

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: 22nd 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 Lockett: 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

Green A, Davidson PM, Lockett T, Abbott P, Delaney P, Delaney J & DiGiacomo M. 2017, 'A framework for an asset-informed approach to service-mapping', *Nurse Researcher*, vol. 25, no. 3, pp. 19-25.

Green A, DiGiacomo M, Lockett T, Abbott P, Davidson PM, Delaney J & Delaney P. 2014, 'Cross-sector collaborations in Aboriginal and Torres Strait Islander childhood disability: a systematic integrative review and theory-based synthesis'. *International Journal for Equity in Health*, vol. 13, no. 1, p. 126.

Conference presentations

Henry V, **Green A**, Abbott P, Delaney P, Delaney J, Davidson PM & DiGiacomo M. Abstract under review, 'Re-imagining the service landscape for Aboriginal children with a disability', oral presentation submitted to the 6th Annual NHMRC Symposium on Research Translation, co-hosted by the Lowitja Institute, Brisbane, Australia, 14-15 November.

Green A, DiGiacomo M, Lockett T, Abbott P, Davidson PM, Delaney J & Delaney P. 2015, 'Cross-sector collaborations in Aboriginal and Torres Strait Islander childhood disability: a systematic integrative review', oral presentation at the 2015 Primary Health Care Research Conference, Adelaide, Australia, 31 July.

Web Resource

Green A. 2017, *AbLE Project (University of Technology Sydney) – Directory of Disability Services*, WentWest Primary Health Network
<<https://westernsydney.healthpathways.org.au/index.htm?286873.htm>>.

**Associated with Australian Research Council Linkage project (LP120200484)
(not reporting findings from the PhD project directly)**

Peer-reviewed Journal Publications

Green A, Abbott P, Davidson PM, Delaney P, Patradoon-Ho P, Delaney J & DiGiacomo M. Under review, 'Interacting with providers: an intersectional exploration of the experiences of carers of Aboriginal children with a disability', submitted to *Qualitative Health Research*, 07/06/2017.

DiGiacomo M, **Green A**, Delaney P, Delaney J, Patradoon-Ho P, Davidson PM & Abbott P. 2017, 'Experiences and needs of carers of Aboriginal children with a disability: a qualitative study', *BMC Family Practice*, vol. 18, p. 96..

Green A, Abbott P, Delaney P, Patradoon-Ho P, Delaney J, Davidson PM & DiGiacomo M. 2016, 'Navigating the journey of Aboriginal childhood disability: a qualitative study of carers' interface with services', *BMC Health Services Research*, vol. 16, no. 1, p. 680.

Conference presentations

DiGiacomo M, **Green A**, Abbott P, Delaney J, Patradoon-Ho P, Delaney J & Davidson PM. 2016, 'Mothers and grandmothers navigating caregiving for Aboriginal children with a disability', oral presentation at the 21st International Council on Women's Health Issues (ICOWHI) Congress, Scale and Sustainability: Moving Women's Health Forward, Baltimore, United States, 6-9 November.

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

2.1.1 Health disparity in Aboriginal and Torres Strait Islander childhood disability	9
2.1.2 Social determinants of health	10
2.1.3 Human rights	13
2.1.4 Impact on developmental and socio-economic outcomes	14
2.1.5 Service access	15
2.1.6 Unlocking the potential of the workforce	19
2.2 Significance and originality	20
2.2.1 The Western Sydney context	20
2.3 References	23
Chapter Three: Integrative literature review	32
3.1 Introduction	32
3.2 Methods	32
3.2.1 Eligibility criteria	32
3.2.2 Search strategy	33
3.2.3 Information sources	34
3.2.4 Study selection	34
3.2.5 Data collection	34
3.2.6 Evaluation and analysis	35
3.3 Results	35
3.3.1 Macro (government) system factors	36
3.3.2 Exo (organisational) system factors	37
3.3.3 Meso (provider) system factors	39
3.4 Discussion	41
3.4.1 Limitations	42
3.5 Conclusions	43

3.6 Summary tables.....	44
3.7 References	48
Chapter Four: Conceptual framework	52
4.1 Introduction.....	52
4.2 Bronfenbrenner’s ecological systems theory.....	53
4.2.1 Candidacy framework.....	55
4.2.2 Collaborative Practice to Enhance Patient Care Outcomes framework.....	56
4.3 Conclusion	57
4.4 References	58
Chapter Five: Methodology and methods	59
5.1 Introduction.....	59
5.2 Research design	59
5.2.1 Epistemology	59
5.2.2 Data collection	61
5.2.3 Sampling strategy	62
5.2.4 Recruitment	64
5.2.5 Participant characteristics	68
5.2.6 Ethical considerations.....	70
5.3 Research process.....	71
5.3.1 Context.....	71
5.3.2 Cultural mentorship.....	72
5.3.3 Interview settings	72
5.3.4 Topic guide.....	73
5.3.5 Positioning statement.....	74
5.3.6 Reflexive account.....	76

5.3.7 Rapport	77
5.3.8 Data management and storage	78
5.4 Research analysis.....	79
5.4.1 Data analysis	79
5.4.2 Rigour (credibility, transferability, dependability, and confirmability)	83
5.5 Conclusion	85
5.6 References	86
Chapter Six: Provider understanding of candidacy for Aboriginal children with a disability and their families accessing services	90
6.1 Introduction	90
6.2 Identification of candidacy – “It’s better to start early intervention quickly”	92
6.3 Navigation of services – “It’s quite a complex trail”	93
6.3.1 Financial factors	93
6.3.2 Information factors	95
6.3.3 System factors.....	96
6.3.4 Geographical factors	98
6.4 Permeability of services – “Why should you have to have a label to get services?”	99
6.4.1 Enhancing permeability through case management.....	102
6.5 Presentation at services – “I had to just change how I operated”	105
6.5.1 Focus on supporting carers.....	106
6.5.2 Awareness of acceptability issues	109
6.5.3 Communication strategies	112
6.5.4 Provider characteristics and obligations	115

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

Chapter Eight: Discussion.....	188
8.1 Introduction.....	188
8.2 Theoretical application of the Candidacy framework.....	188
8.3 Theoretical application of the Collaborative Practice to Enhance Patient Care Outcomes framework.....	191
8.4 Discussion of findings at the macro, exo and meso levels.....	193
8.4.1 Macro (system) level.....	193
8.4.2 Exo (organisational) level.....	198
8.4.3 Meso (provider) level.....	202
8.5 Project strengths and limitations	210
8.6 References	213
Chapter Nine: Conclusion and recommendations.....	220
9.1 Conclusion	220
9.2 Recommendations for policy and practice	223
9.2.1 Macro (system) level.....	224
9.2.2 Exo (organisational) level.....	225
9.2.3 Meso (provider) level.....	226
9.3 Concluding comments.....	226
9.4 References	228
Appendices.....	230

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

ACCHO	Aboriginal Community Controlled Health Organisation
AH&MRC	Aboriginal Health and Medical Research Council
ARC	Australian Research Council
CALD	Culturally and linguistically diverse
FACS	Department of Family and Community Services
GP	General Practitioner
LGA	Local Government Area
MoU	Memoranda of Understanding
NGO	Non-government organisation
NSW	New South Wales
OM	Otitis Media
OOHC	Out-of-home care
WHO	World Health Organisation
WSLHD	Western Sydney Local Health District

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].

Interprofessionalism

The concept of interprofessionalism 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

1. New South Wales Department of Health 2004, *Communicating positively: A guide to appropriate Aboriginal terminology*, New South Wales Department of Health, Sydney.
2. Australian Bureau of Statistics 2010, *Indigenous Statistics for Schools*. Available: <http://www.abs.gov.au/websitedbs/cashome.nsf/4a256353001af3ed4b2562bb00121564/7464946b3f41b282ca25759f00202502!OpenDocument> [Accessed 13/08/2015].
3. National Aboriginal Community Controlled Health Organisation 2013, *Investing in Healthy Futures for generational change, NACCHO 10 Point Plan 2013-2030*, National Aboriginal Community Controlled Health Organisation, Canberra.
4. Dixon-Woods M, Cavers D, Agarwal S, Annandale E, Arthur A, Harvey J, Hsu R, Katbamna S, Olsen R, Smith L & Riley R. 2006, 'Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups', *BMC Medical Research Methodology*, vol. 6, no. 1, p. 35.
5. Vargas-Barón E 2005, *Planning Policies for Early Childhood Development: Guidelines for Action*, UNICEF, Geneva.
6. Ødegård A. 2006, 'Exploring perceptions of interprofessional collaboration in child mental health care', *International Journal of Integrated Care*, vol. 6, no. 4., pp. 1-13.
7. Longoria RA. 2005, 'Is inter-organizational collaboration always a good thing?', *Journal of Sociology and Social Welfare*, vol. 32, no. 3, pp. 123-138.
8. Haynes E, Taylor K, Durey A, Bessarab D & Thompson S. 2014, 'Examining the potential contribution of social theory to developing and supporting Australian Indigenous-mainstream health service partnerships', *International Journal for Equity in Health*, vol. 13, no. 1, p. 75.
9. Freeth DS, Hammick M, Reeves S, Koppel I & Barr H. 2005, *Effective interprofessional education: development, delivery, and evaluation*, Blackwell Publishing Ltd, Oxford, United Kingdom.
10. Coffin J. 2007, 'Rising to the challenge in Aboriginal health by creating cultural security', *Aboriginal and Islander Health Worker Journal*, vol. 31, no. 3, pp. 22-24.
11. National Aboriginal Community Controlled Health Organisation 2011, *Creating the NACCHO Cultural Safety Training Standards and Assessment Process: A background paper*, National Aboriginal Community Controlled Health Organisation, Canberra.
12. Papps E & Ramsden I. 1996, 'Cultural Safety in Nursing: the New Zealand Experience', *International Journal for Quality in Health Care*, vol. 8, no. 5, pp. 491-497.

13. Grant J, Parry Y & Guerin P. 2013, 'An investigation of culturally competent terminology in healthcare policy finds ambiguity and lack of definition', *Australian and New Zealand Journal of Public Health*, vol. 37, no. 3, pp. 250-256.
14. Cross T, Bazron B, Dennis K & Isaacs M 1989, *Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed*, Georgetown University Child Development Center, CASSP Technical Assistance Center, Washington DC.
15. World Health Organisation & World Bank 2011, *World report on disability*, World Health Organisation, Geneva, Switzerland.
16. Manor-Binyamini I. 2014, *School-Parent Collaborations in Indigenous Communities: Providing Services for Children with Disabilities*, Springer, New York.
17. United Nations, *Article 1 - Purpose. Convention on the Rights of Persons with Disabilities*. Available: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html> [Accessed 19/04/2017].
18. Bronfenbrenner U. 1979, *The ecology of human development: experiments by nature and design*, Harvard University Press, Cambridge, Mass.
19. Green A, Abbott P, Delaney P, Patradoon-Ho P, Delaney J, Davidson PM & DiGiacomo M. 2016, 'Navigating the journey of Aboriginal childhood disability: a qualitative study of carers' interface with services', *BMC Health Services Research*, vol. 16, no. 1, p. 680.
20. D'amour D & Oandasan I. 2005, 'Interprofessionality as the field of interprofessional practice and interprofessional education: An emerging concept', *Journal of Interprofessional Care*, vol. 19, no. Suppl. 1, pp. 8-20.
21. Hankivsky O & Christoffersen A. 2008, 'Intersectionality and the determinants of health: a Canadian perspective', *Critical Public Health*, vol. 18, no. 3, pp. 271-283.
22. Collins PH. 1998, 'It's all in the family: Intersections of gender, race, and nation', *Hypatia*, vol. 13, no. 3, pp. 62-82.
23. Collins PH. 2015, 'Intersectionality's definitional dilemmas', *Annual Review of Sociology*, vol. 41, pp. 1-20.
24. Dwyer J, O'Donnell K, Lavoie J, Marlina U & Sullivan P 2009, *The Overburden report: Contracting for Indigenous Health Services*, Flinders University and Cooperative Research Centre for Aboriginal Health, Bedford Park and Casuarina.
25. Buckmaster L 2017, *The National Disability Insurance Scheme: a quick guide*, Department of Parliamentary Services, Canberra.
26. Johnston C, Luscombe D & Fordham L. 2016, 'Working with families as part of early childhood intervention services: Family-centred practice in an individualised funding landscape'. In: Sukkar H, Dunst CJ & Kirkby J (eds.), *Early*

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

Chapter One: Introduction

1.1 Introduction

Aboriginal and Torres Strait Islander peoples are the original inhabitants of Australia and owners of the land [1]. They represent the oldest surviving cultures in the world [2]. The British invasion in 1788 led to colonisation and an ongoing legacy for Aboriginal and Torres Strait Islander peoples of institutionalised discrimination through policies of dispossession and displacement [3, 4]. Colonisation has led to a wide range of health and socio-economic inequities experienced by Aboriginal and Torres Strait Islander peoples [4, 5].

In Australia, Aboriginal and Torres Strait Islander children experience a higher prevalence of disability than other Australian children [6]. Aboriginal and Torres Strait Islander children with a disability are considered as ‘doubly disadvantaged’ due to the disparity in rates of disability, as well as wider disparity experienced by Aboriginal and Torres Strait Islander peoples in relation to experiences of historical trauma and racism, and socio-economic disadvantage [7]. Unaddressed disability can negatively impact developmental and socio-economic outcomes across the life course [7-12]. Intervention through assessment and treatment in the early years of childhood is vital [7, 10, 13-16]. Aboriginal and Torres Strait Islander families of a child with a disability, however, report a range of barriers to service access, impeding early intervention. Two key barriers to mainstream service access are a lack of cultural competence [6, 7, 17-20] and confusion caused by fragmented service provision across the health, education, and social service sectors [7, 17-19, 21].

1.2 Australian Research Council (ARC) Linkage project

This PhD project was undertaken as part of a larger ARC-funded Linkage project (LP120200484), *Doubly disadvantaged: harnessing elements of resilience and establishing information for systems change*. The community-initiated ARC project partnered an Aboriginal Community Controlled Health Organisation (ACCHO) and

University of Technology Sydney researchers to better understand what is needed to facilitate improved service access for Aboriginal families with a child with a disability in Western Sydney, New South Wales (NSW), Australia. LP120200484 developed from the ACCHO-led project funded by the NSW Department of Ageing, Disability and Home Care to facilitate development of capacity across the broader early childhood sector to allow for early identification of Aboriginal and Torres Strait Islander children with a disability. The outputs of this project were a systematic literature review of childhood disability in Aboriginal and Torres Strait Islander peoples [18] and community forums undertaken with providers and carers to determine the factors involved in service access and support [7]. Findings indicated that there was considerable confusion around the existence, roles, and accessibility of health and social services. Challenges in accessing services and navigating the health and social care system contribute to a disconnect between providers and parents/carers. This can result in lost opportunities to help children and their families at a time when early intervention is critical. The researchers documented waiting times for treatment ranging from 6 months to 2 years. These delays could mean the difference between a child keeping up in school or being left behind.

