice to remove her children from her care. She spoke of being “so frightened” and “they just intimidated me and I was just frightened and I just – I didn’t know what my rights were really.” Summarising her emotional response to the removal of her children from her care, and her subsequent interactions with the state government agency, she said:

“Basically, because they were taking the kids away. And then – so, that happened which was very traumatic. Yeah. It was like someone had – it was like my boys had died.”

Statistically, there is an intersectional effect in the incidence of traumatic event that Aboriginal and Torres Strait Islander people are exposed to. They are fifty percent more likely to have been removed or had a close family member removed from their family, or death of relative or close friend; and twice as likely to have experienced a serious health issue.

Table 8.3.1: Trauma Exposure Indicators, Aboriginal and Torres Strait Islander people – by disability status, NATSISS 2014–15.

INDICATOR	Aboriginal and Torres Strait Islander people		
	With severe and profound disability	Without disability	Rate (x times likely)
Removed and/or family member removed from family	50%	37%	1.4
Death of family member or close friend	37%	25%	1.5
Serious illness	26%	8%	3.3

The chapter on intersectional discrimination noted the high frequency with which Aboriginal and Torres Strait Islander people were exposed to various forms of discrimination in their everyday life. In one example, a young Aboriginal man described being racially abused on his walks home from the town centre. Others spoke of being asked to leave shopping centres and eating places. These everyday incidents of racism and ableism, happening as frequently as they do, act as a succession of micro re-traumatisations, which accumulate and keep people in a state of despondency.

How people spoke of being isolated because they were Aboriginal and Torres Strait Islander person differed to how they spoke of being isolated as a person with disability. As a person with disability, they spoke of being ignored, as if their existence did not matter. As an Aboriginal and Torres Strait Islander person, they were recognised, but in being so were subject to intense racial vilification. The disability dimension of isolation is omnipresent, in that it is built into their environment that they could not avoid or escape. Whilst the racial dimension was more episodic, when it arose, it did so with an intensity that was personal. However, for an Aboriginal and Torres Strait Islander person with disability, the disability and Aboriginal and Torres Strait Islander dimensions to their isolation co-exist, hence there is both constancy and acuity to their social isolation.



The ever-present threat of child removal provides a nexus between the intergenerational traumas of the past and the traumatic events of the present.

8.4 THE MANIFESTATION OF PSYCHOLOGICAL DISTRESS

The cumulative effect of discrimination and trauma exposure manifests into various stages of psychological distress, which can be equally or more debilitating than the impact of disability. What disables Aboriginal and Torres Strait Islander people most is not broken ears, broken eyes or broken limbs, it is a broken spirit.

The pattern of intersectionality continues when it comes to mental health outcomes, outlined in Table 4.1. Aboriginal and Torres Strait Islander people with disability are 5.2 times more likely to experience mental health distress compared to Aboriginal and Torres Strait Islander people without disability, and also elevated rates of alcohol and substance misuse.

Table 8.4.1: Mental Health Indicators, Aboriginal and Torres Strait Islander people – by disability status, NATSISS 2014–15.

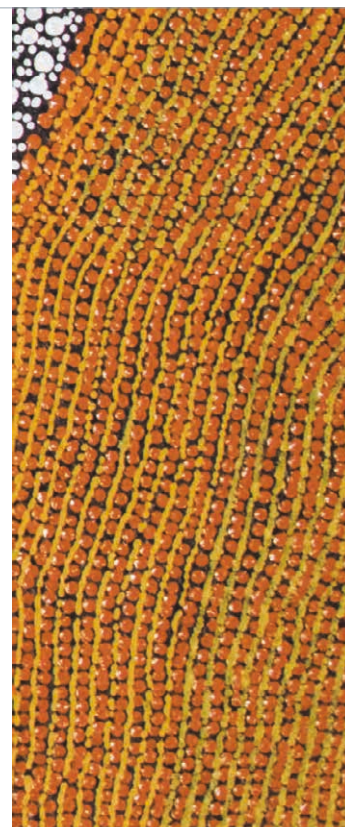
INDICATOR	Aboriginal and Torres Strait Islander people		
	With severe and profound disability	Without disability	Rate (x times likely)
Mental illness	26%	5%	5.2
Drug related problems	9%	3%	3.0
Alcohol related problems	8%	5%	1.6

The majority of participants reported experiencing trauma or distress, either currently or in the past:

"I go through my ups and downs, my phases of depression with it and – but, you don't let it control your life. It's hard. There are days when I – I don't want to face the day. I'll just get up, have my shower and I'm going back to bed."

In exploring the relationship between community ties and wellbeing, the participant group can be categorised into two distinct cohorts; one cohort are living in remote communities, the other cohort are living in metropolitan areas. For people living in remote areas, the access to health services was relatively low compared to metropolitan areas, so appeared as concentrations of people with physical disability which could be attributed to mismanaged healthcare (eg. clusters of people with amputations attributable to diabetes). However, these group of participants tended to speak more positively about their ties to community and how their community looked after each other. This sentiment is evident in the yarnning piece with an elderly man living rough in Chapter 6.6.

For people living in metropolitan areas, access to health services is greater, but this cohort of participants was more likely to report more acute signs of psychological distress. They were also more likely to assert their Aboriginal identity by stating the Aboriginal nation they identified with in their introduction, (whereas people in remote communities were more likely to mention what town or area they were from rather than their Aboriginal nation), display Aboriginal tattoos, or wear clothing which would identify them as Aboriginal. These symbols were portrayed as a source of pride by the participants, and may be reflective of their seeking psychosocial proxies to their Aboriginal heritage to compensate for a lack of direct physical, connection to their home community.



8.5 LIMITATIONS OF CLINICAL MODELS OF MENTAL HEALTH

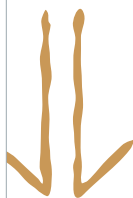
It was rare for participants to use clinical diagnostic terms when describing their mental health status. Despite the high rates of traumatic episodes that the participants were exposed to, only four of the forty-one interviewees used the terms 'depression' or 'anxiety'.

