"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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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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Acknowledgements

It is customary in Australia to commence proceedings with a formal acknowledgement of the traditional owners of the land, the Aboriginal and Torres Strait Islander people. This ceremony is particularly significant for a research project within an Aboriginal and Torres Strait Islander community that has been done by an Aboriginal researcher. My family ancestry lies with the Worimi people of New South Wales. I live on Dharawal land, and I have worked and studied on Gadigal land. In the course of this study, I have been invited onto the traditional lands of many other Aboriginal nations. I pay my respects to the traditional owners, Elders, past, present and future, of all the lands where I have laid my footprints.

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.

Thanks also go to my colleagues at the Australian Bureau of Statistics, with special mention to Fiona Shalley, Michael Bullot, Suraksha Maharaj and Veronica Kerr, for the respectful way in which you have provided access to the statistical data in this study, and in generously giving your expertise on how to work with it.

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 covened 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	*Culture is Inclusion* (Sydney Book Launch)	Australian Human Rights Commission, Sydney
4 December 2018	*Culture is Inclusion* (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	*Culture is Inclusion* (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 Januray 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 Augist 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 tis thesis 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 lslander 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

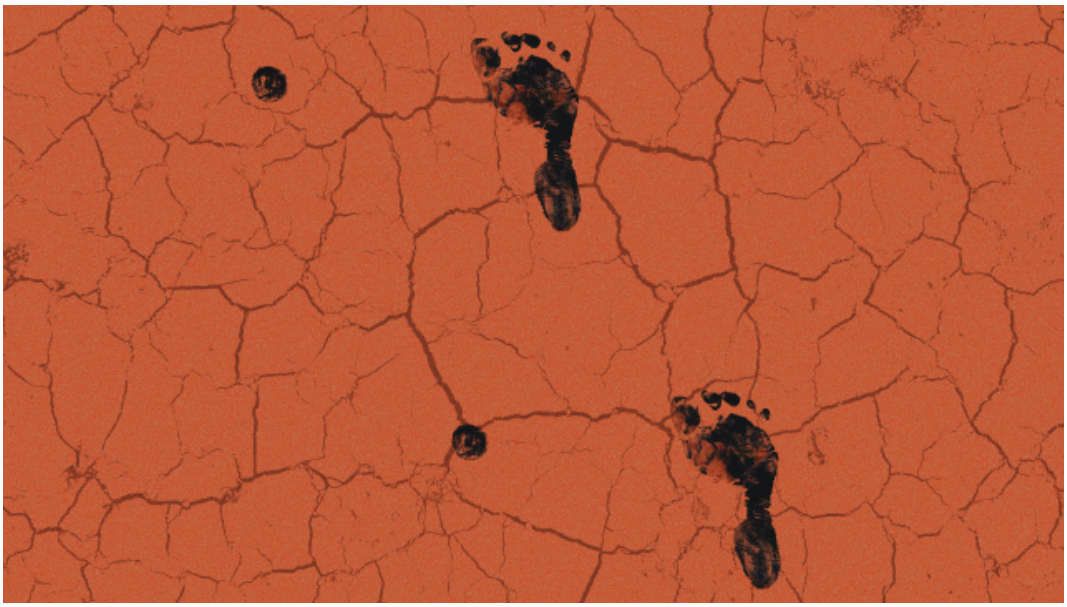
"To understand 'disability' in Aboriginal and Torres Strait Islander communities today, you need to cast your mind back 20,000 years to ancient times.

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