These findings from community forums and interviews with carers highlighted the need to better understand the perceptions, understandings, and experiences of external service providers in relation to their care provision for Aboriginal children and families. Therefore, in addition to LP120200484 documenting the journey through in-depth semi-structured interviews with 19 carers, to better understand what is needed to facilitate improved service access for families, the project team also addressed obtaining provider perspectives. Upon consultation with the LP120200484 ACCHO team, cultural mentor and co-investigator, Patricia Delaney, suggested that the PhD project focus on providers and organisations external to the ACCHO. She felt that exploring non-ACCHO provider experiences of service provision and interaction with the ACCHO sector would help contribute to the larger picture of service provision. The aim and objectives of this PhD project developed from this consultation.

1.3 Research aim, objectives and questions

Despite the many challenges they face, Aboriginal and Torres Strait Islander families often show remarkable resilience. By understanding the factors supporting this resilience, LP120200484 aimed to enable a strengths-based solution to grow from within the community itself, rather than imposed from without. Through using the power of stories, narrative, and reflection, and a strong commitment from the Western Sydney community, LP120200484 built on parent/carer/family strengths and resilience. By facilitating access to services and support, the LP120200484 research team hoped to empower Aboriginal and Torres Strait Islander families and communities. This focus on resilience and a strengths-based approach underpinned this project in exploring the perceptions, understandings, and experiences of non-ACCHO providers from the health, education, and social service sectors, delivering services to these families.

1.3.1 Research aim

The project aimed to inform ways to improve access to non-ACCHO health, education, and social service providers and services for families of Aboriginal children who have a disability in Western Sydney, NSW, Australia.

1.3.2 Research objectives

Objectives of this PhD project were to:

1. Investigate the important components of collaboration in the field of Aboriginal and Torres Strait Islander childhood disability;
2. Better understand non-ACCHO provider perceptions, understandings, and experiences of providing services;
3. Document the barriers and facilitators to service provision;
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.

1.3.3 Research questions

Research questions guiding this PhD project were:

1. What are the important components of collaboration across the health, education, and social service sectors in the field of Aboriginal and Torres Strait Islander childhood disability?
2. What are the perceptions, understandings, and experiences of non-ACCHO providers (health, education, and social services) in delivering care to Aboriginal children with a disability in Western Sydney?
3. In what way do factors inhibit or enable disability service delivery?
4. How can these factors be addressed to enable early intervention and service access for families?

1.4 Research phases

To address the aim and objectives, this project involved three phases: an integrative review of the literature using a systematic approach (Phase one) [22]; development of an asset-informed approach to mapping services relevant to Aboriginal childhood disability in Western Sydney (Phase two) [23]; and a qualitative study of the perceptions, understandings, and experiences of 24 non-ACCHO health, education, and social service providers from Western Sydney (Phase three). Phase one elucidated how collaboration works in practice across and within sectors involved in service provision. It addressed a gap in the literature identified in the narrative literature review of the background in Chapter Two, 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 for carers in Western Sydney. In the absence of standardised guidelines, a framework for conducting an asset-informed approach to service mapping was developed. The framework guided the mapping of services which produced a directory of relevant services for carers while simultaneously identifying relevant providers and stakeholders for Phase three. Phase three involved in-depth semi-structured interviews with 24 non-ACCHO health,

education, and social service providers from Western Sydney. The research design was informed by the epistemology of pragmatism which asks the question of whether or not knowledge has served a purpose [24]. This was important as the PhD project sought to pursue the interests of the partner ACCHO who identified the need to explore non-ACCHO provider perceptions, understandings, and experiences of service provision as important and appropriate.

1.5 Thesis structure

Chapter One has situated this project within the context of the larger ARC-Linkage project. It has described the research aim, objectives, and questions that the project seeks to address and briefly outlined the research design.

Chapter Two provides a narrative literature review of the background to establish the context of the project in relation to the existing literature. It identifies a lack of research on how collaboration works in practice across, and within, sectors involved in service provision to Aboriginal and Torres Strait Islander children with a disability and their families. The chapter also details relevant demographics of Western Sydney to establish the research setting, and establishes the significance and originality of the project.

Chapter Three reports on Phase one, an integrative review of the literature that used a systematic approach to answer the question: What are the important components of collaboration across the health, education, and social service sectors in the field of Aboriginal and Torres Strait Islander childhood disability? It addresses the gap in knowledge identified in Chapter Two, and establishes the need for further research within specific local contexts to explore ways in which collaboration can improve access and be responsive to local needs.

Chapter Four describes Bronfenbrenner's ecological systems theory as the overarching conceptual framework informing the project. The Candidacy, and Collaborative Practice to Enhance Patient Care Outcomes frameworks, applied as a posteriori analytical frameworks to explore the interview findings in Chapters Six and Seven respectively, both utilise the ecological systems approach. These frameworks are

summarised to describe the concept of candidacy in relation to service access for vulnerable populations, and the concept of interprofessionality in relation to interprofessional collaborative practice.

Chapter Five describes the methodology and methods of the Phase three qualitative study. Detail is provided on Phase two on how the asset-informed approach to mapping services informed the recruitment of non-ACCHO providers from the health, education, and social service sectors to participate in interviews.

Chapter Six reports on the providers' perceptions, understandings, and experiences of direct service provision to families in relation to their perception of factors which either impeded or enabled families' access to services. These are explored through an adaptation of the Candidacy framework.

Chapter Seven reports on the providers' perceptions, understandings, and experiences of working together across the health, education and social service sectors in relation to their perception of factors which either impeded or enabled collaboration. These are explored through an adaptation of the Collaborative Practice to Enhance Patient Care Outcomes framework.

Chapter Eight discusses the qualitative study findings in relation to how they contribute to the theoretical extension of the Candidacy, and Collaborative Practice to Enhance Patient Care Outcomes frameworks. The project findings are also discussed in relation to the relevant literature structured by considerations at the macro, exo, and meso levels. Strengths and limitations of the project are presented.

Chapter Nine presents conclusions of the project and recommendations for policy and practice.

1.6 References

1. Queensland Health 2011, *Guidelines for Aboriginal and Torres Strait Islander Terminology*, Queensland Government, Brisbane.
2. Aboriginal and Torres Strait Islander Commission 1998, *As a matter of fact: Answering the myths and misconceptions about Indigenous Australians*, Commonwealth of Australia, Canberra.
3. Dudgeon P, Wright M, Paradies Y, Garvey D & Walker I. 2010, 'The social, cultural and historical context of Aboriginal and Torres Strait Islander Australians'. In: Purdie N, Dudgeon P & Walker R (eds.), *Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice*, Australian Government Department of Health and Ageing, Canberra, pp. 25-42.
4. Sherwood J. 2013, 'Colonisation - It's bad for your health: The context of Aboriginal health', *Contemporary Nurse*, vol. 46, no. 1, pp. 28-40.
5. Australian Government 2009, *Closing the gap on Indigenous disadvantage: The challenge for Australia*, Department of Families, Housing, Community Services and Indigenous Affairs, Canberra.
6. Biddle N, Yap M & Gray M 2013, *CAEPR Indigenous Population Project 2011 Census Papers. Paper 6 Disability*, Australian National University, Canberra.
7. DiGiacomo M, Delaney P, Abbott P, Davidson PM, Delaney J & F, V. 2013, 'Doing the hard yards': carer and provider focus group perspectives of accessing Aboriginal childhood disability services', *BMC Health Services Research*, vol. 13, no. 1, p. 326.
8. Morris PS, Leach AJ, Silberberg P, Mellon G, Wilson C, Hamilton E & Beissbarth J 2005, 'Otitis media in young Aboriginal children from remote communities in northern and central Australia: A cross-sectional survey', *BMC Pediatrics*, vol. 5, no. 1, p. 27.
9. Burrow S, Galloway A & Weisssofner N 2009, *Review of educational and other approaches to hearing loss among Indigenous people*, Australian Indigenous HealthInfoNet, Western Australia.
10. Burns J & Thomson N 2013, *Review of ear health and hearing among Indigenous Australians.*, Australian Indigenous HealthInfoNet, Western Australia.
11. Sherwood J. 1993, 'The Management of Children with Otitis Media', *Aboriginal and Islander Health Worker Journal*, vol. 17, no. 4, p. 15.
12. Australian Institute of Health and Welfare 2014, *Stronger Futures in the Northern Territory: Hearing Health Services 2012-2013*, Australian Institute of Health and Welfare, Canberra.
13. Commission on Social Determinants of Health 2008, *Closing the gap in a generation: health equity through action on the social determinants of health*.

Final Report of the Commission on Social Determinants of Health, World Health Organisation, Geneva.

14. Queensland Health 2009, *Deadly Ears, Deadly Kids, Deadly Communities: 2009-2013*, Queensland Government, Queensland.
15. Thorne J. 2004, 'Middle ear problems in Aboriginal school children cause developmental and educational concerns', *Contemporary Nurse*, vol. 16, no. 1-2, pp. 145-150.
16. Goldblatt P, Siegrist J, Lundberg O, Marinetti C, Farrer L & Costongs C 2015, *Improving health equity through action across the life course: Summary of evidence and recommendations from the DRIVERS project. Report produced as part of the 'DRIVERS for Health Equity' project*, EuroHealthNet, Brussels.
17. Australian Health Ministers' Advisory Council 2004, *Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2004-2009*, Department of Health South Australia, South Australia.
18. DiGiacomo M, Davidson PM, Abbott P, Delaney P, Dharmendra T, McGrath SJ, Delaney J & F, V. 2013, 'Childhood disability in Aboriginal and Torres Strait Islander peoples: a literature review', *International Journal for Equity in Health*, vol. 12, no. 1, p. 7.
19. Gilroy J. 2012, 'The participation of Aboriginal people with a disability in disability services in New South Wales, Australia', PhD thesis, University of Sydney.
20. Gilroy J, Donnelly M, Colmar S & Parmenter T. 2016, 'Twelve factors that can influence the participation of Aboriginal people in disability services', *Australian Indigenous HealthBulletin*, vol. 16, no. 1, pp. 1-9.
21. O'Neill M, Kirov E & Thomson N. 2004, 'A review of the literature on disability services for Aboriginal and Torres Strait Islander peoples', *Australian Indigenous HealthBulletin*, vol. 4, no. 4, pp. 1-29.
22. Green A, DiGiacomo M, Lockett T, Abbott P, Davidson PM, Delaney J & Delaney P. 2014, 'Cross-sector collaborations in Aboriginal and Torres Strait Islander childhood disability: a systematic integrative review and theory-based synthesis', *International Journal for Equity in Health*, vol. 13, no.1, p. 126.
23. Green A, Lockett T, Abbott P, DiGiacomo M, Delaney J, Delaney P & Davidson PM. In press, 'Developing a framework for undertaking an asset-informed approach to service mapping: a systematic integrative review and synthesis', *Nurse Researcher*, accepted 06/10/2016.
24. Cherryholmes CH. 1992, 'Notes on Pragmatism and Scientific Realism', *Educational researcher*, vol. 21, no. 6, pp. 13-17.

Chapter Two: Background

2.1 Background

2.1.1 Health disparity in Aboriginal and Torres Strait Islander childhood disability

The Australian population has access to a first-class universal healthcare system and is relatively healthy [1]. Aboriginal and Torres Strait Islander peoples are an exception to this rule [2, 3]. While this is also found in indigenous populations from comparable countries, Aboriginal and Torres Strait Islander peoples experience some of the largest health disparities [4-8]. The gap in life expectancy between Aboriginal and Torres Strait Islander peoples and other Australians is approximately 9.5 years for females and 10.6 years for males [3, 9, 10]. Aboriginal and Torres Strait Islander people over 15 years of age have been found to be twice as likely to rate their health as fair/poor than other Australians [10, 11]. This disparity extends to disability. Outcomes have improved in areas such as the gap in life expectancy, but there have been no improvements in the high rates of disability with Aboriginal and Torres Strait Islander people experiencing overall disability at 1.5 times the rate experienced by other Australians, and are twice as likely to experience a severe or profound form of disability [9, 12]. Although there are no national data sets for disability in Aboriginal and Torres Strait Islander peoples, or children more generally [8, 13-16], the limited data available identify a range of disparities.

Aboriginal and Torres Strait Islander children experience a higher prevalence of disability than other children [17]. They encounter higher rates of hearing loss [9, 11, 18], which has been linked to the high prevalence of middle ear diseases such as otitis media (OM). Rates of OM experienced by Aboriginal and Torres Strait Islander children are among the highest in the world (as high as 91% in some remote communities [19]), similar to those in developing countries, and at a level classified by the World Health Organisation (WHO) as a significant public health problem [2, 19, 20]. OM is also experienced for longer and more persistent periods by Aboriginal and Torres Strait

Islander children (32 months compared with 3 months for other children) [21]. Hearing impairment can negatively impact speech and language development, cognitive development, attention and behaviour [21-26]. Although much of the literature on Aboriginal and Torres Strait Islander childhood disability focuses on OM, disparities are evident in other areas suggesting the need for a broader focus [27]. Aboriginal and Torres Strait Islander children have been found to have a significantly higher prevalence of communication disorders (64% in one Queensland study [28]), be twice as likely to have an intellectual disability [29], and are 1.3 times more likely to require assistance with self-care, mobility, or communication than other children [30]. Such disparity is also evident in developmental delay [31] and Fetal Alcohol Spectrum Disorder [32].

2.1.2 Social determinants of health

Health disparities are a matter of social justice when they are due to structural determinants and conditions of daily life shaped by political, social, and economic factors that can be avoided [33]. These are the social determinants of health. Not only do social determinants of health impact health outcomes, there also exists a social gradient where lower socio-economic status correlates with worse health outcomes [33, 34]. Healthcare systems act as social determinants of health that influence and are influenced by other social determinants [35]. Persons with a disability in Australia report experiencing social exclusion and discrimination in their daily lives which impact on their access to healthcare [36, 37]. Experiences of discrimination due to institutionalised perceptions of ableism, where normal bodies are considered superior to abnormal bodies, is a social determinant that influences disability [38]. However disability policy in general has been criticised for paying little attention to the social determinants of health [39]. This is doubly experienced by Aboriginal and Torres Strait Islander people with a disability, who not only experience social exclusion and discrimination from their identity as having a disability, but also from their identity as Aboriginal and Torres Strait Islander people [40, 41].

Aboriginal and Torres Strait Islander people with a disability have been described as 'doubly disadvantaged' due to the negative impact of socio-economic

disadvantage and racism on disability which can develop into a cycle of health inequities [42]. Central to the Australian government's *Close the Gap* campaign to reduce Aboriginal and Torres Strait Islander disadvantage is recognition of the important role of addressing the social determinants of health on closing the gap [26]. Aboriginal and Torres Strait Islander people who attained school completion at year 10 level or below have been found to be twice as likely to assess their health as fair/poor than those who completed year 12 [26]. Life stressors such as a death in the family or a serious illness can negatively impact on health outcomes. Almost two-thirds of Aboriginal and Torres Strait Islander children in 2008 reported experiencing at least one life stressor within the previous 12 months with stressors more common for children living in non-remote areas [2]. The negative impact of life stressors on indigenous children globally has been observed among reservation-based Native American children. Life stressors such as witnessing violence, poverty and racism were found to be linked to a vulnerability to psychiatric disorders [43]. The Commission on Social Determinants of Health's report identifies indigenous populations as having a unique status in terms of their experiences of colonisation that need to be examined separately from discussions around universal experiences of social exclusion [35].