Indeed, clinical models of mental health appear grossly inadequate in describing the prevailing sense of sadness and abandonment. Many people maintained that they were seeing counsellors, "as they are supposed to", but found them ineffective in relating to their experience, both as an Aboriginal and Torres Strait Islander person and as a person with disability:

"If that person – psychiatrist was a deaf person, or if they understood me or understood Indigenous people, it might be better. But at the moment I'm trying to work my way back into the Deaf community. I just resigned from work three weeks – a month ago because it was really affecting my mental health. I had anxiety attacks. I ended up in hospital because of anxiety. It became too much for me."

Others mentioned seeking to compensate for gaps in the clinical model of mental health service provision by sourcing cultural models of healing:

"So, on the coast there's an organisation called Cultural Healing. It's an Aboriginal organisation and within that team they have mental health workers. So, I go to them if I need help. But they're not part of the unit? [disability support unit], they're separate."



8.6 TRAUMA AS AN INFECTIOUS DISEASE

The research also noted the presence of 'trauma clusters', where there were large proportions of people in a small community who displayed signs of trauma. The tight-knit nature of these communities meant that everyone within that community has had some personal or community exposure to trauma.

Scientific literature is inadequate in explaining the overwhelming sense of sadness and abandonment that is felt in communities. Not only was it felt by all of the people within the community, the overwhelming sadness and despondency was also felt by the researchers when visiting those communities. This experience of 'catching trauma' can't be described using the normal vocabulary of a researcher. The most apt description of the personal experience that came with witnessing intense concentrations of people affected by trauma during the research is crossing a boundary line and entering another world.

The vicarious nature of trauma was observed in these small communities as operating more like an infectious disease within a community than a bio-medical condition of an individual. In these cases, daily re-traumatisations are almost guaranteed. In effect, individuals who have experienced personal trauma are in a community engulfed by trauma.

Despite the prevalence of community-wide trauma, and its contagious nature, the interventions that people spoke of were individually focussed psychotherapy. The dominance of cognitive behavioural therapies as a solution to trauma are again an example of personal agency taking the place outside the environment in which the individual exists. The environmental context in which people live renders their individually focussed therapies useless. In this respect, depression and alcohol misuse become trauma suppressants, (as opposed to clinical diagnoses as they might be regarded in a clinical model of mental health). Further, the evidence in this research, both statistical and narrative, suggests that depression and alcohol misuse appear to have greater efficacy as a coping strategy than clinical models of cognitive behavioural therapy.

8.7 EMBERS OF HOPE

Alongside a sense of despondency in many communities, there is a strong narrative of resilience and survival. This presented itself through a variety of emotions, ranging from anger, defiance, and even humour.

There were embers of hope which shined through. The holding of hope was captured by one participant from a community in which there were excessively high rates of trauma, who said:

"There is something stronger in here",

pointing to his heart,

"but I've just got to get there."

All the communities and the people who participated welcomed the research. People wanted to tell their story. In some places, the participants lined up and waited, some for more than an hour, to share their life experiences through the research. Some of the participants even expressed their gratitude at being able to share their experience.

The response by the Aboriginal and Torres Strait Islander disability community as participant-owners of the research reinforces a process in which 'lived experience' as testimony, being heard and being believed, is critical in the process of healing and transformation. Narrative models of social transformation as used in this research have reach beyond the Aboriginal and Torres Strait Islander disability community, and can be applied more broadly to address vulnerability in other marginalised populations.



Not ruined by the sadness

The interview is approaching the half hour mark, and with some idle chatter, the discussion is starting to peter out. I look to close out the interview by providing an opportunity to put on the record what she hasn't already spoken about. Then comes a bombshell disclosure.

INTERVIEWER: So, this is your story, and I'm just wondering if there's anything that you wanted to say for the record, that you feel like, you haven't spoken of already. You don't have to say anything, but if there's something that you just kind of go, 'I want to be able to say this', given that we're collecting your story. Is there anything over and above what you've spoken about already?

PARTICIPANT: There is one thing. Like, the main thing that keeps me going is, like, my girlfriend actually committed suicide five months ago.

The revelation and its timing came as a bolt from the blue, as we had already covered so much personal terrain – education, employment, health, transport – during the interview. It has only come at the last moment when things appeared to be winding up, yet it was sitting there all along. It speaks to the intensely personal nature of suicide and trauma, and how its impact can remain buried, despite feeling that you are in on an open and transparent discussion.

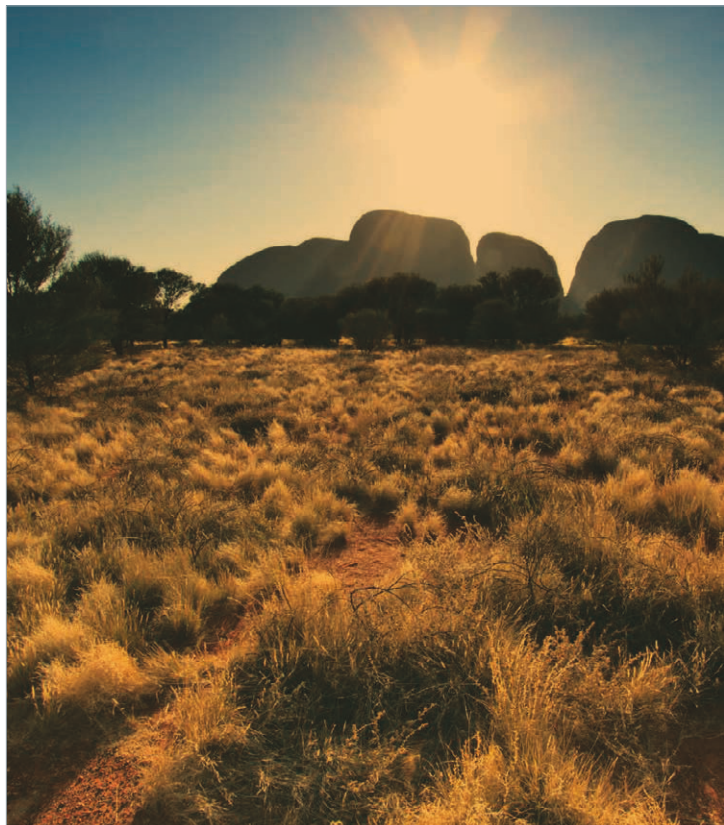
The discussion re-opens again. It's like we start over again.

She reveals the closeness of their relationship, and how it had impacted upon her at a time she was having her own health concerns. I remind her that it's okay for her to stop if it's making her feel uncomfortable talking about it, but she says it is something she wants off her chest.

