Families with an Aboriginal and Torres Strait Islander child with disability: System, service and provider perspectives

Anna Green MDev, BSocSci

Thesis submitted in fulfilment of the degree of
Doctor of Philosophy
2018

University of Technology Sydney
Certificate of Original Authorship

I, Anna Ruth Green 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 referenced 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 research is supported by an Australian Government Research Training Program Scholarship.

Signature of Student:

Production Note:
Signature removed prior to publication.

Date: 22\textsuperscript{nd} April 2018
Acknowledgments

The culmination of this thesis would not have been possible without the sustained support of the people below.

To the providers who participated in this study: You do amazing work in a complex space, thank you for setting aside the time to share your stories.

To my principle supervisor Associate Professor Michelle DiGiacomo: You have an incredible ability to develop the skills of your students as researchers, while also providing personal encouragement and support. I am so fortunate to be guided by you. Thank you for making this journey so enjoyable.

To my cultural mentors Patricia and John Delaney: I am forever grateful to you for so generously helping to develop my cultural competence. Thank you for cultivating such a strong foundation from which to continue to learn.

To my co-supervisor Dr Tim Luckett: Thank you for always encouraging me to strive to be the most rigorous researcher that I can.

To my co-supervisor Dr Penelope Abbott: Thank you for guiding me through this research area with such invaluable skill and kindness.

To my co-supervisor Professor Patricia Davidson: Without your mentorship and encouragement, I would not have undertaken this journey. Thank you for being such a wonderful human being.

To my fellow cohort of PhD students: Thank you for providing the humour, friendship, and understanding essential to weathering the highs and lows of a PhD.

To my lifelong friends Cec and Maddie: To have such talented women by my side throughout life is truly a blessing. Thank you both for being my sounding board over the years. A special thank you to Cec for helping to design the figures in this thesis.

To my siblings, Simon and Ella, and their partners, Sage and Jeremy: Thank you for reminding me that there is always time for yum cha. And to my nephew Ocky, for bringing such joy to our lives.
To my husband and partner in life John: Thank you for supporting me to dedicate the last few years to this project. Your wry sense of humour always makes me laugh; your honesty keeps me on my toes. And to my puppies Oliver, Archie, and Jet, who are always available for cuddles.

Finally to my parents Jillian and Barry: I cannot thank you enough for all the love and support throughout my life. I hope that I can provide the same incredible foundation for my soon-to-be daughter (and any of her future siblings).
Outputs to Date

Thesis

Peer-reviewed Journal Publications


Conference presentations


Web Resource

Green A. 2017, AbLE Project (University of Technology Sydney) – Directory of Disability Services, WentWest Primary Health Network


Associated with Australian Research Council Linkage project (LP120200484) (not reporting findings from the PhD project directly)
Peer-reviewed Journal Publications


Conference presentations

Abstract

Background:
Aboriginal and Torres Strait Islander children experience a higher prevalence of disability and socio-economic disadvantage than other Australian children. Early intervention involving the health, education, and social service sectors is vital for improving outcomes, but complex and fragmented services limit access and can compound disadvantage.

Aim and objectives:
This project aimed to inform ways to improve access to non-Aboriginal community controlled health, education, and social service providers and services for families of Aboriginal and Torres Strait Islander children who have a disability in Western Sydney, New South Wales, as part of a larger community-initiated Australian Research Council Linkage project (LP120200484). The objectives were to: 1) investigate the important components of collaboration in the field of Aboriginal and Torres Strait Islander childhood disability; 2) better understand non-Aboriginal Community Controlled Health Organisation provider perceptions, understandings, and experiences of providing services; 3) explore the barriers and facilitators to service provision; and 4) identify optimal approaches to developing interdisciplinary collaboration to support the multidimensional needs of families in their quest to ensure their children’s health and well-being.

Setting:
As part of Australian Research Council Linkage project (LP120200484), University of Technology Sydney researchers partnered with an Aboriginal Community Controlled Health Organisation to better understand how to facilitate improved service access for Aboriginal families with a child with a disability in Western Sydney, New South Wales, Australia.

Design:
Phase one involved an integrative review of the literature using a systematic approach to elucidate how collaboration works in practice across and within sectors involved in service provision. This addressed a gap in the literature and informed development of the topic guide for Phase three.