Little attention has been paid to research on the social determinants of health in disability policy [39]. The main issue affecting action on the influence of social determinants of health for disability is that it requires a shift in thinking as they are often considered indirect to the traditional responsibilities of health, education, and social service sectors [44, 45].

Social determinants of health for Aboriginal and Torres Strait Islander people include lack of access to appropriate health services, racism, lack of education, and unemployment [46, 47]. These can be divided under three broad categories: historical trauma, racism and socio-economic status. Historical trauma is associated with poorer health outcomes and has been linked to distrust of mainstream organisations and providers [2, 7, 42, 48-50]. It was less than 50 years ago that Aboriginal and Torres Strait Islander people were officially acknowledged as citizens of Australia with the right to vote [51]. Institutionalised discrimination through policies of dispossession and displacement have led to a fear among some Aboriginal and Torres Strait Islander

people that their children will be taken from them if they interact with mainstream services [13, 27]. This fear is influenced by the fact that from the very start of European colonisation, Aboriginal and Torres Strait Islander children were forcibly removed from their families [52]. Specific policies that legislated the forcible removal of children from approximately 1910 to the late 1960s created what is known as the Stolen Generation [52].

A recent survey on Aboriginal and Torres Strait Islander peoples' experiences of racism found that in the preceding year, 97% of the 755 respondents had experienced at least one incident of racism [26]. Experiences of racism among Aboriginal and Torres Strait Islander youth aged 16-20 years has been found to be associated with anxiety, depression and poor mental health more generally [53]. Experiences of racism are so common for some Aboriginal and Torres Strait Islander peoples that they can become de-sensitised, impacting their ability to explain what they have experienced to healthcare providers [54]. It is also reported that delays in diagnosis and treatment, due to stereotyping by health professionals, are linked to poorer health outcomes for this population [55]. Not only are Aboriginal and Torres Strait Islander persons with a disability negatively impacted by historical trauma and racism, they can experience disability specific discrimination, or disablism, which is also associated with poorer outcomes [39]. Racism and discrimination influence low socio-economic status. Globally, colonisation and associated discrimination and racism has also denied indigenous people access to the resources to improve socio-economic status [56].

Aboriginal and Torres Strait Islander peoples are among the most socio-economically disadvantaged populations in Australia. It is reported that disparities in socio-economic status account for between one-third and a half of the gap in health outcomes [48]. Low education attainment and low income experienced by carers are associated with inequitable access to health services for Aboriginal and Torres Strait Islander children [47]. Almost half of Aboriginal and Torres Strait Islander households are in the lowest income group and are four times less likely to be in the highest group than other Australians [2, 48]. In 2006, almost half of Aboriginal and Torres Strait Islander children were in families who were jobless [2] and the unemployment rate increased from 7% to 11% between 2001 and 2008, higher than the rate for other

Australians [48]. Aboriginal and Torres Strait islander people with a disability also experience higher levels of unemployment than other Australians with a disability [17]. The relationship between disability and poverty is bi-directional; each can increase the risk of the other and contribute to lifelong cycles of disadvantage [17, 38, 42, 56, 57]. Socio-economic disadvantage compounds the experience of hearing loss as well as intellectual and developmental disability, with socio-economic status and being indigenous identified as factors of poorer childhood development [9, 25, 45, 58]. A study of Aboriginal and Torres Strait Islander childhood development in South Western Sydney found the more socio-economic risk factors there were, the lower the child's overall mental development score [59]. Poverty and social disadvantage is a contributing factor to OM-related hearing loss in Aboriginal and Torres Strait Islander children [15, 23, 60]. These social determinants have been linked with a higher likelihood of Aboriginal and Torres Strait Islander people with mental and cognitive impairment coming into contact with criminal justice than other disadvantaged groups of people [61].

2.1.3 Human rights

Action on the social determinants of health is based within a human rights framework. The rights of Aboriginal and Torres Strait Islander children with a disability are guaranteed under a number of international laws ratified or endorsed by the Australian government [62-64], and which aim to preserve the identities and improve the economic and social conditions of children with disabilities. These include the United Nations Convention of the Rights of Persons with Disabilities (ratified by Australia in 2008), the United Nations Declaration on the Rights of Indigenous Peoples (endorsed by Australia in 2009), and the United Nations Convention on the Rights of the Child (ratified by Australia in 1990). These laws enshrine children's rights to the highest standard of attainable health, access to healthcare services, education, non-discrimination on the basis of either their indigenous identity or disability identity, and equality of opportunity. The Australian government's obligations under these international instruments include consulting with persons, including children, with a disability in the formation of policy [65], involving indigenous people in decision

making affecting their rights [64], ensuring education is provided in a culturally appropriate manner to maximise social and academic development [65], paying special attention to the rights and special needs of indigenous children with a disability in improving their social and economic conditions [64], taking steps to ensure the full realisation of the right to the highest attainable standard of health [64], providing services for early identification and intervention of disabilities [65], and providing the full range of health, education, and social services required for the special needs of children with a disability [62]. These laws guarantee the rights of Aboriginal and Torres Strait Islander children with a disability to the highest standard of attainable health, access to healthcare services, education, non-discrimination on the basis of their identities, equality of opportunity and improvement of their economic and social conditions [62-64].

The right to non-discrimination is also guaranteed under national laws in the Disability Discrimination Act [66] and the Racial Discrimination Act [67]. The rights to non-discrimination are addressed in the Australian Charter of Healthcare Rights endorsed by all Australian healthcare ministers in 2008 which ensures cultural safety and respect in the provision of healthcare services by including the right to respect of *“culture, beliefs, values and personal characteristics”* [68](p.1). The Australian Human Rights Commission has drawn attention to a number of human rights violations faced by Aboriginal and Torres Strait Islander persons with a disability. These include individual rights to health and education which are impacted by the high levels of socio-economic disadvantage experienced at the systemic level [14].

2.1.4 Impact on developmental and socio-economic outcomes

The high prevalence of disability and socio-economic disadvantage experienced by Aboriginal and Torres Strait Islander children can negatively impact their life course and reinforce the cycle of disadvantage [15, 42]. Unaddressed disability can negatively affect speech, language, and social development, as well as health, education, and employment outcomes [19, 23, 25, 42, 69, 70]. Hearing impairment in Aboriginal and Torres Strait Islander children contributes to 30% fewer year 12 completions [71]. For Aboriginal and Torres Strait Islander children with undiagnosed hearing loss, their

invisible disability can intersect with their cultural identity to create the ground for racism in the form of teachers labelling them as disruptive or ignorant [69]. Evidence links low educational achievement to involvement in the criminal justice system [25, 58, 72]. Once an Aboriginal or Torres Strait Islander child comes into contact with juvenile justice they are likely to offend as an adult continuing a life-long trajectory and increasing the likelihood of adult incarceration [73, 74]. Currently the rate of Aboriginal and Torres Strait Islander youth in youth justice supervision is 14 times higher than the rate of other Australian youth [11]. Aboriginal and Torres Strait Islander youth in contact with the juvenile justice system are four to five times more likely to have an intellectual disability than the general population [75]. A study of young Aboriginal people in a youth detention facility recently found that 89% had Fetal Alcohol Spectrum Disorder or other neurodevelopmental impairments [76]. Aboriginal and Torres Strait Islander adults with mental and cognitive disabilities are also over-represented in the criminal justice system [61]. The negative impact on developmental and socio-economic outcomes for Aboriginal and Torres Strait Islander children also impact parents and carers. Parents and carers can experience adverse health and social outcomes as a consequence of caregiving responsibilities and have worse mental and physical health, higher rates of depression and experience greater financial hardship than the general population [38, 77].

2.1.5 Service access

2.1.5.1 Importance of early intervention

Unaddressed disability can have life-long consequences for indigenous peoples [56]. Investment in early childhood through policies that address the social determinants of health can potentially reduce disparities within a generation and is fundamental to addressing health inequity [25, 33, 42, 58, 78, 79]. In Australia, findings from the Gudaga Study of Indigenous childhood development in South Western Sydney support the need for investment in early interventions that encourage essential skills for development such as language and fine motor skills and support to families impacted by socio-economic disadvantage [59]. Increased access to early intervention services for Aboriginal and Torres Strait Islander children with ear health

problems has been linked to a decrease in rates of hearing impairment (from 23% to 8%) [70]. Lack of access to appropriate diagnosis and support in early childhood is associated with the over-representation of adults with mental and cognitive impairments in the criminal justice system underlying the importance of effective early intervention for positive trajectories in later life [61]. Early intervention is also more cost effective than intervening later in life [7, 80]. However, Aboriginal and Torres Strait Islander families with a child with a disability face a number of barriers to service access impeding early intervention.

2.1.5.2 Barriers to service access

Service access is important in the prevention and management of health problems and addressing health disparities [4, 18]. Aboriginal and Torres Strait Islander persons with a disability are less likely to access services than other Australians despite experiencing higher rates of disability [42, 81, 82]. Barriers to service access include socio-economic disadvantage [1, 14, 27], insufficient supply of programs [17, 42], long waiting times [42], lack of child care [42], lack of transportation [13, 27, 42, 49, 50], social marginalisation [42], inadequate housing [27], lack of knowledge of entitlements and processes [13, 49], bureaucratic processes [49], lack of culturally appropriate services [42], mistrust of government services [1, 17, 42, 49, 50], cultural attitudes towards disability [13, 27, 42, 49], racism [1, 27, 49], system complexity [42], confusion over available services [13, 42], and lack of coordination and communication between services and levels of government [1, 13, 27, 42, 49].

2.1.5.3 Cultural competence

One of the key barriers to mainstream service access is a lack of cultural competence within these services. Strategies that support cultural competence at all levels, and working within a cultural competence framework, are necessary to improve service access and engagement [3, 83, 84]. This includes appreciating differences in cultural conceptualisations of disability, assessing children in a holistic way, and recognition by service providers that children can be cared for by someone other than their parents often via informal arrangements [27, 42]. For urban Aboriginal and Torres

Strait Islander populations, engagement with mainstream services is particularly relevant due to the high concentration of these services in urban areas and, therefore, it is important that these services focus on increasing cultural competence in order to become more accessible [84]. Despite the importance of increasing cultural competence of the workforce, an Australian literature review found a lack of health provider attendance at cultural competence training despite some evidence suggesting it can increase knowledge and improve the attitudes and skills of health providers [85]. Cultural competence also facilitates sustainable collaboration between Aboriginal and Torres Strait Islander and other Australian organisations, providers and communities [83, 85].

2.1.5.4 Collaboration

Recognition of the complex social determinants of health for Aboriginal and Torres Strait Islander peoples has led to a shift from purely medical interventions to inclusion of non-medical approaches involving collaboration across sectors [7]. A holistic model of health and wellbeing for services is required to improve service access [4, 84]. Different sectors and levels of government working in silos is a key barrier to the collaboration required to address the complexities of Aboriginal and Torres Strait Islander childhood disability [27, 48, 86]. Improved collaboration between health, education, and social service sectors is key to improving service access and addressing the confusion caused by complex and fragmented service provision [8, 23, 27, 42, 87]. Despite the links between health, education, and social circumstances, these sectors have continued to work in silos, resulting in a failure to address entrenched socio-economic and health disparities. Even within sectors, such as health professionals from different disciplines, providers are educated in a silo format that discourages interprofessional collaboration, emphasising the complexity of effective collaboration [88]. Collaboration between mainstream services and ACCHOs are particularly important in effective service provision to Aboriginal and Torres Strait Islander people as ACCHOs lack the capacity to provide services everywhere while mainstream services lack the ability to meet the cultural needs of Aboriginal and Torres Strait Islander people [89]. Key barriers to effective collaboration include the

fragmented decentralised government structure, which weakens streamlined policymaking capacity [89], Australia's history of colonisation influencing both previous and current policy [90, 91], and inefficient and complex funding models for ACCHOs [92].

The need for collaborative responses to disability is recognised both internationally and nationally [57]. The WHO policy on addressing health inequities and disability aims to promote whole-of-government and inter-sector collaborative approaches [33, 35, 57]. One of the recommendations from the World Report on Disability is for further research into barriers to service access and ways to overcome them in specific contexts [57]. The international policy shift towards collaboration began with the Declaration of Alma Alta in 1978 which recognised that health outcomes are linked to social and economic factors and therefore a need for cross-sector service coordination [93]. The intersection between health and socio-economic factors was further recognised in the Ottawa Charter for Health Promotion in 1986 which again called for coordination and collaboration across sectors and all levels of government to counter negative health outcomes [94]. Cross-sector collaboration to address health disparities was also called for in the 2008 World Health Report and the 2011 Rio Political Declaration on Social Determinants of Health [35, 95]. Nationally, the Australian government's *Close the Gap* campaign to reduce Aboriginal and Torres Strait Islander disadvantage advocates the need for collaboration across all sectors and levels of government for effective service coordination [96]. The 1986 Disability Services Act provided early recognition of the importance of disability services collaborating with mainstream services [97] which was then further endorsed in the National Disability Agreement in 2009, which highlighted that improved outcomes for persons with a disability relies on effective service coordination across government services [98, 99]. The 2010-2020 National Disability Strategy is based within a human rights framework and recognises the need for all mainstream services involved with persons with a disability including health, education, indigenous reform, and housing, to work within a collaborative whole-of-government approach to address service fragmentation [40]. Both the 2013 National Standards for Disability Services and the

2013 National Disability Insurance Scheme Act advocate for collaborative partnerships and a nationally consistent approach to service provision [100, 101].

Specific health policies for Aboriginal and Torres Strait Islander peoples also reflect this shift of emphasis to whole-of-government collaboration [4]. The National Indigenous Reform Agreement binds national, state and territory governments to closing the gap in health outcomes for Aboriginal and Torres Strait Islander peoples within a generation with integration through collaboration across all levels of government and sectors as one of the principles underpinning service delivery [96]. Inter-sector and agency collaboration and whole-of-government coordination was a key priority specific to Aboriginal and Torres Strait Islander persons with a disability in the 2003-2013 National Strategic Framework for Aboriginal and Torres Strait Islander Health [102] and is a key part of the 2013–2023 National Aboriginal and Torres Strait Islander Health Plan [103, 104].

Despite the policy shift towards cross-sector collaboration in disability, in practice, policy directives do not always translate into collaborative action [33, 45]. This mismatch between policy and practice could be due to the complexities inherent in cross-sector collaboration and breaking free of the influence of professional silos. Collaborative partnerships are not always effective and collaboration itself can be a frustrating concept in practice [105, 106]. Unlike the existing research in this section that has drawn-out the importance of early intervention and barriers to service access, particularly around lack of cultural competence, there is a lack of research into how collaboration works in practice in the context of Aboriginal and Torres Strait Islander childhood disability. More needs to be known to improve service access.