"It's like there's a lot of stigma around suicide as well and I think, it needs to be talked about a lot more and a lot more people need to be educated about not only suicide, but mental illness and the whole, like, aspect and everything about it as well. And, just the whole treatment needs to be improved, no matter if it's public or private. It all just needs to be improved."

In the face of the personal impact of multi-faceted discrimination and trauma, she has transformed her personal experiences into a source of strength. It is the authenticity of her lived experience of disability and trauma that shines through as a penetrating insight into how resilience is made intrinsic to people with disability. It does not come across as a belligerent 'stuff you' to the world. Instead, it is a desire that her experiences of distress are a beacon to circumvent the unnecessary distress experienced by others. It is representative of a worldview of humanity that I come across in the disability community, time and time again.

"It really did show me that, like, instead of letting it, like, ruin me with sadness, I just really want to use it to change peoples' lives and to motivate me to get my degree, to get out there and to make change happen to improve the system, and to prevent this from happening to other people...It has really inspired me just to continue and just to continue to improve the system and just to keep going and, yeah. Not only for myself, but for her."



9 CULTURE IS INCLUSION: A FIRST PEOPLES CULTURAL MODEL OF DISABILITY

KEY FINDINGS

- Aboriginal and Torres Strait Islander people with disability participate in social activities and events within their community at the same rate as Aboriginal and Torres Strait Islander people without disability.
- The parity in social participation by Aboriginal and Torres Strait Islander people with disability within their communities is the categorical exception to the inequalities that they experience in their interaction with systems and supports outside their community structure.
- Inclusive participation in cultural and community events has a positive impact on social health and wellbeing and moderates the harm of inequalities experienced in daily life.
- This finding is a contemporary expression of a culture of inclusion that has survived despite other disruptive influences upon community functioning.

9.1 PARITY IN CULTURAL AND COMMUNITY PARTICIPATION

Parity in cultural and community participation by Aboriginal and Torres Strait Islander people within their communities is reflected quantitatively through data drawn from the NATSISS, as presented in Table 9.1.1.

For all indicators on cultural and community participation collected by the NATSISS, from general indicators, Aboriginal and Torres Strait Islander people reported participation in cultural and community events, including involvement in ceremony, speaking an Indigenous language, and other cultural activities, at the same rate as other Aboriginal and Torres Strait Islander people. Parity in the participation of cultural and community activities is reflected in the indicators by participation rate of Aboriginal and Torres Strait Islander people with disability which is 1.0 to 1.1 times that of Aboriginal and Torres Strait Islander people without disability.

Table 9.1.1: Cultural Inclusion Indicators, Aboriginal and Torres Strait Islander people – by disability status, NATSISS 2014–15.

INDICATOR	Aboriginal and Torres Strait Islander people		
	With severe and profound disability	Without disability	Rate (x times likely)
Participated in cultural activities	62%	65%	1.0
Involved in ceremony	67%	62%	1.1
Identifies with clan, tribal or language group	67%	61%	1.1
Speaks an Indigenous language	20%	19%	1.1

The parity of cultural and social participation by people with disability in Aboriginal and Torres Strait Islander communities is the categorical exception in the data on the inequalities that Aboriginal and Torres Strait Islander people with disability experience with respect to their access to 'mainstream' services, such as access to disability services, healthcare, employment and education referred to in Chapter 6. As a population wide result, Aboriginal and Torres Strait Islander people with disability experience social inclusion within their community structures, but regress towards social isolation upon leaving the protective forces of their community structures and start interacting with systems outside.

9.2 NARRATIVES FROM A LIFE OF CULTURAL INCLUSION

A longing for traditional Aboriginal and Torres Strait Islander cultures seeped through into the narratives.

For some, cultural longing took a form of reminiscing the 'good old days' when traditional cultural values dominated social life:

"Sharing and caring was with our people before white people came to this country. Responsibility was with the family and the community."

For others, the reminiscence was far more personal, recalling days when they could do things that they physically could no longer do, but had managed to maintain a spiritual connection with cultural life, just by being there. One of the participants, an Aboriginal woman using a wheelchair, spoke of her younger days when she was a hunter-gatherer for her family:

"Hunting. Camping out. Hunting. Always. Then we lived and we raised – I raised my first son so we didn't go out – we did go out just for a day, come back, go out the next day, go and get bush turtles. Go at night time shooting kangaroo."

Nowadays, her mobility impairment means that she doesn't get into the thick of the hunting, and that role has now has passed to her husband, (who, by her account, isn't as good at sourcing traditional foods as she was, so sometimes they just have to go to the shop and buy things). However, she maintains a spiritual and emotional connection to the traditional life, which is one of inclusion:

"We go hunting together. He goes out, I sit in the car and wait when he goes out hunting."

The operative pronoun in this narrative is the use of the collective 'we', not the singular 'he'. 'We go hunting'. Despite not being the one who physically throws the spear, she is emotionally and spiritually connected to the activity. She is included.



Art has a particularly special place in cultural life of people with disability as a facilitator of their inclusion. In some cases, art was presented as a means of communicating between generations, and between Deaf people and the hearing world:

"[My grandmother], she used to teach me a lot of things. You know, she taught me all about Aboriginal art, and she didn't know how to sign, and I didn't know how to communicate with her, but I've become very successful with my Aboriginal art, so I'm really proud of my grandmother." ¹¹³

The affirming properties of art as 'story-telling' emerged as people spoke of their art as a way that they could personally connect with their own personal Aboriginal and Torres Strait Islander heritage:

"I've worked in disability for the last ten years specifically with Indigenous disabilities. So, about eight years ago I started painting. And, I'd always liked painting but, kept saying to my partner at the time, I've got these paintings in my head I want to start doing some stuff... For my 50th birthday she bought me a canvas and paints and said, "Look, stop talking about it, just do it." And, that totally had a whole new chapter in my life with the art. [I gravitated to] the dot style painting. Traditional stuff. Telling stories." ¹¹⁴

Others had extended their personal connection with culture through art by promoting it as a medium to connect to others and to their community and culture:

"So, some of the good stuff I'm doing now is part of [an Aboriginal] Art Group, that Uncle runs. So, it's an art group for people with disabilities. So, I've done a lot of, like, paintings and stuff that have gone on exhibition so that, sort of, keeps me strong. Because I like my art and I look forward to doing it. I find it really helps with stress." ¹¹⁵

113 TRS
114 TR26
115 TR28



"Sharing and caring was with our people before white people came to this country. Responsibility was with the family and the community."