Phase two involved an asset-informed approach to mapping services relevant to Aboriginal childhood disability. The approach advocates the use of assets that already exist within communities to develop solutions for community-identified issues. This produced a directory of relevant services for families, and identified relevant providers and stakeholders for Phase three recruitment as well as advancing the methodological rigor of asset-informed mapping.

Phase three involved in-depth semi-structured interviews with 24 non-Aboriginal community controlled health, education, and social service providers informed by the epistemology of pragmatism. Data analysis was informed by the general inductive approach. The Candidacy, and Collaborative Practice to Enhance Patient Care Outcomes, frameworks were employed as analytical frameworks to explore provider perceptions, understandings, and experiences. The concept of candidacy describes the joint negotiation between families and providers of the eligibility of Aboriginal children with a disability and their families for services. The Collaborative Practice to Enhance Patient Care Outcomes framework explores the processes and determinants of interprofessional collaboration in this context.

Results:

The perceptions, understandings, and experiences of providers in delivering care to Aboriginal children with a disability in Western Sydney fell into two main categories: 1) direct service provision to children and their families, and 2) drivers of those collaborating with other providers in this field.

Providers’ perceptions, understandings, and experiences of providing direct services to families centred on their perceptions of factors that either impeded or enabled families’ access to their services. Candidacy is influenced by interactions throughout the following stages: Identification of candidacy, Navigation of services, Permeability of services, Presentation at services, Provider adjudications, and Offers and resistance to
services. The process of candidacy is managed within operating conditions at the macro level related to the impact of the socio-political context of colonisation and the Stolen Generation, and funding and current policy directives.

Providers’ perceptions, understandings, and experiences of working together across the health, education, and social service sectors centred on their perception of factors which either impeded or enabled collaboration. Interprofessional collaborative practice was influenced by interdependent interactional and organisational factors. Interactional factors fit within one of two dimensions: the ability of providers to share common goals and vision within a complex cross-sector service landscape, and sense of belonging in regard to factors that influenced trusting relationships and willingness to work together, particularly with Aboriginal providers and services. Organisational factors also fit within one of two dimensions: the influence of governance in relation to its important role in coordination and unlocking the strength of schools as service settings, and the essential role of the formalisation of processes to effective interprofessional communication. The processes of interprofessional collaborative practice were managed within the context of systemic factors of policy and funding at the macro level.

Conclusion:

Early intervention is vital to improving outcomes for Aboriginal and Torres Strait Islander children with a disability. Facilitating improved service access for families is key to ensuring that children receive early intervention. This will require holistic and collaborative responses from the health, education, and social service sectors involved in service provision. This thesis has advanced the field conceptually and methodologically by developing a framework for undertaking an asset-informed approach to service mapping. It has also contributed to the theoretical application of the Candidacy, and Collaborative Practice to Enhance Patient Care Outcomes, frameworks beyond their original focus on healthcare services to consider the interplay of factors related to the involvement of providers from the health, education, and, social service sectors.
# Table of Contents

Certificate of Original Authorship ................................................................. ii

Acknowledgments ............................................................................................ iii

Outputs to Date .................................................................................................. v

Abstract .............................................................................................................. vii

Table of Contents .............................................................................................. x

List of Tables ....................................................................................................... xvi

List of Figures ..................................................................................................... xvii

List of Appendices ............................................................................................. xviii

List of Abbreviations .......................................................................................... xix

Glossary of Terms .............................................................................................. xx

References .......................................................................................................... xxiv

Chapter One: Introduction ................................................................................... 1

1.1 Introduction .................................................................................................. 1

1.2 Australian Research Council (ARC) Linkage project ................................. 1

1.3 Research aim, objectives and questions ..................................................... 3

1.3.1 Research aim ......................................................................................... 3

1.3.2 Research objectives .............................................................................. 3

1.3.3 Research questions .............................................................................. 4

1.4 Research phases ......................................................................................... 4

1.5 Thesis structure ........................................................................................... 5

1.6 References .................................................................................................. 7

Chapter Two: Background ................................................................................. 9

2.1 Background ................................................................................................. 9
6.6 Provider adjudications – “I don’t have any preconceived issues with Aboriginal families” ................................................................. 118

6.6.1 Impact of past adjudications ........................................................................ 119

6.6.2 Elements enabling positive adjudications ............................................. 120

6.7 Offers and resistance to services – “They don’t want us” .................................. 121

6.8 Operating conditions and local production of candidacy .............................. 124

6.8.1 Socio-political context – “It’s something that’s still alive in the minds of people” ................................................................................................................... 125