2.1.6 Unlocking the potential of the workforce

One of the recommendations from the World Report on Disability is to improve human resource capacity identifying health, education, and social service providers involved in disability as key to improving service access for persons with a disability [57]. Health professionals, in particular have been identified as key to addressing health inequities and the impact of social determinants of health through acting as advocates with unique understanding of local contexts [34, 55]. Within the Australian

context, building the capacity of Aboriginal Health Workers has been identified as critical to improving service access for Aboriginal and Torres Strait Islander children with a disability [42] as well as increasing the cultural competence of mainstream providers [51].

2.2 Significance and originality

Data on Aboriginal and Torres Strait Islander children with a disability are limited, particularly in urban populations, and this inhibits adequate service planning [107]. Despite 79% of the Aboriginal and Torres Strait Islander population living in urban or regional areas, most of the research on Aboriginal and Torres Strait Islander childhood disability is on rural/remote populations [2, 7, 13, 42, 108]. It is important to address this gap in knowledge as Aboriginal and Torres Strait Islander populations can be less visible in urban areas and available services are not necessarily appropriate or accessible [13, 24, 42, 84, 109]. This project will contribute to addressing service access in the socio-cultural and environmental context of Western Sydney. The researcher is embedded in a research team of both Aboriginal community members and university researchers, with demonstrated collegiality and respect. This project represents a collaborative approach shifting from consultation and information to involving, collaborating, and empowering Aboriginal and Torres Strait Islander communities, ensuring consumer involvement in research. The academic rigor of this project is augmented by cultural mentorship and immersion in the data, further details of which are provided in Chapter Five.

2.2.1 The Western Sydney context

NSW has the largest population of Aboriginal and Torres Strait Islander residents in Australia, with the majority residing in Western and South Western Sydney [11, 110, 111]. The partner ACCHO plays an integral role in delivering culturally appropriate and comprehensive health, social and cultural services to the Aboriginal and Torres Strait Islander community of Western Sydney and its surrounding areas. The partner ACCHO is located in Mt Druitt and lies within the boundary of Deerubbin Local Aboriginal Land Council; an area that encompasses Western Sydney Local Health

District (WSLHD) and includes nine Local Government Areas (LGA). The WSLHD includes Westmead, Blacktown/Mount Druitt, Auburn and Cumberland hospitals, the Children's Hospital at Westmead and 7 Community Health Centres [112]. Blacktown LGA, which encompasses Mt Druitt, is one of the most socio-economically disadvantaged areas in Sydney according to the Socio-Economic Indexes for Areas of disadvantage (a score of 968 compared with the score of 1011 for Sydney) [112, 113]. Lower scores in the index of disadvantage indicate areas where there is more disadvantage. In comparison to the general Aboriginal and Torres Strait Islander population in NSW, a lower proportion of the population in this area hold formal qualifications, there is a lower rate of year 12 completions (19.5% compared with 58.5% and 22.4% respectively for the Aboriginal and Torres Strait Islander population) and a higher rate of unemployment (20% compared with 17%) [114]. A high rate of Aboriginal and Torres Strait Islander children aged between 0-11 years old also live in the area [114].

Consistent with international and national policy, current NSW policy addressing disability and service access advocates a cross-sector collaborative approach and early intervention to address service complexity and fragmentation, and disparities [115, 116]. The NSW Aboriginal Health Plan 2013-2023 recognises the key role that social determinants of health play in health inequities and includes building partnerships and ensuring integrated service delivery as strategic directions [117]. The 2014 NSW Disability Inclusion Bill passed by the NSW Parliament in August 2014 recognises that Aboriginal and Torres Strait Islander people with a disability face multiple disadvantages and the need for a coordinated whole-of-government approach to service provision [118]. Multidisciplinary and multiagency collaboration is also one of the service standards for the NSW Health Building Strong Foundations for Aboriginal Children, Families and Communities Program [119]. The WSLHD strategic plan includes integrated care and collaboration and partnerships as strategic principles, and the Blacktown City Council Disability Inclusion Plan 2012-2015 recognises that barriers to service access can be physical, procedural or social and undertakes to make sure there is equitable service access and a whole of council organisational philosophy [120].

Data from the local community forums conducted as part of the project that preceded LP120200484, discussed in Chapter One Section 1.2, were explored within Penchansky and Thomas's dimensions of healthcare access framework which defines access for healthcare as constituted by availability, affordability, accessibility, accommodation and acceptability [121]. Specific factors impacting service access for this community included long waiting lists and insufficient programs (availability), childcare, respite and transport (affordability), system complexity, lack of communication between services, and rigid service eligibility criteria (accessibility), deficiencies in the language used by providers, short duration of appointments, and lack of holistic assessment approaches (accommodation), and experiences of racism and mistrust of mainstream services (acceptability) [42]. Although not specifically recognised in the framework, the forums found factors that came under an additional concept of awareness which included a lack of awareness by providers and carers of available support/services due to a lack of information/promotion [42].

The narrative review of the background literature in this chapter has established the context of the project in relation to the existing literature. In Section 2.1.5.4 the review identified a lack of research on how collaboration works in practice across, and within, sectors involved in service provision to Aboriginal and Torres Strait Islander children with a disability and their families. More needs to be known to improve service access. The next chapter reports on the Phase one integrative review of the literature using a systematic approach to address this gap in knowledge.

2.3 References

1. Australian Health Ministers' Advisory Council 2004, *Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2004-2009*, Department of Health South Australia, South Australia.
2. Australian Institute of Health and Welfare 2011, *The health and welfare of Australia's Aboriginal and Torres Strait Islander people: an overview*, Australian Institute of Health and Welfare, Canberra.
3. Wise S 2013, *Improving the early life outcomes of Indigenous children: implementing early childhood development at the local level. Issues paper no. 6. Produced for the Closing the Gap Clearinghouse*, Canberra: Australian Institute of Health and Welfare & Melbourne: Australian Institute of Family Studies.
4. Australian Medical Association 2005, *Position Statement on Aboriginal and Torres Strait Islander Health 2005*, Australian Medical Association, Canberra.
5. Freemantle J, Officer K, McAullay D & Anderson I 2007, *Australian Indigenous Health—Within an International Context*, Cooperative Research Centre for Aboriginal Health, Darwin.
6. Nelson A & Allison H. 2007, 'Relationships: the key to effective occupational therapy practice with urban Australian Indigenous children', *Occupational Therapy International*, vol. 14, no. 1, pp. 57-70.
7. Bowes J & Grace R 2014, *Review of early childhood parenting, education and health intervention programs for Indigenous children and families in Australia. Issues paper no. 8 produced for the Closing the Gap Clearinghouse*, Canberra: Australian Institute of Health and Welfare & Melbourne: Australian Institute of Family Studies.
8. Manor-Binyamini I. 2014, *School-Parent Collaborations in Indigenous Communities: Providing Services for Children with Disabilities*, Springer, New York.
9. Steering Committee for the Review of Government Service Provision 2014, *Overcoming Indigenous Disadvantage: Key Indicators 2014*, Productivity Commission, Canberra.
10. Australian Institute of Health and Welfare 2016, *Australia's health 2016: in brief. Cat. no. AUS 201*, Australian Institute of Health and Welfare, Canberra.
11. Australian Institute of Health and Welfare 2015, *Aboriginal and Torres Strait Islander Health Performance Framework 2014 report: New South Wales. Cat. no. IHW 162*, Australian Institute of Health and Welfare, Canberra.
12. Australian Institute of Health and Welfare 2016, *Australia's health 2016. Australia's health series no. 15. Cat. no. AUS 199*, Australian Institute of Health and Welfare, Canberra.

13. O'Neill M, Kirov E & Thomson N. 2004, 'A review of the literature on disability services for Aboriginal and Torres Strait Islander peoples', *Australian Indigenous Health Bulletin*, vol. 4, no. 4, pp. 1-26.
14. Australian Human Rights Commission 2009, *Inquiry into hearing health in Australia: Australian Human Rights Commission submission to the Senate Community Affairs Committee*, Australian Human Rights Commission, Sydney.
15. Senate Community Affairs References Committee 2010, *Hear us: inquiry into hearing health in Australia*, Parliament of Australia: Senate, Canberra.
16. Australian Institute of Health and Welfare 2012, *A picture of Australia's children 2012*, Australian Institute of Health and Welfare, Canberra.
17. Biddle N, Yap M & Gray M 2013, *CAEPR Indigenous Population Project 2011 Census Papers. Paper 6 Disability*, Australian National University, Canberra.
18. Australian Bureau of Statistics 2006, *National Aboriginal and Torres Strait Islander Health Survey 2004-05*, Australian Bureau of Statistics, Canberra.
19. Morris PS, Leach AJ, Silberberg P, Mellon G, Wilson C, Hamilton E & Beissbarth J 2005, 'Otitis media in young Aboriginal children from remote communities in northern and central Australia: A cross-sectional survey', *BMC Pediatrics*, vol. 5, no. 1, p. 27.
20. World Health Organisation 2004, *Chronic suppurative otitis media: burden of illness and management options*, World Health Organisation, Geneva.
21. Williams CJ & Jacobs AM. 2009, 'The impact of otitis media on cognitive and educational outcomes', *The Medical Journal of Australia*, vol. 191, no. 9, p. S69.
22. Ministerial Advisory Committee: Students with Disabilities 2007, *Aboriginal Students with Disabilities: Otitis Media and Conductive Hearing Loss*, Government of South Australia, South Australia.
23. Burrow S, Galloway A & Weisssofner N 2009, *Review of educational and other approaches to hearing loss among Indigenous people*, Australian Indigenous HealthInfoNet, Western Australia.
24. Kirkham LA, Wiertsema S, Smith-Vaughan H, Thornton R, Marsh R, Lehmann D, Leach A, Morris P & Richmond P. 2010, 'Are you listening? The inaugural Australian Otitis Media (OMOZ) workshop - towards a better understanding of otitis media', *Medical Journal of Australia*, vol. 193, no. 10, pp. 569-571.
25. Burns J & Thomson N 2013, *Review of ear health and hearing among Indigenous Australians.*, Australian Indigenous HealthInfoNet, Western Australia.
26. Australian Institute of Health and Welfare 2015, *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples 2015. Cat. no. IHW 147.*, Australian Institute of Health and Welfare, Canberra.
27. DiGiacomo M, Davidson PM, Abbott P, Delaney P, Dharmendra T, McGrath SJ, Delaney J & F, V. 2013, 'Childhood disability in Aboriginal and Torres Strait

Islander peoples: a literature review', *International Journal for Equity in Health*, vol. 12, no. 1, p. 7.

28. Aldred R, Forsingdal S & Baker R. 2002, 'Working together to improve the health status and health outcomes for Indigenous children and their families living in urban settings: the speech pathologist's role', *ACQuiring Knowledge in Speech, Language and Hearing*, vol. 4, no. 3, pp. 166-169
29. Leonard H, Petterson B, De Klerk N, Zubrick S.R., Glasson E, Sanders R & Bower C. 2005, 'Association of sociodemographic characteristics of children with intellectual disability in Western Australia', *Social Science & Medicine*, vol. 60, no. 7, pp. 1499-1513.
30. Pink B & Allbon P 2008, *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples 2008*, Australian Bureau of Statistics & Australia Institute of Health and Welfare, Canberra.
31. Bennett B, McDonald J, Knight J, Comino E & Henry R. 2010, 'Assessing development of urban Aboriginal infants', *Journal of Paediatrics and Child Health*, vol. 46, no. 7-8, pp. 384-391.
32. Hayes L, D'Antoine H & Carter M. 2014, 'Addressing Fetal Alcohol Spectrum Disorder in Aboriginal Communities'. In: Dudgeon P, Milroy H & Walker R (eds.) *Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice*, 2nd, Commonwealth of Australia, Canberra, pp. 355-372.
33. Commission on Social Determinants of Health 2008, *Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health*, World Health Organisation, Geneva.
34. Allen M, Allen J, Hogarth S & Marmot M 2013, *Working for Health Equity: The Role of Health Professionals*, UCL Institute of Health Equity, London.
35. World Health Organisation 2008, *The World Health Report 2008 - Primary Health Care (Now More Than Ever) Introduction and Overview*, World Health Organisation, Geneva.
36. National People with Disabilities and Carer Council 2009, *SHUT OUT: The Experience of People with Disabilities and their Families in Australia*, Commonwealth of Australia, Canberra.
37. Goddard L. 2010, 'The Health Empowerment Learning Partnership (HELP) model: undergraduate nursing students working with families of children with intellectual disabilities to improve their health', PhD thesis, University of Western Sydney.
38. Berger RJ. 2013, *Introducing Disability Studies*, Lynne Rienner Publishers, Inc, United States.
39. Emerson E, Madden R, Graham H, Llewellyn G, Hatton C & Robertson J. 2011, 'The health of disabled people and the social determinants of health', *Public Health*, vol. 125, no. 3, pp.145-147.

40. Commonwealth of Australia 2011, *2010-2020 National Disability Strategy: An initiative of the Council of Australian Governments*, Commonwealth of Australia, Canberra.
41. Hollinsworth D. 2013, 'Decolonizing Indigenous disability in Australia', *Disability & Society*, vol. 28, no. 5, pp. 601-615.
42. DiGiacomo M, Delaney P, Abbott P, Davidson PM, Delaney J & F, V. 2013, '“Doing the hard yards’: carer and provider focus group perspectives of accessing Aboriginal childhood disability services', *BMC Health Services Research*, vol. 13, no. 1, p. 326.
43. Brockie TN, Heinzelmann M & J, G. 2013, 'A Framework to Examine the Role of Epigenetics in Health Disparities among Native Americans', *Nursing Research and Practice*, vol. 2013, pp. 1-9.
44. Baum F. 2007, 'Cracking the nut of health equity: Top down and bottom up pressure for action on the social determinants of health', *Promotion and Education*, vol. 14, no. 2, pp. 90-95.
45. Clarke K & Denton M. 2013, 'Red Dirt Thinking on Child Wellbeing in Indigenous , Rural and Remote Australian Communities: The SpICE Model "I just don't want my kid to struggle like I did at school"', *Australian Journal of Indigenous Education*, vol. 42, no. 2, pp. 136-144.
46. Campbell D, Pyett P & L, M. 2007, 'Community development interventions to improve Aboriginal health: Building an evidence base', *Health Sociology Review*, vol. 16, no. 3-4, pp. 304-314.
47. Ou L, Chen J, Hillman K & Eastwood J. 2010, 'The comparison of health status and health services utilisation between Indigenous and non-Indigenous infants in Australia', *Australian and New Zealand Journal of Public Health*, vol. 34, no. 1, pp. 50-56.
48. Australian Health Ministers’ Advisory Council 2012, *Aboriginal and Torres Strait Islander Health Performance Framework 2012 Report*, Australian Health Ministers’ Advisory Council, Canberra.
49. Gilroy J. 2012, 'The participation of Aboriginal people with a disability in disability services in New South Wales, Australia', PhD thesis, University of Sydney.
50. 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*, vol. 16, no. 1, pp. 1-9.
51. Davidson PM, DiGiacomo M, Thompson SC, Abbott P, Davison J, Moore L, Daly J, McGrath SJ, Taylor KP & Usherwood T. 2011, 'Health workforce issues and how these impact on Indigenous Australians', *Journal of Australian Indigenous Issues*, vol. 14, no. 4, pp. 69-84.
52. National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from their Families (Australia), Wilson RD & Australia Human Rights and Equal Opportunity Commission 1997, *Bringing them home: Report of the*

National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from their Families, Human Rights and Equal Opportunity Commission, Sydney.