Scott Avery

There is a risk of over-romanticising the culture of inclusion, as it is not perfect. A small number of cases emerged, particularly within the Deadly Deaf Mob, where their aspirations for cultural inclusion had not been realised. One Deaf Aboriginal person spoke of wanting to participate in the local Land Council, but had been denied access to an Auslan interpreter, with funding constraints cited as the reason. His self-advocacy for his right to participate came as a shock to them "because they'd never heard about people with disabilities wanting to be involved", but through persistence he is now a member and an active participant.

"But, the issue I have is the communication and sometimes they do struggle with the fact that I'm a deaf person. I would like to have an interpreter turn up to NAIDOC week. Maybe we could have a deaf organisation represented at NAIDOC week because it represents all the deaf Aboriginals."

This experience serves as a point of reflection for Aboriginal organisations who are the service providers, representative bodies and advocates for Aboriginal and Torres Strait Islander people, that they remain grounded in the culturally inclusive traditions that are innate in the social life of communities. There is a temptation for Aboriginal organisations to mimic the non-inclusive systems and structures they are required to interface with, but cultural authenticity will come through, grounded in the traditions of inclusiveness.



9.3 A FIRST PEOPLES CULTURAL MODEL OF DISABILITY AND INCLUSION

The narrative opens up the prospect of culture as an affirming and inclusive force in the health and wellbeing of First Peoples with disability.

The metaphysical dimension of cultural inclusion upon wellbeing is unintelligible to orthodox science, which is not yet able to observe or explain how it works as a phenomenon. However, the presence of culture is real and it is there in the narratives. Narratives such as “we go hunting together” all point to a higher conceptualisation of social participation, one that is over and above the physical undertaking of a particular function or activity, albeit one in which western scientific thought does not yet have the capacity to explain. It is a phenomenon which happens innately in Aboriginal and Torres Strait Islander communities, and for an Aboriginal and Torres Strait Islander person, it is logical and rational, and the evidence shows it to be as effective as any other disability aid that the disability support system has to offer.

Rather than being rebuked for its unknown, abstract qualities, divining the metaphysical properties of culture into a practice and policy model of support for people with disability presents something of a new frontier of scientific enquiry. It may take ten, twenty or even one hundred years to understand the phenomena of culture using the language of western science. It may also be that we are never meant to know. But in looking at the current state of the evidence, connecting people with their First Peoples culture is most likely to rapidly improve their quality of life.

Aboriginal and Torres Strait Islander people with disability will still walk in ‘two worlds’, their Aboriginal and non-Aboriginal world. The numbers and the narratives presented in earlier chapters show that on

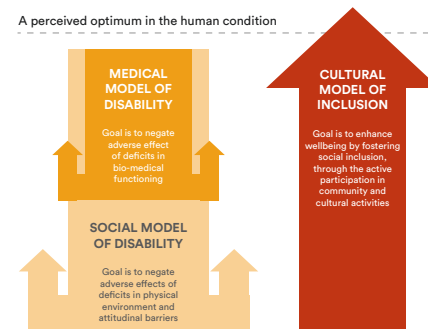
balance Aboriginal and Torres Strait Islander people with disability experience the worst of both worlds, in that their cultural normalising of disability means they do not access services at the level they need, yet they still suffer from the ill effect of negative stereotyping, labelling and discrimination. Aboriginal and Torres Strait Islander people with disability face a conundrum in trying to improve their position – in order to access the services they need in a non-cultural model, they effectively have to disable themselves, a concept that is antithetical to their core cultural beliefs.

The therapeutic potential of a cultural model of inclusion is illustrated by contrasting it to other interpretive models of disability, namely the medical model and the social model of disability, mentioned in Chapter 2. Both the medical and social models frame disability as a deficit against a perceived optimum human condition. As an interpretive model, the medical model presents disability as a deficit in bio-medical condition. The medical model of disability aims to mitigate the adverse bio-medical impact of what is perceived as a negative cognition, and the utopian end-point is cure. As an interpretive model, the social model of disability presents the deficit in terms of the environment, which may be either the built environment (eg. housing, footpaths in remote communities) and/or the social environment (eg. attitudes barriers, stigmas and discrimination). As an interpretive model, the goal of the social model is to overcome the defects in the environment, and its utopian end-point is to accommodate people within a fully inclusive community in which negativity in the environment does not exist.

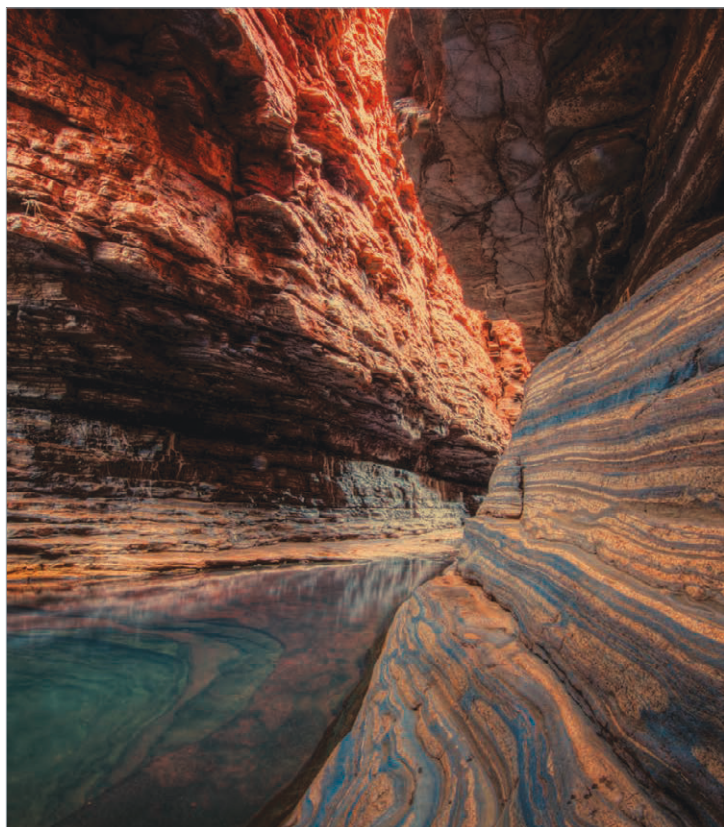
To reiterate, in both the medical and social models of disability, the goal is to reduce the impact of a perceived negativity against a perceived optimum.