6.8.2 Program changes creating policy and funding uncertainty for families and providers – “Having to tell their story again” ........................................................ 135

6.9 Summary of key findings ..................................................................................... 140

6.10 References ......................................................................................................... 143

Chapter Seven: Provider understanding of factors influencing interprofessional collaborative practice .......................................................... 144

7.1 Introduction ......................................................................................................... 144

7.2 Interactional (meso) Factors ............................................................................... 146

7.2.1 Sharing goals and visions – “All providers come in with different agendas” ............................................................................................................................... 146

7.2.2 Sense of belonging – “A good relationship makes things easier” ................. 149

7.3 Organisational (exo) Factors .............................................................................. 164

7.3.1 Governance – “There needs to be better connections” ............................. 164

7.3.2 Formalisation – “The better you communicate...the better the outcomes” 170

7.4 Systemic (macro) Factors .................................................................................. 181

7.4.1 Policy and funding factors – “It needs to come from above” ...................... 181

7.5 Summary of key findings ..................................................................................... 185

7.6 References ........................................................................................................... 187
List of Tables

Table 3.1 Summary of included peer-reviewed articles...........................................44
Table 3.2 Summary of included grey literature.........................................................46
Table 5.1 Participant demographics........................................................................69
# List of Figures

**Figure 3.1** Electronic database search strategy example......................................................33

**Figure 3.2** PRISMA flowchart of search procedure for peer-reviewed journal articles..36

**Figure 3.3** Inter- and intra-sector collaboration factors in the field of Aboriginal and Torres Strait Islander childhood disability.................................................................41

**Figure 4.1** Ecological systems theory...............................................................54

**Figure 4.2** Collaborative Practice to Enhance Patient Care Outcomes framework........57

**Figure 5.1** Deerubbin Local Aboriginal Land Council boundary............................63

**Figure 5.2** Reporting template for conducting an asset-informed approach to service mapping of formal institutions.................................................................65

**Figure 6.1** Provider understanding of candidacy for Aboriginal children with a disability and their families accessing services.................................................................91

**Figure 7.1** Provider understanding of factors influencing interprofessional collaborative practice.................................................................145

**Figure 9.1** Key recommendations.................................................................................224
List of Appendices

Appendix 1: Integrative literature review publication........................................230

Appendix 2: Quality appraisal of literature included in the integrative literature review
.........................................................................................................................246

Appendix 3: Asset-informed approach to service mapping accepted publication........252

Appendix 4: Invitation to participate in qualitative study.....................................259

Appendix 5: Ethics approvals..................................................................................261

Appendix 6: Participant information sheet and consent form..............................273

Appendix 7: Brainstorm map for topic guide development.................................279

Appendix 8: Interview topic guide.......................................................................280

Appendix 9: Self-care plan....................................................................................281
## List of Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACCHO</td>
<td>Aboriginal Community Controlled Health Organisation</td>
</tr>
<tr>
<td>AH&amp;MRC</td>
<td>Aboriginal Health and Medical Research Council</td>
</tr>
<tr>
<td>ARC</td>
<td>Australian Research Council</td>
</tr>
<tr>
<td>CALD</td>
<td>Culturally and linguistically diverse</td>
</tr>
<tr>
<td>FACS</td>
<td>Department of Family and Community Services</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>LGA</td>
<td>Local Government Area</td>
</tr>
<tr>
<td>MoU</td>
<td>Memoranda of Understanding</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-government organisation</td>
</tr>
<tr>
<td>NSW</td>
<td>New South Wales</td>
</tr>
<tr>
<td>OM</td>
<td>Otitis Media</td>
</tr>
<tr>
<td>OOHHC</td>
<td>Out-of-home care</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
</tr>
<tr>
<td>WSLHD</td>
<td>Western Sydney Local Health District</td>
</tr>
</tbody>
</table>
Glossary of Terms

Aboriginal and Torres Strait Islander

In this thesis, the term Aboriginal and Torres Strait Islander refers to the Australian Indigenous population nationally. Both peoples have a wide diversity of traditions and languages [1]. For the purposes of this research:

an Aboriginal or Torres Strait Islander is a person of Aboriginal or Torres Strait Islander descent, who identifies as being of Aboriginal or Torres Strait Islander origin and who is accepted as such by the community with which the person associates [2](para. 1).