53. Priest NC, Paradies YC, Gunthorpe W, Cairney SJ & Sayers SM. 2011, 'Racism as a determinant of social and emotional wellbeing for Aboriginal Australian youth', *Medical Journal of Australia*, vol. 194, no. 10, pp. 546-550.
54. Coffin J. 2007, 'Rising to the challenge in Aboriginal health by creating cultural security', *Aboriginal and Islander Health Worker Journal*, vol. 31, no. 3, pp. 22-24.
55. Cunningham J, Cass A & Arnold PC. 2005, 'Bridging the treatment gap for Indigenous Australians', *Medical Journal of Australia*, vol. 182, no. 10, pp. 505-506.
56. Loppie Reading C & Wien F 2009, *Health Inequalities and Social Determinants of Aboriginal Peoples' Health*, National Collaborating Centre for Aboriginal Health, British Columbia, Canada.
57. World Health Organisation & World Bank 2011, *World report on disability*, World Health Organisation, Geneva, Switzerland.
58. Queensland Health 2009, *Deadly Ears, Deadly Kids, Deadly Communities: 2009-2013*, Queensland Government, Queensland.
59. McDonald J, Webster V, Knight J & Comino E. 2014, 'The Gudaga Study: Development in 3-year-old urban Aboriginal children', *Journal of Paediatrics and Child Health*, vol. 50, no. 2, pp. 100-106.
60. Ministerial Advisory Committee: Students with Disabilities 2003, *Aboriginal Students with Disabilities*, Government of South Australia, South Australia.
61. Baldry E, McCausland R, Dowse L & McEntyre E 2015, *A predictable and preventable path: Aboriginal people with mental and cognitive disabilities in the criminal justice system*, University of New South Wales, Sydney.
62. United Nations 1989, *Convention on the Rights of the Child*, United Nations, New York.
63. United Nations, *Article 1 - Purpose. Convention on the Rights of Persons with Disabilities*. Available: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html> [Accessed 19/04/2017].
64. United Nations 2008, *United Nations Declaration on the Rights of Indigenous Peoples*, United Nations, New York.
65. United Nations 2008, *Convention of the Rights of Persons with Disabilities* United Nations, New York.
66. Australian Government 1992, *Disability Discrimination Act 1992*, Australian Government, Canberra.
67. Australian Government 1975, *Racial Discrimination Act 1975*, Australian Government, Canberra.

68. Australian Commission on Safety and Quality in Healthcare 2008, *Australian Charter of Healthcare Rights*, Australian Commission on Safety and Quality in Healthcare, Sydney.
69. Sherwood J. 1993, 'The Management of Children with Otitis Media', *Aboriginal and Islander Health Worker Journal*, vol. 17, no. 4, pp. 15-18.
70. Australian Institute of Health and Welfare 2014, *Stronger Futures in the Northern Territory: Hearing Health Services 2012-2013*, Australian Institute of Health and Welfare, Canberra.
71. Helme S & Lamb S 2011, *Closing the school completion gap for Indigenous students. Produced for the Closing the Gap Clearinghouse*, Australia Institution of Health Welfare & Australian Institute of Family Studies, Canberra & Melbourne.
72. Weatherburn D, Snowball L & Hunter B. 2006, 'The economic and social factors underpinning Indigenous contact with the justice system: Results from the 2002 NATSISS survey', *Crime and Justice Bulletin*, vol. 104, pp. 1-16.
73. Chen S, Matruglio T, Weatherburn D & Hua J. 2005, 'The transition from juvenile to adult criminal careers', *Crime and Justice Bulletin*, vol. 86, pp. 1-12.
74. Steering Committee for the Review of Government Service Provision 2009, *Overcoming Indigenous Disadvantage: Key Indicators 2009*, Productivity Commission, Canberra.
75. Calma T 2008, *Preventing Crime and Promoting Rights for Indigenous Young People with Cognitive Disabilities and Mental Health Issues*, Australian Human Rights Commission, Sydney.
76. Bower C, Watkins RE, Mutch RC, Marriott R, Freeman J, Kippin NR, Safe B, Pestell C, Cheung CSC, Shield H, Tarratt L, Springall A, Taylor J, Walker N, Argiro E, Leitão S, Hamilton S, Condon C, Passmore HM & Giglia R. 2018, 'Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia', *BMJ Open*, vol. 8, p. e019605
77. Edwards B, Higgins DJ, Gray M, Zmijewski N & M., K. 2008, *The nature and impact of caring for family members with a disability in Australia*, Australian Institute of Family Studies, Melbourne.
78. Thorne J. 2004, 'Middle ear problems in Aboriginal school children cause developmental and educational concerns', *Contemporary Nurse*, vol. 16, no. 1-2, pp. 145-150.
79. Goldblatt P, Siegrist J, Lundberg O, Marinetti C, Farrer L & Costongs C 2015, *Improving health equity through action across the life course: Summary of evidence and recommendations from the DRIVERS project. Report produced as part of the 'DRIVERS for Health Equity' project*, EuroHealthNet, Brussels.
80. ARTD Consultants 2008, *Evaluation of the Aboriginal otitis media screening program: Final Report*, New South Wales Health, Sydney.

81. Australian Institute of Health and Welfare 2011, *Aboriginal and Torres Strait Islander people with disability: Wellbeing, participation and support*, Australian Institute of Health and Welfare, Canberra.
82. Gilroy J, Donnelly M, Colmar S & Parmenter T. 2013, 'Conceptual framework for policy and research development with Indigenous people with disabilities', *Australian Aboriginal Studies*, vol. 2013, no. 2, pp. 42-58.
83. Burton J 2012, *Opening Doors Through Partnerships: Practical approaches to developing genuine partnerships that address Aboriginal and Torres Strait Islander community needs April 2012*, Secretariat of National Aboriginal and Islander Child Care, Victoria.
84. Ware V-A 2013, *Improving the accessibility of health services in urban and regional settings for Indigenous people. Resource sheet no. 27. Produced for the Closing the Gap Clearinghouse*, Australian Institute of Health and Welfare & Australian Institute of Family Studies, Canberra & Melbourne.
85. Farrelly T & Lumby B. 2009, 'A Best Practice Approach to Cultural Competence Training', *Aboriginal and Islander Health Worker Journal*, vol. 33, no. 5, pp. 14-22.
86. McSwan D, Ruddell D & Searston I 2001, *Report: A Whole Community Approach to Otitis Media-reducing its incidence and effects*, Rural Education, Research & Development Centre, James Cook University, Townsville.
87. Western Australia Education and Health Standing Committee 2012, *Report on key learnings from the Committee research trip 11-17 March 2012.*, Parliament of Western Australia, Perth, Western Australia.
87. Vanderbilt AA, Dail MD & Jaber P. 2015, 'Reducing health disparities in underserved communities via interprofessional collaboration across health care professions', *Journal of Multidisciplinary Healthcare*, vol. 8, pp. 205-208.
89. Baeza JI & Lewis JM. 2010, 'Indigenous health organizations in Australia: connections and capacity', *International Journal of Health Services*, vol. 40, no. 4, pp. 719-742.
90. Haynes E, Taylor K, Durey A, Bessarab D & Thompson S. 2014, 'Examining the potential contribution of social theory to developing and supporting Australian Indigenous-mainstream health service partnerships', *International Journal for Equity in Health*, vol. 13, no. 1, p. 75.
91. Tsou C, Haynes E, Warner WD, Gray G & Thompson SC. 2015, 'An exploration of inter-organisational partnership assessment tools in the context of Australian Aboriginal-mainstream partnerships: a scoping review of the literature', *BMC Public Health*, vol. 15, no. 1, p. 416.
92. Askew D, B.J., Brown A, Cass A, Davy C, DeVries J, Fewquandie B, Hackett M, Howard M, Ingram S, Lavoie J, Liu H, Mentha R, Peiris D, Simon P, Rickards B, & Togni S. 2014, *Complex needs and limited resources: Influences on the provision of primary healthcare to Aboriginal and Torres Strait Islander peoples living*

with chronic disease, Kanyini Qualitative Study Monograph Series: No. 4, Kanyini Vascular Collaboration, Sydney.

93. World Health Organisation 1978, *Declaration of Alma-Ata. International conference on primary health care, Alma-Ata, USSR, 6-12 September 1978*, World Health Organisation, Geneva.
94. World Health Organisation 1986, *The Ottawa Charter for Health Promotion, First International Conference on Health Promotion, Ottawa, 21 November 1986*, World Health Organisation, Geneva.
95. World Health Organisation 2011, *Rio Political Declaration on Social Determinants of Health*, World Health Organisation, Geneva.
96. Council of Australian Governments 2008, *National Indigenous Reform Agreement (Closing the Gap)*, Commonwealth of Australia, Canberra.
97. Australian Government 1986, *Disability Services Act 1986*, Australian Government, Canberra.
98. Council of Australian Governments 2009, *National Disability Agreement*, Council of Australian Governments, Canberra.
99. Australian Institute of Health and Welfare 2011, *Disability support services 2009-10: report on services provided under the National Disability Agreement. In Disability series*, Australian Institute of Health and Welfare, Canberra.
100. Australian Government 2013, *National Standards for Disability Services*, Australian Government, Canberra.
101. Australian Government 2013, *National Disability Insurance Scheme Act 2013*, Australian Government, Canberra.
102. Commonwealth of Australia 2007, *National Strategic Framework for Aboriginal and Torres Strait Islander Health 2003-2013, Australian Government Implementation Plan 2007-2013*, Commonwealth of Australia, Canberra.
103. Australian Government 2013, *National Aboriginal and Torres Strait Islander Health Plan 2013–2023*, Commonwealth of Australia, Canberra.
104. Department of Health 2015, *Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan 2013-2023*, Australian Government, Canberra.
105. Huxham C & Vangen S. 2005, *Managing to collaborate: The theory and practice of collaborative advantage*, Routledge, United States.
106. Hunter DJ, Perkins N, Bambra C, Marks L, Hopkins T & Blackman T 2010, *Partnership Working and the Implications for Governance: issues affecting public health partnerships*, NIHR Service Delivery and Organisation Programme, London.
107. Comino E, Craig P, Harris E, McDermott D, Harris M, Henry R, Jackson Pulver L, Kemp L & Knight J. 2010, 'The Gudaga Study: establishing an Aboriginal birth cohort in an urban community', *Australian and New Zealand Journal of Public Health*, vol. 34, no. s1, pp. S9-S17.

108. Australian Bureau of Statistics 2016, *About the National Aboriginal and Torres Strait Islander Social Survey*, Australian Bureau of Statistics, Canberra.
109. Davidson B, Hill AE & Nelson A. 2013, 'Responding to the World Report on Disability in Australia: Lessons from collaboration in an urban Aboriginal and Torres Strait Islander school', *International Journal of Speech-Language Pathology*, vol. 15, no. 1, pp. 69-74.
110. Australian Bureau of Statistics 2006, *Population distribution of Aboriginal and Torres Strait Islander Australians*, Australian Bureau of Statistics, Canberra.
111. Australian Bureau of Statistics 2012, *Australian demographic statistics, March quarter 2012*, Australian Bureau of Statistics, Canberra.
112. Western Sydney Local Health District 2013, *Western Sydney Local Health District Strategic Plan July 2013 - June 2016*, New South Wales Health, Sydney.
113. Blacktown City Council 2011, *Blacktown City 2011 Census Results*, Blacktown City Council, Sydney.
114. Blacktown City Council, *Census results Blacktown City, comparison year: 2006, benchmark area: New South Wales*, Blacktown City Council, <http://profile.id.com.au/blacktown> [Accessed: 06/12/2014].
115. New South Wales Government 2006, *Stronger Together: A new direction for disability services in NSW 2006-2016*, New South Wales Government, Sydney.
116. New South Wales Government 2010, *Stronger Together: A new direction for disability services in NSW 2006-2016. The next phase 2011-2016*, New South Wales Government, Sydney.
117. New South Wales Ministry of Health 2012, *NSW Aboriginal Health Plan 2013 - 2023*, New South Wales Ministry of Health, Sydney.
118. New South Wales Government 2014, *Disability Inclusion Bill 2014*, New South Wales Government, Sydney.
119. New South Wales Kids and Families 2015, *Building Strong Foundations for Aboriginal Children, Families and Communities (BSF) Program Service Standards*, New South Wales Health, Sydney.
120. Blacktown City Council 2012, *Blacktown City Council Disability Inclusion Plan 2012-2015*, Blacktown City Council, Sydney.
121. Penchansky R & Thomas JW. 1981, 'The concept of access: definition and relationship to consumer satisfaction', *Medical Care*, vol. 19, no. 2, pp. 127-140.

Chapter Three: Integrative literature review

3.1 Introduction

Section 2.1.5 in Chapter Two reviewed the existing literature on service access and found that most of the research centers on the importance of early intervention and barriers to service access, particularly around lack of cultural competence in service provision to families. The review found that despite the policy imperative towards collaboration, there has been no systematic attempt to elucidate how collaboration works in practice across and within sectors involved in service provision. To address this, an integrative literature review [1](Appendix 1) was undertaken (Phase one) to answer the question: What are the important components of collaboration across the health, education, and social service sectors in the field of Aboriginal and Torres Strait Islander childhood disability? Understanding these components will be essential in improving service provision and access for Aboriginal and Torres Strait Islander children with a disability and their families.

3.2 Methods

An integrative literature review was conducted using a systematic approach to identify components of collaboration.

3.2.1 Eligibility criteria

Included articles focused on Aboriginal and Torres Strait Islander children with a disability and/or their families/carers, or providers of services to this population, as well as reference to collaboration or interaction within or across two or more providers/sectors. Articles were included if they were written in English, specifically addressed Australian issues, were peer-reviewed or grey literature. No limits were imposed on publication date or study design. Articles were excluded if their sole focus was on adolescent or adult disability or a population other than Aboriginal and Torres Strait Islander peoples.

3.2.2 Search strategy

A systematic electronic database search strategy using Boolean terms was developed in collaboration with a health librarian (see Figure 3.1 for an example). Search terms were Medical Subject Heading terms and keywords including derivatives of the key terms collaboration, child, disability, and indigenous. The grey literature was searched using variations of the key search terms from each of these groupings.