A First Peoples cultural model presents a philosophically different approach based on the premise that there is ‘no world for disability’, hence negativity is not observed. In this respect the utopian end-point of the medical and social models of disability – cure and accommodate – is the starting point of an Indigenous cultural model of inclusion. By contrast, the First Peoples model is the only model that seeks to improve the human condition through positive affirmation, as distinct to merely negating the adverse impact of difference. The affirmative philosophy of a First Peoples cultural model of inclusion, and how it can co-exist with medical and social models of disability, is illustrated in Figure 9.3.1 below:

Figure 9.3.1: Comparative philosophies of medical and social models of disability and a First Peoples cultural model of inclusion.



As stated early in the chapter, the status of the research is not sufficiently advanced to be prescriptive on how this translates into policy and practice. Instead, a model of cultural inclusion is presented as a vision and direction for a future Aboriginal and Torres Strait Islander disability research agenda.



10 A FIRST PEOPLES DISABILITY RESEARCH AGENDA



Establishing a cultural model of inclusion sets a positive direction for advancing the health and wellbeing of Aboriginal and Torres Strait Islander people within a research, policy and practice development agenda.

There are steps to get there. As extensive as the issues covered in this report have been, it is a synoptic overview and further depth in the knowledge base is needed. Issues such as the social and cultural foundations of inclusion, and the impact of colonisation from a disability perspective, have only been touched on in the opening chapter. Chapter 4 provided an initial screening of the data to establish baseline prevalence and profile of Aboriginal and Torres Strait Islander disability, but the data is rich and further iterations and analysis will bring greater insights.

Chapters 5 and 6 showed how Aboriginal and Torres Strait Islander people suffer greatly from the effects of multiple forms of discrimination, both in people's attitudes and in the systems that provide support to them. Much of the discussion has focused on the detrimental impact of institutionalised bias and discrimination. Exposing the harm that Aboriginal and Torres Strait Islander people with disability are exposed to is only an initial step in elevating awareness of bias from the unconscious to the conscious. The next step is a collective focus from researchers, public service agencies and practitioners on reform of delivery systems to stem the flow of harm.

The other area of research development is continuing a First Peoples disability research philosophy. This is the work program on the community-led research processes which underpin each of the thematic research areas. Community-directed research is an emerging area in social policy research, and the participatory method utilised for this research sets a precedent for continued innovation in community-based research. As a model of research, it could conceivably be exported into a project involving other marginalised groups within Australian society, and taking an international perspective, other Indigenous peoples worldwide.

There are four research streams proposed to set the direction for future First Peoples disability research.



Stream 1:

The Cultural Foundations of Inclusion

This research provides a snapshot of the contemporary narrative from Aboriginal and Torres Strait Islander people with disability, but the historical narratives are still unaccounted for. The introductory chapters only provide a fleeting reference to the cultural and social context of Aboriginal and Torres Strait Islander disability and serve as a pointer to a fields of further inquiry, such as the cultural dimension of inclusion and a disability perspective of colonisation.

This research has avoided using scholarly theories of colonisation as this is not the language that the participants used. However, looking forward, critical theories of colonisation theory can be used to segment this stream into three perspectives:

- **Pre-colonial perspectives:** This perspective entails a further understanding of how disability and diversity has evolved within Aboriginal and Torres Strait communities, including nuanced variations amongst Aboriginal and Torres Strait Islander cultures, from the time of the one-legged Mungo man until colonisation.
- **Post-colonial perspective:** This perspective entails a further exposition of the legacies of colonisation, how the importation of a western model of disability has pejoratively affected Aboriginal and Torres Strait Islander people, and the collision in the histories of the incarceration of Aboriginal and Torres Strait Islander people and the institutionalisation of people with disability.
- **Neo-colonial perspectives:** this perspective is a future focused perspective of how Aboriginal and Torres Strait Islander peoples with disability can be empowered as a minority in a post-colonial nation, encompassing questions such as; What does reconciliation, treaty and restitution means for a people with disability as a marginalised group within a broader marginalised population?; and How do political strategies for empowerment interface with wellness and healing approaches to empowerment?

Stream 2: Mitigating Systemic Harm

Chapters 5 and 6 revealed a consistent pattern of discrimination within the support system and consistent and acute forms of discrimination and inequality that Aboriginal and Torres Strait Islander people with disability report experiencing. In summary, to positively progress the quality of life for Aboriginal and Torres Strait Islander people, strategies need to be developed to mitigate the harm that they are currently exposed to.

Exposing the discrimination and its institutional nature has been a key outcome of this research. One of the defences of institutionalised discrimination is unconscious bias, or 'I did not know'. This research has elevated awareness on the incidence and nature of discrimination from the unconscious to the conscious. So now you know.

The next steps in the research stream are how to dismantle the discrimination within the system. This will require collaboration and critical reflection with those who run the systems. The Australian Government's Plan to Improve Outcomes for Aboriginal and Torres Strait Islander people with disability provides a structure for this, and the future focussed studies building upon this research can be organised accordingly:



Inclusive communities



Justice



Education



Economic security and employment



Health

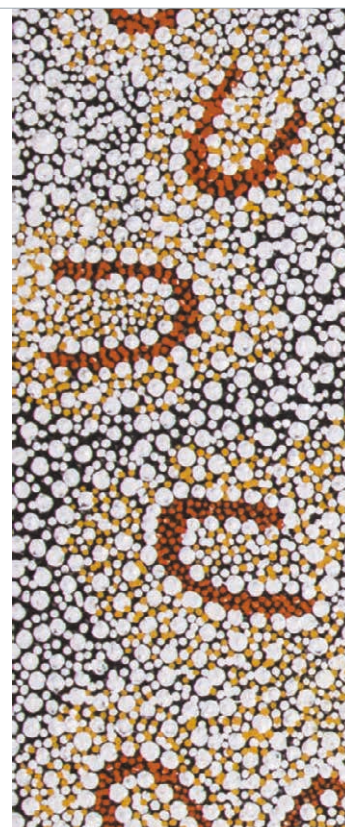
Whilst this research has extensively discussed racism and ableism as forms of discrimination, these two forces alone appear to fall short in explaining why there has been so little systemic reform responding to the substantial evidence of unequal access. If it is accepted on face value that there is a critical mass of people working within the system who as individuals are well-meaning and capable, then this leaves the question: why is it that so many well-meaning and capable people are unable to change an inherently racist and ableist system?