The term Aboriginal reflects the Indigenous population of New South Wales (NSW), as they constitute the majority of Indigenous people residing in the state.

Aboriginal Community Controlled Health Organisation (ACCHO)

ACCHOs play a vital role in delivering culturally appropriate primary healthcare to Aboriginal and Torres Strait Islander communities. According to the national representative body, the National Aboriginal Community Controlled Health Organisation [3]:

ACCHOs range from large multi-functional services employing several medical practitioners and providing a wide range of services to small services that rely on Aboriginal Health Workers and/or nurses to provide the bulk of primary care services, often with a preventative focus on health education [3](p. 3).

Candidacy

The concept of candidacy in relation to access to services for vulnerable populations is defined as:

the ways in which people’s eligibility for medical attention and intervention is jointly negotiated between individuals and health services...candidacy is a dynamic and contingent process, constantly being defined and redefined through interactions between individuals and professionals [4](p. 7).

Child

In this thesis, the term child, and its derivatives, is defined as the period of early childhood from 0-8 years of age [5].
Collaboration

No universal definition of collaboration exists due to its complexity and a lack of consistent terminology [6,7]. The definition of collaboration in this thesis takes into account the broad contexts in which collaboration can happen while recognising that it is ultimately carried out between people [6,8], and the need to avoid attaching value statements [7]. For the purpose of this research, collaboration is defined as “an active and ongoing partnership, often between people from diverse backgrounds, who work together to solve problems or provide services” [9](p. xiii).

Cultural competence

Cultural competence is a complex concept often used interchangeably with cultural awareness and cultural safety [10]. Cultural awareness involves basic understanding of a cultural issue that does not necessarily lead to action [10,11]. Cultural safety emphasises self-reflexivity for professionals based on recognition of the power imbalance between a dominant culture and cultural minorities [11,12]. Cultural competence incorporates elements of both terms and is recognised in the majority of literature as the preferred concept [13]. It is argued that it is something to be constantly striving for rather than something you achieve [14].

This thesis uses the definition of cultural competence as outlined by the National Aboriginal Community Controlled Health Organisation. Cultural competence is defined as a concept existing on a continuum with a:

focus on addressing attitudes, improving knowledge and changing behaviour at both individual and institutional/systemic levels that result in effective care for Aboriginal Peoples as a right. It shares an emphasis on participants developing an understanding and appreciation of the impact of dominant culture on Aboriginal Peoples through past and ongoing practices of colonisation [11](pp. 12-13).

Disability

Disability is a concept with no universally agreed definition [15]. A core challenge to a universal definition is that professionals involved in disability come from a range of disciplines that employ different definitions to suit different purposes [16]. This thesis
uses the definition of disability as outlined in the United Nations Convention on the Rights of Persons with Disabilities. For the purposes of this research:

persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others [17](para. 2).

Ecological systems theory

This thesis is informed by ecological systems theory [18]. The theory is typically illustrated as a number of concentric circles with the child situated at the centre. Each circle represents a different system level that influences and is influenced by the encasing levels. For the purpose of this research, the macro (government, socio-political, systems), exo (organisations), and meso (providers) levels are employed. Experiences at the micro level of the child and family are reported elsewhere [19, DiGiacomo et al. manuscript under review, Green et al. manuscript under review].

Interprofessionality

The concept of interprofessionality in relation to interprofessional collaborative practice is defined as:

the development of a cohesive practice between professionals from different disciplines...It is the process by which professionals reflect on and develop ways of practicing that provides an integrated and cohesive answer to the needs of the client/family/population [20](p. 9).

Intersectionality

Intersectionality refers to categories of a person’s identity which can mutually construct each other to inform experiences of discrimination and oppression [21,22,23].

Mainstream

Use of the term mainstream in this thesis refers to “non-indigenous systems, institutions and practices” [24](p. vii).

National Disability Insurance Scheme

The National Disability Insurance Scheme is an initiative by the Australian federal government to provide services and support for people with a disability across
Australia. In the pursuit of a nationally consistent approach, individual states and territories will no longer be responsible for the provision of specialist disability services [25]. The National Disability Insurance Scheme provides individualised funding packages for eligible people with a disability with the aim of enabling control and choice over their access to services and supports [25]. The initiative is currently being trialled in a number of locations, with full rollout expected in 2019 [26].
References


Childhood Intervention: Working with Families of Young Children with Special Needs, Taylor and Francis, United Kingdom, pp. 129-142.