Search strategy for PsycInfo

1. exp. indigenous (DE "Indigenous Populations") OR Australian Indigenous OR Australian Aboriginal OR Aborigine OR Oceanic ancestry group OR ATSI OR Torres Strait Islander.
2. exp. disability (DE "Learning Disorders" OR DE "Developmental Disabilities" OR DE "Disabilities" OR DE "Speech Disorders" OR DE "Hearing Disorders" OR DE "Physical Disorders" OR DE "Learning Disabilities") OR exp. intellectual disability (DE "Vision Disorders") OR learning disorder OR exp. language disorder (DE "Language Disorders") OR exp. communication disorder (DE "Communication Disorders") OR hearing impaired OR hearing loss OR hearing disorder OR visually impaired OR mentally disabled OR developmental disability OR exp. attention deficit (DE "Attention Deficit Disorder with Hyperactivity" OR DE "Attention Deficit Disorder") OR disruptive behavior disorders OR child behavior disorders OR child development disorders OR motor skills disorders OR cognition disorder OR exp. Speech (DE "Speech Disorders") OR language disorders OR exp autism (DE "Autism") OR autistic disorder OR exp. Asperger syndrome (DE "Aspergers Syndrome") OR physical disability.
3. child OR newborn OR baby OR babies OR infant OR infants OR children OR childhood OR neonate*.
4. exp. collaboration (DE "Collaboration") OR exp. collaborative (DE "Integrated Services") OR patient care team OR joint practice OR multidisciplinary care team OR interdisciplinary team OR inter-sector OR intra-sector OR cross-sector OR multidisciplinary OR whole of government OR exp. interdisciplinary (DE "Interdisciplinary Treatment Approach") OR interdisciplinary communication OR intradisciplinary OR inter-professional learning.
5. 1 AND 2 AND 3 AND 4

Figure 3.1 Electronic database search strategy example*. *Search terms varied slightly for each database.

3.2.3 Information sources

In consultation with a health librarian, a systematic search of health, education, social science, multidisciplinary and indigenous electronic databases and search engines was conducted to identify articles published in peer-reviewed journals. The electronic databases Cumulative Index to Nursing and Allied Health Literature, EMBASE, PsycInfo, Medline, Education Resources Information Center, Social Services Abstracts, Sociological Abstracts, Academic Search Complete, Health Collections, Indigenous Studies Bibliography, Australian Public Affairs Information Service, Australian Public Affairs Information Service - Health, Aboriginal and Torres Strait Islander Health, Health & Society, Multicultural Australia and Immigration Studies - Aboriginal and Torres Strait Islander Subset, Rural and Remote Health Database, Australian Indigenous HealthInfoNet and Google Scholar search engine were searched. Reference lists were also searched for relevant articles. Grey literature was identified through a search of websites of Aboriginal and Torres Strait Islander and disability representative organisations, the National Disability Organisation's Clearinghouse, Trove theses database, and Mednar.

3.2.4 Study selection

Returned articles published in peer-reviewed journals were imported into EndNote software. To establish consistency in the application of inclusion/exclusion criteria, the first 100 articles were assessed against eligibility criteria independently by two researchers (AG and MD). Any inconsistencies were discussed until consensus was reached. One researcher (AG) assessed the remaining articles.

3.2.5 Data collection

Data were extracted from included articles into an a priori designed electronic spreadsheet by one researcher (AG). Data items included the setting, design, disability/impairment, population, aims, and methods. Data items specific to collaboration were extracted and grouped according to the discipline of providers involved in collaboration, collaborative models, components of collaboration, and key conclusions or recommendations.

3.2.6 Evaluation and analysis

Quality appraisal of all included articles published in a peer-reviewed journal was conducted, using relevant critical appraisal tools, independently by two researchers (AG-MD/TL) who met to establish agreement on final ratings. Any disagreements were resolved through discussion. All included articles were evaluated using the Level of Evidence ranking system by Melnyk and Fineout-Overholt [2]. Data analysis was guided by the narrative synthesis approach by Popay et al. [3]. After developing the preliminary synthesis of findings, a search for a conceptual model was conducted. The model needed to provide a holistic framework centered on the child and their family that encompassed the different system levels of collaboration and how they interact with one another. An adaptation [4, 5] of Bronfenbrenner's ecological systems theory of child development [6] represented a conceptual model in which the relationships in the data could be explored at the macro (government), exo (organisational), and meso (provider) system levels (see Figure 3.3). The theory has previously been referenced in the context of addressing factors influencing equitable service access for underserved populations with a communication disability [7]. With the exception of Zubrick et al. [8], it has not before been applied specifically to service access issues in the field of Aboriginal and Torres Strait Islander childhood disability.

3.3 Results

The database search and peer-reviewed article selection is shown in Figure 3.2. Thirteen peer-reviewed articles met inclusion criteria (Table 3.1). The majority of studies were qualitative (n=5), followed by discussion papers (n=3), observational (n=2), mixed methods (n=1), a literature review (n=1), and intervention (n=1). The grey literature search retrieved 18 articles that met the inclusion criteria (Table 3.2). In total, 31 articles were included in the review. The literature predominantly reported on hearing impairment and related disability, such as learning impairments (n=17). Quality appraisal of the articles published in a peer-reviewed journal was conducted as part of a systematic approach to provide an overview of quality, but was not given weighting in the analysis and synthesis of data due to the lack of formal methods for this in integrative reviews (see Appendix 2 for quality appraisal).

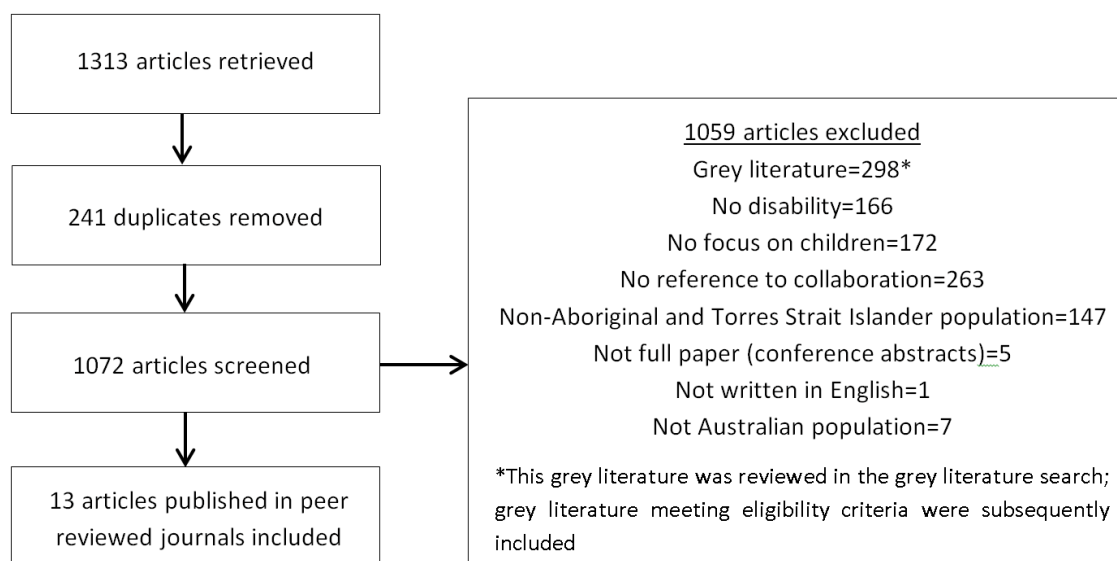


Figure 3.2 PRISMA flowchart of search procedure for peer-reviewed journal articles

The following section provides a narrative synthesis of the findings using the macro (government), exo (organisational), and meso (provider) system levels to demonstrate the components of collaboration across the health, education, and social service sectors in the field of Aboriginal and Torres Strait Islander childhood disability.

3.3.1 Macro (government) system factors

3.3.1.1 Structure of government departments and agencies

The siloed structure of health, education and social service departments and agencies was found to impede service integration and the ability of providers to work collaboratively [9]. Silos of service provision across government departments and agencies and between levels of government [10] negatively impacts service access for families when they have to navigate different waiting lists and assessment processes, and receive disparate pieces of information from professionals working in isolation [9, 11, 12]. The fragmentation and complexity of government services [13] impede opportunities for collaboration, with some providers reporting difficulties in locating and communicating with relevant services [13, 14]. The adoption of a consultative approach across health, education and social service departments has been recommended as a solution for reducing service duplication and fragmentation and is

more aligned with the needs of the child; these are beyond the biomedical and include social, cultural, economic and psychological issues [11].

3.3.1.2 Policies

Collaboration at the level of policy making can address the barriers generated by existing structures of government departments and agencies. Formalised agreements like Memoranda of Understanding (MoU) and collaborative frameworks between government sectors can facilitate collaboration at the level of service provision [15]. MoUs between the health and education sectors have promoted collaboration between health professionals and school staff in screening and treatment of middle ear disease to prevent hearing loss [15, 16]. Frameworks for whole-of-government approaches have been recognised as important in providing coordinated interagency responses [17-19]. Formalised agreements should focus on detailing a set of long-, medium- and short-term strategies as it provides clarity around collaborative programs for local providers [16, 20].

3.3.2 Exo (organisational) system factors

3.3.2.1 Communication - Awareness

Although multiple agencies and services may be involved with the care of a child with a disability, this does not mean that they are all aware of each other's existence, which can lead to duplication of resources [21]. Both families and providers have identified the lack of communication between, and knowledge of, the different agencies and services as a barrier to accessing available support [14]. Raising awareness of collaborative partnerships through the distribution of educational resources across agencies and services facilitates collaboration and the professional development of providers with little knowledge of disability [13, 16, 17]. Distribution of these resources helps providers in remote areas of Australia who have reported feeling like they work in isolation [22]. Advertising collaborative projects and the participating personnel also aids collaboration by reducing the risk associated with providers working outside their professional boundaries [11]. Good community awareness of the organisation that is providing a program has also been reported to

facilitate the establishment of collaborative organisational partnerships with local services [23].

3.3.2.2 Communication – Lack of role clarity and responsibility

Ambiguity and lack of role clarity and responsibilities of different providers, agencies and organisations is a key barrier to collaboration at the exo (organisational) system level [18]. The role of Aboriginal Health Workers is unclear to some mainstream providers leading to their underutilisation, despite the important role they play [24]. Formally communicating the role and responsibility of each team member is reported as an essential step when putting into practice an inter-agency or multi-disciplinary model [11].

3.3.2.3 Financial and human resources

Barriers to the uptake and sustainability of collaborative models include difficulty providing them in sectors which are already facing service provision within a tightening financial environment [9] and a lack of the levels of funding required for providing holistic care approaches [25, 26]. Where organisations continue to provide collaborative models of service provision despite appropriate funding, they report that this is done “*on sheer good will*” [25](p. 4) with staff often working beyond their normal hours [26]. Furthermore, building effective and trusting collaborative relationships across different organisations, agencies and services takes time [18, 23, 27]. Collaboration can be impeded when providers lack the time to develop the skills and build the networks required [14].

3.3.2.4 Service delivery setting

The effectiveness of a collaborative program is influenced by the setting in which it is delivered. Collaboration is facilitated by the delivery of mainstream programs in culturally safe environments for Aboriginal and Torres Strait Islander providers, communities, and families [12, 14, 28]. Delivering collaborative health services within schools has been reported to reduce the stigma and the socio-economic impact of having to attend services in mainstream settings for Aboriginal

and Torres Strait Islander families, while increasing program participation [28, 29]. Basing health services within schools also allows the services to be responsive to local needs and promotes increased awareness of disability and relevant services among education providers [16, 29]. Collaboration between health and education services based in a single setting provides a one-stop-shop, which facilitates the sharing of information between different services and organisations [13].

3.3.3 Meso (provider) system factors

A number of key factors of collaboration are found at the front line of collaborative service provision within the meso (provider) system where the interactions occur between providers, communities, and Aboriginal and Torres Strait Islander families and their children.

3.3.3.1 Relationships

A key facilitator to collaboration at this level is the coordinator or linking role. The appointment of a person external to the services or agencies involved whose role is to link the different players and act as a trainer, motivator and sustainer can be important to a collaborative inter-disciplinary approach [11, 30, 31]. In the context of Aboriginal and Torres Strait Islander childhood disability, this person is usually local to the community (eg. a community liaison person, Aboriginal Health or Education Worker) and is a conduit between providers, communities and families, also promoting the cultural competence of services [13, 21, 26, 28-31].

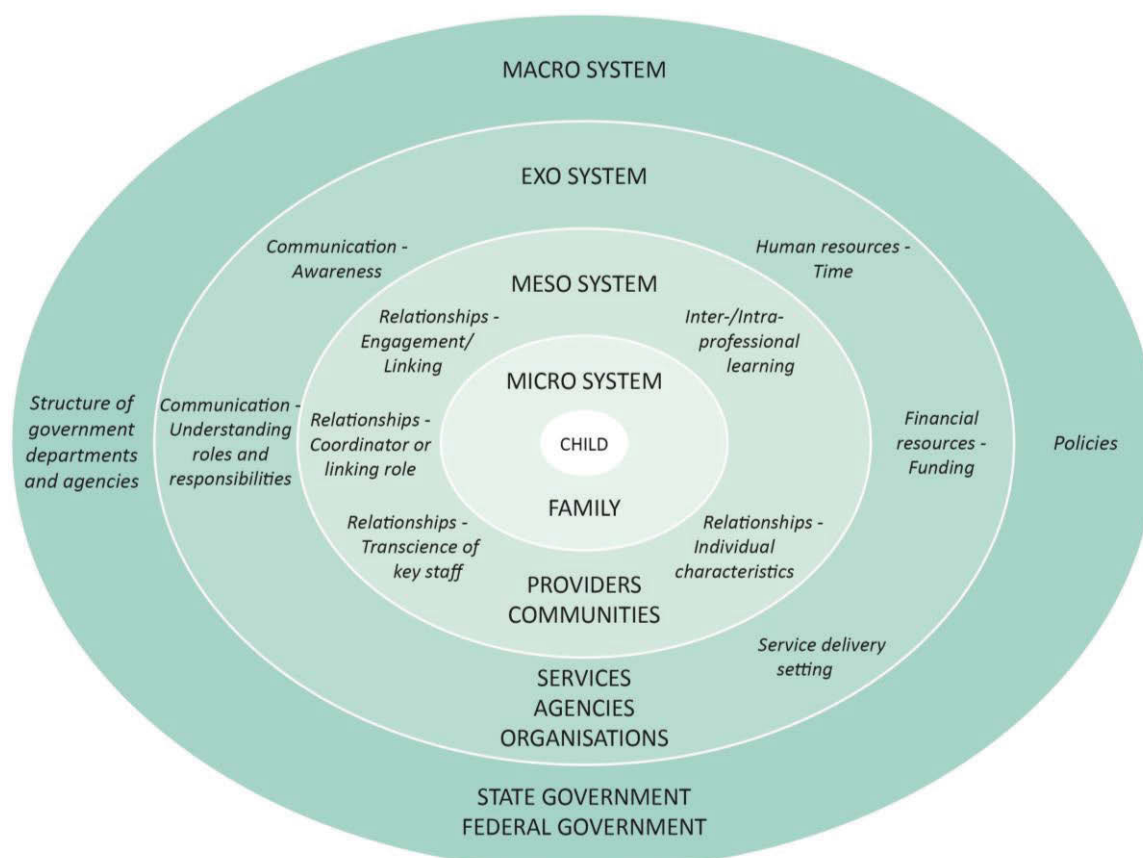
The effectiveness of the coordinator or linking role in facilitating collaboration is influenced by the individual's characteristics. Being open and inclusive and having personal contacts among decision makers in the organisations, agencies, and services involved promotes collaboration [11]. The effect of individual characteristics on collaborative relationships extends to providers. Collaboration can be impeded by specialist providers choosing to only draw knowledge and skills from their traditional disciplines [9]. Aboriginal and Torres Strait Islander provider experiences of racism and historical trauma can obstruct engagement with mainstream services [14]. Awareness of cultural difference and individual attitudes [34] and getting along well with people

[28] are individual provider characteristics that can facilitate collaborative relationships. Transience and turnover of key staff can disrupt collaborative efforts [11, 17, 30].