This reflection points to a potential third category of bias over and above considerations of racism and ableism – the "too hard basket". There is support for this hypothesis coming from recently released neuroscience research, which shows the perception of difficulty in performing a task has as much impact upon cognitive bias as the actual difficulty of performing a task.¹¹⁶ In other words, just thinking something is too hard to begin with is enough to avoid action, even if the action is not actually as hard as it looks. Working within siloed systems of support, ill-equipped to deal with complexity, the issues within this report may appear imponderable. Further research is needed in how to undertake meaningful reform of complex systems that is sensitive to issues of intersectionality. There are two suggested aims for this research focus:

- to untangle the unnecessary complexity in the inter-connectivity of disability support systems; and
- to directly address the subconscious perception of complexity in the administration of social programs, where it does not exist.

In solving these problems, the community-directed methods used in this research can make a different type of contribution to research activity. This research has positioned the First Peoples disability community as unique holders of 'insider' knowledge on their own lived experience. This is a position that can be transposed to providers of an independent 'outsider' perspective in research that critiques the support systems which they do not run, but are served by.

116 Hugura N., Haggard P., Diedrichsen J., (2017) 'Perceptual decisions are biased by the cost to act' eLife 2017;6:e18422.



Stream 3: A cultural model of inclusion for policy and practice

This stream of research involves the translation into policy frameworks and practice models. This stream of research closely aligns to stream 4 of the research agenda, which is the ongoing infusion of a First Peoples disability research methodology in the development of practice standards and protocols.

The size and scale of the implementation of the National Disability Insurance Scheme in Aboriginal and Torres Strait Islander communities is enough to warrant its own line in a research agenda.

Whilst this research project was not designed as an evaluation of the NDIS, it nonetheless provides baseline data on issues requiring closer scrutiny in future evaluations. It has also unearthed a number of significant limitations to its establishment design principles, particularly around what constitutes 'reasonable and necessary support' in regard to the social circumstances of Aboriginal and Torres Strait Islander people with disability. It also noted that there is no apparent attention to avoidable costs within the research, and what early interventions are required to relieve future cost burdens upon the Scheme that will otherwise be inherited through failings in systems that are antecedent pathways to the NDIS.

The chapter on inclusive communities showed that access to technology in the provision of fit-for-purpose disability aids is particularly poor in remote Aboriginal and Torres Strait Islander communities, who are currently reliant on work-arounds which mask failings in support systems. Increased use of technology, particularly when driven by Aboriginal and Torres Strait Islander people's cultural knowledge, provides exciting potential for innovation research with rapid advancements in social impact.

Finally, the continued development of an Aboriginal and Torres Strait Islander disability information strategy, which is commensurate with the size of the sector, runs parallel to policy practice development. This project has shown how putting data in the hands of community is a form of empowerment which can drive social change. Beyond the transformative power of data and knowledge from a social perspective, it serves a practical function in providing the tools for business planning and risk management to support the economic development of a sector in growth.

Stream 4: First Peoples disability research methodology

This research has redefined what grounded research looks like in practice, when led by community. Its legacy is a First Peoples disability research philosophy, underpinned by ethical principles for research in marginalised and traumatised populations, respectful of community protocols, and capable of delivering research outcomes.

There is an increasing desire coming from within the research community to become involved in research with populations that experience vulnerability, but there is not a lot of knowledge that exists on how to do it safely and respectfully. Within the published academic literature, community based research methodologies are sparse.

There is a sense that aspects of the First Peoples disability research philosophy can be replicated, but the organic pathways that this project took will need to be critiqued and refined to assess how and in what circumstances this can be transported into research methods involving other marginalised groups.

The four streams proposed for the First Peoples disability research agenda are presented in the attached diagram.

Elevating a vision of culturally-led inclusion

Whilst there was a research brief to be met, the underlying motive for this study was always about elevating and promoting the voices of Aboriginal and Torres Strait Islander people with disability.

In pursuing this research agenda, it is important not to lose sight of the vision and aspirations expressed by Aboriginal and/or Torres Strait Islander people with disability, which is for a life in which they can freely embrace their Aboriginal and/or Torres Strait Islander identity and/or their disability identity as they so choose, strengthened by family, culture and community. It is a vision for the best of two worlds, one which provides access to support they need, but without the labels.

Keeping with the spirit of this document as a narrative owned and told by the First Peoples disability community, a final word on this vision goes to one of the participants of the research:

"Look, I'm very proud because I've got two identities of who I am. And I want to say thanks to Mum for moving to the city to give me a better education. And, thanks to my dad for, you know, making me who I am today. So – and the positive and being, you know – my life experience of the main culture and the cultural changes that I've experienced... I've learned to accept diversity, you know, of all different communities. I've learned to accept that. And, the positive... to what I've achieved to now is because of my parents. If it wasn't for my parents – I've got a good job now. I've got good qualifications. And, I've got a beautiful family. And, what more can I have? That's why I'm happy."

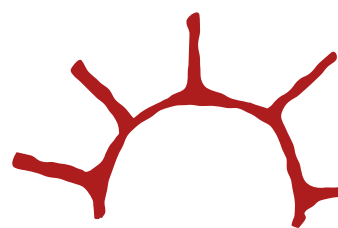


Figure 10.1 A First Peoples Disability Research Agenda





EPILOGUE

A prospectus for community-directed service development

As an exploratory study, this research has laid out a business case to address the specific needs of Aboriginal and Torres Strait Islander people with disability. The issues have been laid bare with honesty by Aboriginal and Torres Strait Islander people with disability themselves.

It is also a prospectus for doing business the way of the First Peoples Disability community. The First Peoples disability community members are the custodians of this research and are therefore the rights-holders for commercialising this research through its translation into policies and services.