Building relationships integral to collaboration at the local level is facilitated by face-to-face provider engagement and linking with communities [9, 19, 35]. Provider-to-provider engagement is facilitated by demonstrating mutual respect and understanding [11, 34], having access to direct links for communication, and using open and respectful communication strategies [11, 12]. The importance of engagement is reflected in the collaborative Specialist Integrated Community Engagement model which is based around the concept of linking different sectors and the community through engagement to build social capital and a community of learners to sustain the collaborative process [9]. Engaging the community can be important to the success of collaborative programs [36] and tapping into existing collaborative relationships in the community can facilitate the engagement process [29]. Where a mainstream organisation is unknown to a community, attending interagency meetings in the local area by their providers can facilitate engagement with Aboriginal and Torres Strait Islander organisations [23].

3.3.3.1 Inter- and intra-professional learning

The modeling of inter- and intra-professional collaboration by clinical educators from different disciplines for university students on placement has been reported to facilitate a well-coordinated and holistic approach to learning [34]. The sustainability of collaborative practices is increased by empowering students to incorporate the lessons learned into their future practice [34]. Inter- and intra-professional learning also facilitates collaboration by creating supportive relationships between providers from different disciplines [28].



Source: Adapted from the Australian Institute of Health and Welfare 2012 [4] & [5], in Green A et al. 2014, 'Cross-sector collaborations in Aboriginal and Torres Strait Islander childhood disability: a systematic integrative review and theory-based synthesis', *International Journal for Equity in Health* [1], reprinted by permission of copyright holder BioMed Central.

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

3.4 Discussion

The complex nature of childhood development, particularly for Aboriginal and Torres Strait Islander children, has seen recognition of the need for a shift from a purely medical view of disability to collaborative approaches which also take into account social and environmental factors [7, 9, 14]. Divisions between mainstream, specialist and non-mainstream services can result from top-down approaches that do not work for addressing complex problems that require buy-in to collaborative approaches at all levels [37, 38]. In the move towards collaboration, however, it is important to recognise that collaboration is, in itself, a complex concept which has the potential to inspire innovative solutions or create frustration [39]. Further research is required into collaborations in the field of Aboriginal and Torres Strait Islander

childhood disability to maximise the potential, and minimise any negative impacts, of collaborative approaches. The paucity of research on Aboriginal and Torres Strait Islander children with a disability [40] means exploring the experiences of children and their families in accessing services is important to completing a holistic picture in order to improve service access.

The importance of respectful communication and culturally appropriate program delivery demonstrates the need for cultural competence as a central pillar of collaboration in the field of Aboriginal and Torres Strait Islander childhood disability. Cultural competence requires promotion of attitudes, knowledge, and behavior at individual, institutional, and systemic levels in order to deliver effective care for Aboriginal and Torres Strait Islander peoples [41]. Culturally competent organisations and systems need to be reflective of the diverse populations they serve, including at leadership and management levels, and through policies that facilitate cross-cultural communication and access [42]. An increased focus on cultural competence may help to address the negative impact of racism on service access and provision.

Although the review focused on Aboriginal and Torres Strait Islander children and is not necessarily generalisable to other indigenous populations, similar health disparities are experienced by indigenous populations worldwide [7, 43-45]. Investment of time as a facilitator to building sustainable collaborations in the face of government policy and funding cycles is reflected in Canada's collaborative Aboriginal Head Start program to improve indigenous child development outcomes. A key element to the positive impact of the community-based program is the time it took (more than a decade) to establish credibility within communities and build a trained and experienced workforce to work collaboratively [44]. Long-term commitment to sustainable and collaborative relationships with indigenous organisations and communities is also a strategy identified by Aboriginal and Torres Strait Islander organisations to achieve genuine partnerships [46].

3.4.1 Limitations

The focus of the review on Aboriginal and Torres Strait Islander children with a disability across Australia may mean that it is not generalisable to indigenous

populations in other countries or to specific Aboriginal and Torres Strait Islander populations within Australia. This review provides a broad national snapshot of collaboration, but further research within specific local contexts is required to explore ways in which collaboration can improve access and be responsive to local needs [46, 47]. Due to the focus of the review on collaboration across sectors, no data for the micro system of the family and the individual child were collected. The intra- and inter-personal factors and interactions at this level, however, both influence and are influenced by the factors of collaboration at the meso (provider), exo (organisational) and macro (government) system levels.

3.5 Conclusions

The policy shift towards inter-sector collaborative approaches represents a strong opportunity for the health, education, and social service sectors and their providers to work collaboratively with each other in innovative ways. As this review has shown however, collaboration is not a simple concept. Many barriers and facilitators exist at the macro (government), exo (organisational), and meso (provider) system levels that influence the effectiveness of collaborative efforts. By identifying the components of collaboration across the health, education, and social service sectors this review provides information to guide future efforts at developing collaborative solutions to improve service access for Aboriginal and Torres Strait Islander children with a disability and their families.

3.6 Summary tables

Table 3.1 Summary of included peer-reviewed articles

First Author (year)	Population	Aims	Methods
Qualitative Studies			
Davidson (2013) [34]	Aboriginal and Torres Strait Islander children	Report on lessons learned from an inter-professional clinic.	Survey with open ended questions; Informal feedback
DiGiacomo (2) (2013) [14]	Government and NGO service providers; carers	Determine the factors involved in accessing services and support.	Forums
McSwan (2001)* [30]	Rural/remote Indigenous children	Develop a whole of community approach to OM.	Questionnaires and interviews
Nelson (2004, 2007) [28, 29]	Indigenous children	Investigate components of a socially and culturally appropriate occupational therapy service.	Focus groups and interviews; Semi-structured qualitative survey
Discussion Papers			
Aldred (2002) [24]	Aboriginal children under 5 years	Detail how a speech pathology position in an Indigenous Hearing Health Service has addressed hearing health issues of speech and language impairment.	NA
Clarke (2013) [9]	Rural/remote Aboriginal children	Discussion of what works to promote child wellbeing and to put forward the SpICE Model.	NA

Kirkham (2010) [20]	Indigenous children	Share findings from the Australian OM workshop.	NA			
Observational Studies						
Adams (2004) [27]	Indigenous children 0-11 years	Evaluate the Gippsland Indigenous Hearing Health Program.	Analysis of screening outcomes and management			
Smith (2012)** [36]	Indigenous children	Examine the outcomes of a screening service.	Retrospective review of service activity			
Mixed Method Study						
Raman (2011) [25]	Aboriginal children	Evaluate the KARI clinic and outcomes.	Semi-structured interviews; clinical data review			
Literature Review						
DiGiacomo (1) (2013) [12]	Aboriginal and Torres Strait Islander children	Determines the factors impacting on the prevention, recognition, and access to support and management.	Integrative review			
First Author (year)	Population	Aims	Methods	Intervention type	Intervention duration	Intervention Evaluation
Intervention Study						
Elliott (2010)*** [32]	Aboriginal and Torres Strait Islander children 0-6 years	Feasibility of integrating a mobile telehealth-service with community health services.	Consenting children, referral rate, and rating the quality of screening images	Mobile telehealth screening service	6 months	Feasibility community acceptance, integration with existing community-based services, and the technical/practical feasibility of presenting diagnostic information for telemedicine consult.

*Same study as grey literature report McSwan (2001). **Same service as Elliott (2010). *** Same service as Smith (2012).

Table 3.2 Summary of included grey literature

First Author (year)	Design	Focus/Setting
Grey Literature		
EarInfoNet (2006) [22]	Content overview	Aboriginal children; Information on the Indigenous EarInfoNet.
Telethon Speech Hearing Centre (2013) [48]	Description of the Earbus program	Description Earbus Program in Western Australia.
ARTD Consultants (2008) [16]	Mixed methods	To provide information to support decisions about the appropriateness of the Aboriginal OM Screening Program.
Australian Institute of Health and Welfare (2014) [49]	Evaluation	Data on the Child Hearing Health Coordinator initiative.
Burns (2013) [10]	Narrative literature review	Up-to-date review of ear health and hearing.
Burrow (2009) [19]	Literature review	Summary of the literature regarding educational and other approaches to hearing loss.
Burton (2012) [26]	Interviews; reports on 9 case studies	Explore the steps mainstream service providers, Aboriginal Community Controlled Organisations and government can take to develop partnerships.
Gilroy (2012) [21]	Thesis; Focus groups and interviews	Describes the factors that influence the participation of Aboriginal people in disability services as perceived by non-Aboriginal and Aboriginal employees in NSW government services.
Higgins (2010) [33]	Interviews; Case study	Report on the Early Days Project on Autism Spectrum Disorders.

McSwan (2001)* [11]	Evaluation	Final report of project, 'A Whole Community Approach to Otitis Media: reducing its incidence and effects'.
Ministerial Advisory Committee: Students with Disabilities (2003) [13]	Interviews; Forum	Identify issues related to the education of Aboriginal students with disabilities in South Australia.
Ministerial Advisory Committee: Students with Disabilities (2007) [17]	Mixed methods	Examine programs established in South Australia to address OM and conductive hearing loss.
NSW Ombudsman (2010) [35]	Mixed methods	Examine the initiatives taken by Ageing, Disability and Home Care to meet the goals set out in the Aboriginal Policy Framework and Aboriginal Consultation Strategy to improve access.
Purcal (2013) [23]	Mixed methods	Evaluation of Northcott Disability Service's school readiness program for Aboriginal children with additional needs.
Queensland Health (2009) [18]	Framework description	Describes an interagency statewide strategic framework to improve ear health across Queensland.
Scholes (2010) [50]	Discussion paper	Describes the partnership population based approach of Deadly Ears Speech Pathology service.
Simmons (2012) [31]	Program description	Describes the role of the Child Hearing Health Coordinator positions in the Northern Territory to coordinate regional programs that are inclusive of hearing health.
Western Australia Education and Health Standing Committee (2012) [15]	Forums; Briefings	Health and educational issues in North West Western Australia; key issues identified during the Committee's meetings.

* Reports on the same study as peer-reviewed article by McSwan (2001).

3.7 References

1. Green A, DiGiacomo M, Luckett T, Abbott P, Davidson PM, Delaney J & Delaney P. 2014, 'Cross-sector collaborations in Aboriginal and Torres Strait Islander childhood disability: a systematic integrative review and theory-based synthesis', *International Journal for Equity in Health*, vol. 13, no. 1, p. 126.
2. Melnyck BM & Fineout-Overholt E. 2005, *Evidence-based practice in healthcare*, Lippincott, Philadelphia.
3. Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M, Britten N, Roen K & Duffy S 2006, *Guidance on the conduct of narrative synthesis in systematic reviews. A product from the ESRC Methods Programme. Version 1*, Lancaster University, Lancaster.
4. Australian Institute of Health and Welfare 2012, *Social and emotional wellbeing: development of a Children's Headline Indicator. Cat. no. PHE 158*, Australian Institute of Health and Welfare, Canberra.
5. Dunlop AW. 2002, 'Perspectives on children as learners in the transition to school'. In: Fabian H & Dunlop A (eds.) *Transitions in the early years: debating continuity and progression for young children*, Routledge Falmer, London, pp. 98-108.
6. Bronfenbrenner U. 1979, *The ecology of human development: experiments by nature and design*, Harvard University Press, Cambridge, Mass.
7. Westby C. 2013, 'Implementing recommendations of the World Report on Disability for indigenous populations', *International Journal of Speech-Language Pathology*, vol. 15, no. 1, pp. 96-100.
8. Zubrick SR, Lawrence DM, Silburn SR, Blair E, Milroy H, Wilkes T, Eades S, D'Antoine H, Read A, Ishiguchi P & Doyle S 2004, *The Western Australian Aboriginal Child Health Survey: The Health of Aboriginal Children and Young People*, Telethon Institute for Child Health Research, Perth.
9. Clarke K & Denton M. 2013, 'Red Dirt Thinking on Child Wellbeing in Indigenous , Rural and Remote Australian Communities: The SpICE Model "I just don't want my kid to struggle like I did at school"', *Australian Journal of Indigenous Education*, vol. 42, no. 2, pp. 136-144.
10. Burns J & Thomson N 2013, *Review of ear health and hearing among Indigenous Australians.*, Australian Indigenous HealthInfoNet, Western Australia.
11. McSwan D, Ruddell D & Searston I 2001, *Report: A Whole Community Approach to Otitis Media-reducing its incidence and effects*, Rural Education, Research & Development Centre, James Cook University, Townsville.
12. DiGiacomo M, Davidson PM, Abbott P, Delaney P, Dharmendra T, McGrath SJ, Delaney J & F, V. 2013, 'Childhood disability in Aboriginal and Torres Strait Islander peoples: a literature review', *International Journal for Equity in Health*, vol. 12, no. 1, p. 7.

13. Ministerial Advisory Committee: Students with Disabilities 2003, *Aboriginal Students with Disabilities*, Government of South Australia, South Australia.
14. DiGiacomo M, Delaney P, Abbott P, Davidson PM, Delaney J & F, V. 2013, 'Doing the hard yards': carer and provider focus group perspectives of accessing Aboriginal childhood disability services', *BMC Health Services Research*, vol. 13, no. 1, p. 326.
15. Western Australia Education and Health Standing Committee 2012, *Report on key learnings from the Committee research trip 11-17 March 2012.*, Parliament of Western Australia, Perth, Western Australia.
16. ARTD Consultants 2008, *Evaluation of the Aboriginal otitis media screening program: Final Report*, New South Wales Health, Sydney.
17. Ministerial Advisory Committee: Students with Disabilities 2007, *Aboriginal Students with Disabilities: Otitis Media and Conductive Hearing Loss*, Government of South Australia, South Australia.
18. Queensland Health 2009, *Deadly Ears, Deadly Kids, Deadly Communities: 2009-2013*, Queensland Government, Queensland.
19. Burrow S, Galloway A & Weissosfner N 2009, *Review of educational and other approaches to hearing loss among Indigenous people*, Australian Indigenous HealthInfoNet, Western Australia.
20. Kirkham LA, Wiertsema S, Smith-Vaughan H, Thornton R, Marsh R, Lehmann D, Leach A, Morris P & Richmond P. 2010, 'Are you listening? The inaugural Australian Otitis Media (OMOZ) workshop - towards a better understanding of otitis media', *Medical Journal of Australia*, vol. 193, no. 10, pp. 569-571.
21. Gilroy J. 2012, 'The participation of Aboriginal people with a disability in disability services in New South Wales, Australia', PhD thesis, University of Sydney.
22. EarInfoNet. 2006, 'Australian Indigenous EarInfoNet and InfoNetwork', *Aboriginal and Islander Health Worker Journal*, vol. 30, no. 3, pp. 20-21.
23. Purcal C, Newton BJ, Fisher KR, Eastman C & Mears T 2013, *School readiness program for Aboriginal children with additional needs: working with children, families, communities and service providers. Interim evaluation report.*, Social Policy Research Centre, University New South Wales, Sydney.
24. Aldred R, Forsingdal S & Baker R. 2002, 'Working together to improve the health status and health outcomes for Indigenous children and their families living in urban settings: the speech pathologist's role', *ACQuiring Knowledge in Speech, Language and Hearing*, vol. 4, no. 3, pp. 166-169.
25. Raman S, Reynolds S & Khan R. 2011, 'Addressing the well-being of Aboriginal children in out-of-home care: Are we there yet?', *Journal of Paediatrics and Child Health*, vol. 47, no. 11, pp. 806-811.
26. Burton J 2012, *Opening Doors Through Partnerships: Practical approaches to developing genuine partnerships that address Aboriginal and Torres Strait*

Islander community needs April 2012, Secretariat of National Aboriginal and Islander Child Care, Victoria.