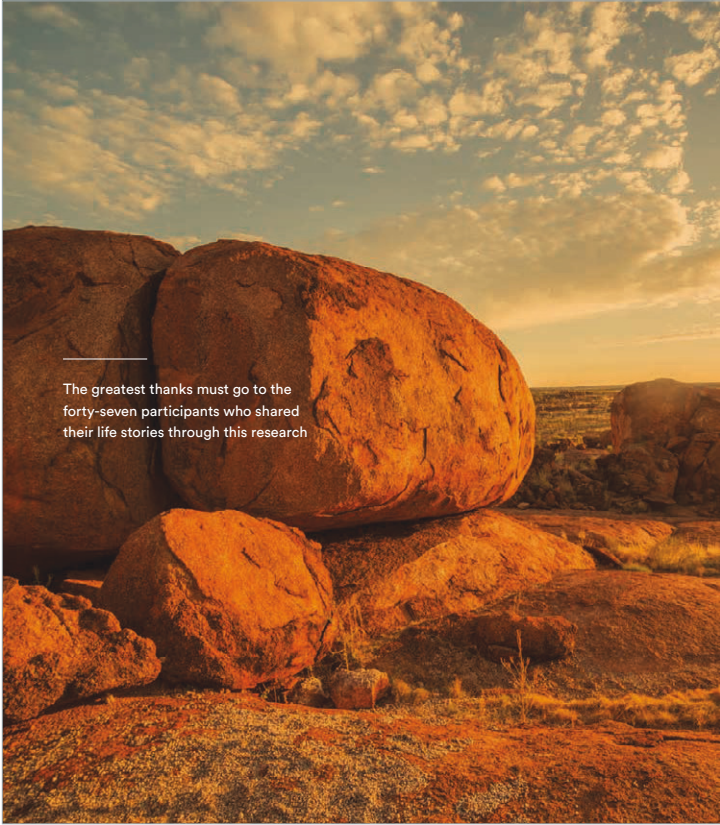
The models of co-production and collaboration used in this research are now established. The next step of the research is to translate these concepts and models into sustainable community-directed services and practice.

A culture of inclusion is a way of life for all

One of the things that has stayed with me over the past two years is how the research has brought people together, enabled their participation and assembled a bigger picture. I can vividly recall many times when people were lining up, keen to tell their story. I'm sure that part of this was because they wanted someone to hear – and believe – their story, but for others my sense is it was because they were lonely and wanted someone to talk to. But, that is a reflective paper for another day.

There is a bigger message that comes from the research, beyond what to do next. It is about the power of research to build communities. It is when we come together and stick together, we can get things done that have a sense of purpose. It is when people are isolated and go it alone that they find themselves struggling.

So, with a culture of inclusion comes a message that connects the people that make up the First Peoples disability community, and also reaches out to others. The message of inclusion is: You are not alone. You are our community, and we are yours. If we can come together and stick together, then nothing can divide us.



ACKNOWLEDGEMENTS

Firstly, I pay respect to the Elders past, present and future, of the many Aboriginal nations that I have visited while undertaking this research. I also acknowledge the nations of those who have been part of this research, either as participants, helpers or cheer squad.

There's a saying that it takes a village to raise a child, and that is very much the case for this book. I had had a great privilege to work on this book from the First Peoples Disability Network. It is a truly uplifting experience to be part of a community organisation that fights the good fight day in, day out. Everyone I have met through First Peoples Disability Network carries themselves with grace, humour and tenacity, and it is this character I've consciously tried to recreate when writing for this book. To Damian, June, Paul, Lisa, Sara, Lai Ha, Auntie Gayle, Auntie Kay, Auntie Maureen, Uncle Lester, Jake, Mel, Donna, Michelle, Ben, Mikayla Sereako, Dianne and an ever growing First Peoples disability community – you made this book come to life, and its story belongs with you. A special thanks to Lisa Hindman and Sara Irvine for your dedication in getting this book to print.

Thank you also to our designers Tracy James and Fleur Feller for amazing me with the way you have brought the words to life with your creative and beautiful imagery.

I am fortunate to work with some of the most open-minded and creative researchers within the academy. Our Academic Advisory Panel began with Professor Joanne Travaglia, Dr Megan Williams and Professor Melissa Haswell, who were soon joined by Professor Leanne Dowse and Dr Ruth McCausland, along with Dr Deborah Debono, who I regard as an honorary member of the Academic Advisory Panel. You have all pushed us to make this research as good as it possibly could be, while allowing the members of the First Peoples disability community to speak for themselves.

This also could not have been possible without the generous advice and support from my friends and colleagues at the Australian Bureau of Statistics. With special thanks to wonderful people at Centre of Excellence for Aboriginal and Torres Strait Islander Statistics, and Disability, Ageing, Carers and Mental Health Section, you have set the bar in showing our organisation respect.

It is also not possible to do a research of this scope on goodwill alone. I'm grateful to the Lowitja Institute for supporting Aboriginal and Torres Strait Islander disability research. They jumped on board early when this project was just a dream and I'm very proud to call myself a Lowitja Scholar. I also acknowledge the funding support that came through the National Disability Research and Development Agenda that has enabled something much grander in scope than otherwise would have been possible.

There was a time when this research journey felt more like walking through a bindi patch. This is where my family came in. Alison, Zoe and Tegan, you were always there, and always will be.

Of all, the greatest thanks must go to the forty-seven participants who shared their life stories through this research. Each interview was a personal tuition in humanity, gifting me with a sense of honour and responsibility. Through your testimony, each of you have added to the knowledge of this nation, and the scholars who carry this research agenda forward will forever be in your debt.

Scott Avery

July 2018.

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First Peoples
Disability Network
Australia



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Appendix H:

A pictorial essay of the research journey

Travelling around the research sites



Getting to some of the Aboriginal communities that were research sites meant driving down a dirt track like the one left for up to 80 kilometres.



*There is no more handy research tool than barbecue tongs for community based research.
Tennant Creek, Northern Territory, March 2018.*



Tennant Creek in the Northern Territory become a spiritual home for the research, and I formed a bond with many of the men from the community mens group.

In community



The Deadly Deaf Mob interviews were conducted in Auslan. In South Australia, our interpreter became unavailable at the last moment. We ended up doing them via Skype, with the participants and myself in Adelaide, one interpreter in Sydney, and another interpreter in Brisbane.



With the dogs. Elliott, Northern Territory, which was a 250 kilometre road trip north of Tennant Creek



Here I am painted up (right) for a traditional ceremony at the Garma Festival at Arnhem Land in the Northern Territory, August 2016.

Etchings of research concepts

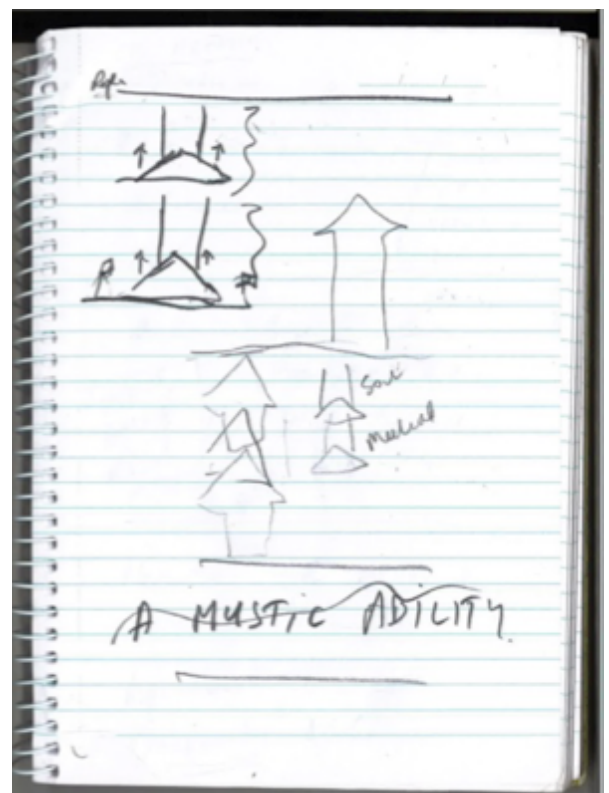
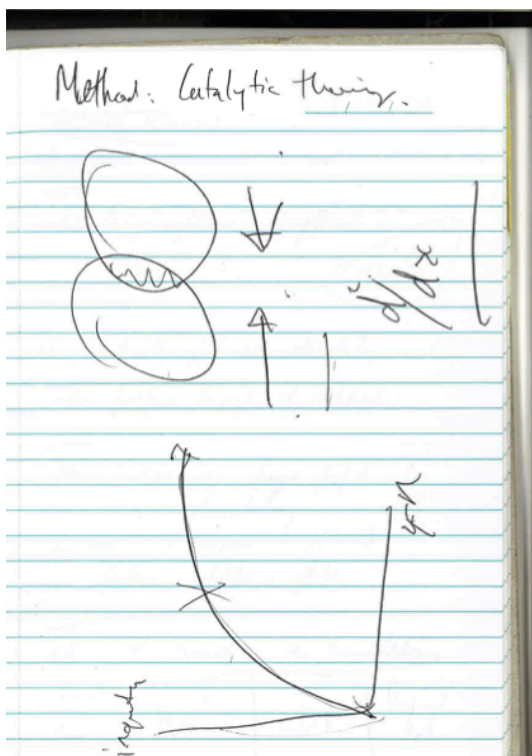
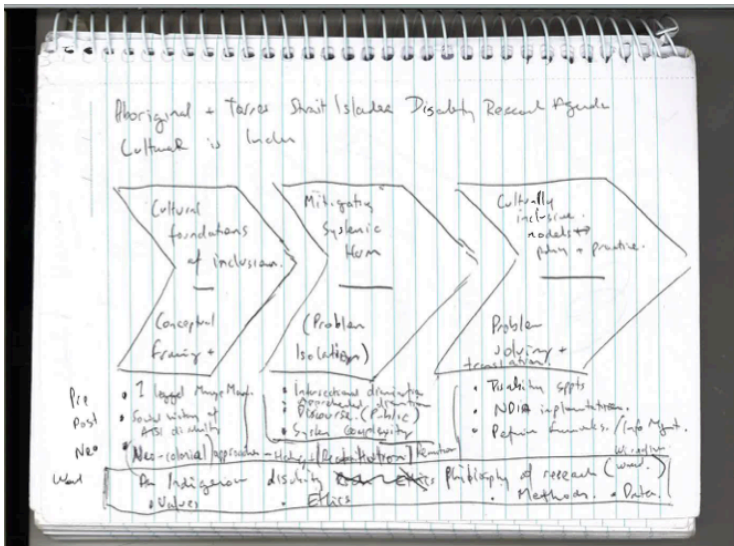
Sitting on a plane was a good time to sketch out some of my thinking. These are some of the original etchings from my research notebooks which evolved into concepts in the thesis.

Clockwise from the top:

First Peoples disability research agenda (March 2018);

A cultural model of disability (March 2018);

Intersectionality and a paradox of low hanging fruit (June 2017).



International Conference presentations



32nd Pacific Rim Disability and Diversity Conference Hawaii, USA, April 2016. I returned to the 33rd Pacific Rim Disability and Diversity Conference in October 2017 to present some preliminary findings.



Nga Pae O Te Maramatanga International Indigenous Knowledges Conference, Auckland, New Zealand, November 2016 .

United Nations representations



With Damian Griffis CEO First Peoples Disability Network (foreground), at the United Nations Convention Against Torture sessional hearing for Australia, Geneva, Switzerland, November 2014.



9th Conference of State Parties on the Convention on the Rights of Persons with Disabilities (COSP 9), New York, USA, June 2016.



Reading an intervention relating to my paper 'Intersectional Dimensions on the Right to Health for Indigenous Peoples – A Disability Perspective' at the Expert Mechanism on the Rights of Indigenous Peoples, Geneva, Switzerland, July 2016.



Presenting at a side event at the Expert Mechanism on the Rights of Indigenous Peoples on access to justice for First Peoples with disability, Geneva, Switzerland, July 2016. With Damian Griffis CEO First Peoples Disability Network (left) and representatives from the Canadian Aboriginal disability community (first and second from right).

Launch of *Culture is Inclusion*,
Australian Human Rights Commission, Sydney,
26 July 2018



*Being interviewed by Mark Walters
from Sylanvale.*



*With my supportive Team Avery - wife
Alison and daughters Tegan and Zoe.*



The PhD



When I was in a writing funk, a friend suggested having a special PhD hat might help me write my way out of it. At my hideaway in Kandos, New South Wales, October 2018.



Presenting at my Stage 3 assessment, UTS, Sydney, November 2018.



With my fantastic supervisory team Professor Joanne Travaglia (right) and Dr Deborah Debono, at my last review meeting.