27. Adams K, Dixon T & Guthrie J. 2004, 'Evaluation of the Gippsland Regional Indigenous Hearing Health Program - January to October 2002', *Health Promotion Journal of Australia*, vol. 15, no. 3, pp. 205-210.
28. Nelson A & Allison H. 2004, 'A Visiting Occupational Therapy Service to Indigenous Children in School: Results of a Pilot Project', *Australian Journal of Indigenous Education*, vol. 33, pp. 55-60.
29. Nelson A & Allison H. 2007, 'Relationships: the key to effective occupational therapy practice with urban Australian Indigenous children', *Occupational Therapy International*, vol. 14, no. 1, pp. 57-70.
30. McSwan D, Clinch E & Store R. 2001, 'Otitis Media, Learning and Community', *Education in Rural Australia*, vol. 11, no. 2, pp. 27-32.
31. Simmons K, Rotumah V, Cookson M & Grigg D. 2012, 'Child Hearing Health Coordinators Tackle Ear and Hearing Health in the NT', *The Chronicle*, vol. 23, no. 1, pp. 22-23.
32. Elliott G, Smith AC, Bensink ME, Brown C, Stewart C, Perry C & Scuffham P. 2010, 'The feasibility of a Community-Based Mobile Telehealth Screening Service for Aboriginal and Torres Strait Islander Children in Australia', *TELEMEDICINE and e-HEALTH*, vol. 16, no. 9, pp. 950-956.
33. Higgins J & Beecher S 2010, *The Secretariat of National Aboriginal and Islander Child Care (SNAICC) Early Days Project on Autism Spectrum Disorders August 2010*, Secretariat of National Aboriginal and Islander Child Care, Victoria.
34. Davidson B, Hill AE & Nelson A. 2013, 'Responding to the World Report on Disability in Australia: Lessons from collaboration in an urban Aboriginal and Torres Strait Islander school', *International Journal of Speech-Language Pathology*, vol. 15, no. 1, pp. 69-74.
35. New South Wales Ombudsman 2010, *Improving service delivery to Aboriginal people with a disability: a review of the implementation of ADHC's Aboriginal Policy Framework and Aboriginal Consultation Strategy.*, New South Wales Ombudsman, Sydney.
36. Smith AC, Armfield NR, Wu WI, Brown CA & Perry C. 2012, 'A mobile telemedicine-enabled ear screening service for Indigenous children in Queensland: activity and outcomes in the first three years', *Journal of Telemedicine and Telecare*, vol. 18, no. 8, pp. 485-489.
37. Hunt J 2013, *Engaging with Indigenous Australia—exploring the conditions for effective relationships with Aboriginal and Torres Strait Islander communities. Issues paper no. 5.*, Australian Institute of Health and Welfare & Australian Institute of Family Studies, Canberra and Melbourne.
38. Llewellyn G, Thompson K & Fante M. 2002, 'Inclusion in early childhood services: Ongoing challenges', *Australian Journal of Early Childhood*, vol. 27, no. 3, 18-23.

39. Huxham C & Vangen S. 2005, *Managing to collaborate: The theory and practice of collaborative advantage*, Routledge, United States.
40. Biddle N, Yap M & Gray M 2013, *CAEPR Indigenous Population Project 2011 Census Papers. Paper 6 Disability*, Australian National University, Canberra.
41. National Aboriginal Community Controlled Health Organisation 2011, *Creating the NACCHO Cultural Safety Training Standards and Assessment Process: A background paper*, National Aboriginal Community Controlled Health Organisation, Canberra.
42. Betancourt J, Green A, Carrillo J & Ananeh-Firempong 2nd O. 2003, 'Defining cultural competence: a practical framework for addressing racial/ethnic disparities in health and health care', *Public Health Reports*, vol. 118, no. 4, pp. 293-302.
43. Australian Institute of Health and Welfare 2011, *Aboriginal and Torres Strait Islander people with disability: Wellbeing, participation and support*, Australian Institute of Health and Welfare, Canberra.
44. Ball J. 2009, 'Supporting Young Indigenous Children's Language Development in Canada: A Review of Research on Needs and Promising Practices', *Canadian Modern Language Review*, vol. 66, no. 1, pp. 19-47.
45. Banks S & Miller D. 2005, 'Empowering Indigenous Families who have Children with Disabilities: An Innovative Outreach Model', *Disability Studies Quarterly*, vol. 25, no. 2.
46. Burton J 2012, *Coming Together: The journey towards effective integrated services for Aboriginal and Torres Strait Islander children and families*, Secretariat of National Aboriginal and Islander Child Care, Victoria.
47. World Health Organisation & World Bank 2011, *World report on disability*, World Health Organisation, Geneva, Switzerland.
48. Telethon Speech Hearing Centre. 2013, 'Otitis media: helping to close the gap in Indigenous Australia', *Medicus (Nedlands, WA)*, vol. 53, no. 2, pp. 46-47.
49. Australian Institute of Health and Welfare 2014, *Stronger Futures in the Northern Territory: Hearing Health Services 2012-2013*, Australian Institute of Health and Welfare, Canberra.
50. Scholes J. 2010, 'Deadly Ears Speech Pathology: Working through partnerships to limit the impact of otitis media on the communication development of Aboriginal and Torres Strait Islander children', *Talkabout*, vol. 23, no. 2, pp. 20-21.

Chapter Four: Conceptual framework

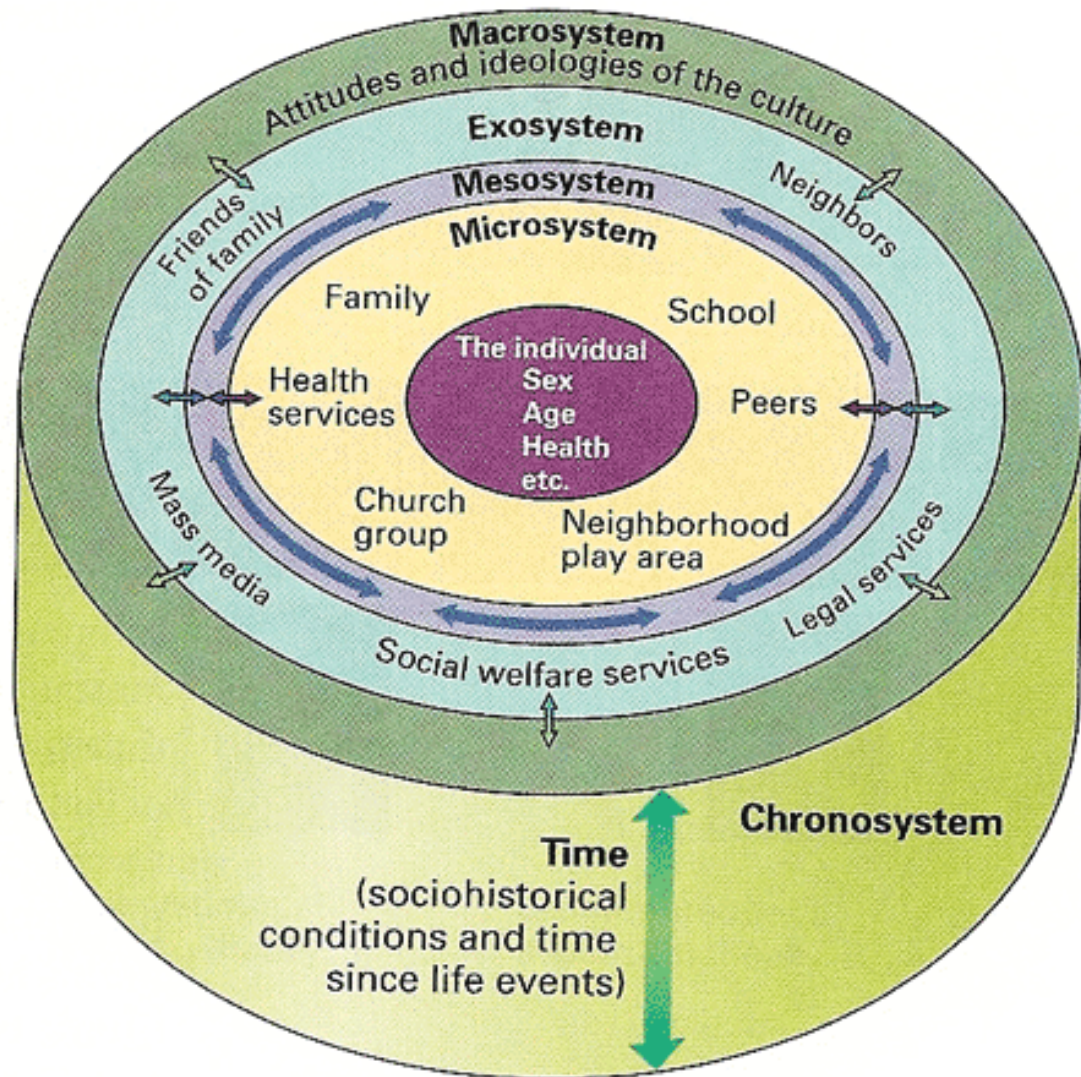
4.1 Introduction

Chapter Two established the background and context of the project in light of the existing literature. Chapter Three provided an integrative review using a systematic approach to address the gap in knowledge identified in Chapter Two on how collaboration works in practice across and within sectors involved in service provision. This chapter describes the overarching conceptual framework informing the project.

Factors at the community, service, and policy levels have been identified by Aboriginal carers of a child with a disability in Western Sydney as influencing their journeys to access support and services [1]. The literature review of components of inter- and intra- sector collaboration in service provision to families in Chapter Three also revealed factors existing at the meso, exo, and macro levels, demonstrating the need for a holistic approach to address service access issues for this population. This project is thus aligned using Bronfenbrenner's ecological systems theory that focuses on interactions between systems of individuals, families, cultures, communities, and policies; all playing an equal role in human development [2]. Further elucidating the application of these principles, the frameworks of Candidacy [3], and Collaborative Practice to Enhance Patient Care Outcomes [4] have been applied as a posteriori analytical frameworks, in Chapters Six and Seven respectively, to explore the perceptions, understandings, and experiences of non-ACCHO providers of service provision to families and working with other providers. Both frameworks utilise an ecological systems approach to describe the concept of candidacy in relation to service access for vulnerable populations, and the concept of interprofessionality in relation to interprofessional collaborative practice, respectively. This chapter summarises the ecological systems theory [2], the overarching conceptual framework for this project, as well as the frameworks of Candidacy [3], and Collaborative Practice to Enhance Patient Care Outcomes [4], as an outline for understanding the qualitative study findings in Chapters Six and Seven, and discussion of the implications of the findings for policy, practice, education, and research, in Chapter Eight.

4.2 Bronfenbrenner's ecological systems theory

This project is informed by Bronfenbrenner's ecological systems theory [2] (Figure 4.1). 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. Working from the child outwards, the immediate circle is the micro system which consists of settings that directly engage the child (e.g. preschool, school, home), followed by the meso system which contains the interrelations between different micro systems (e.g. between school and home), followed by the exo system containing wider environmental structures which do not directly engage the child (e.g. the community, social services), followed by the macro system which contains the overarching cultural, economic, political and societal structures that shape the other systems (e.g. government policy, legal systems, social values) [5]. Encompassing these levels is the chronosystem, which *"involves the patterning of environmental events and transitions over the life course"* [6](p. 49). This organising framework allows for the analysis of the multidimensional factors that interact to influence service access for Aboriginal and Torres Strait Islander families of a child with a disability, the impact of social interaction, and recognition of the influence of early intervention on the ongoing trajectory of the journeys of children and their families. Addressing each factor discretely without considering the interdependency of factors is unlikely to achieve desirable outcomes. This framework assists in ensuring that the project avoids replicating a silo view of service provision and access.



Source: Santrock JW. 2007, *Child development* [6], reprinted by permission of copyright holder McGraw-Hill Education.

Figure 4.1 Ecological systems theory

The principles of ecological systems theory have been adopted and adapted widely in conceptual frameworks relating to a range of areas in health research, including childhood disability [7]. Both a posteriori analytical frameworks used to further explore the inductive preliminary analysis of the perceptions, understandings, and experiences of non-ACCHO providers in Chapters Six and Seven, elucidate these principles in relation to their respective areas of application. The frameworks of Candidacy, and Collaborative Practice to Enhance Patient Care Outcomes, are summarised below.

4.2.1 Candidacy framework

The Candidacy framework emerged in relation to access to health services for vulnerable populations. This focus of the framework and its ecological systems approach made it especially applicable to the focus of the project. Dixon-Woods et al. [3] define the concept of candidacy as describing:

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 [3](p. 7).

Seven stages of candidacy are identified. First, 'Identification of candidacy' is an important part of patients being able to assert candidacy. Identification involves *"how people recognise their symptoms as needing medical attention"* [3](p. 7). Second, 'Navigation of services' involves both having an awareness of available services and the ability to mobilise required resources. Third, the 'Permeability of services' refers to how easily patients are able to use services, with porous services defined as those requiring *"few qualifications of candidacy to use them, and...the mobilisation of relatively fewer resources"* [3](pp. 7-8). Fourth, 'Appearances' at health services requires patients to make a claim to candidacy which *"requires a set of competencies, including the ability to formulate and articulate the issue for which help is being sought, and the ability to present credibly"* [3](p. 8). Fifth, 'Adjudications' are made by providers reflecting their decisions and judgments that *"allow or inhibit continued progression of candidacy"* [3](p. 8). Sixth, 'Offers and resistance' refers to patients who may choose to refuse offers made by health services, such as referrals to other providers or for medication. Seventh, these stages are managed within the context of 'Operating conditions and the local production of candidacy'. Operating conditions:

are influenced by individuals, the setting and environment in which care takes place, situated activity, the dynamics of face-to-face activity, and aspects of self (such as gender), the typifications staff use in categorising people and diseases, availability of economic and other resources such as time, local pressures, and policy imperatives [3](p. 7).

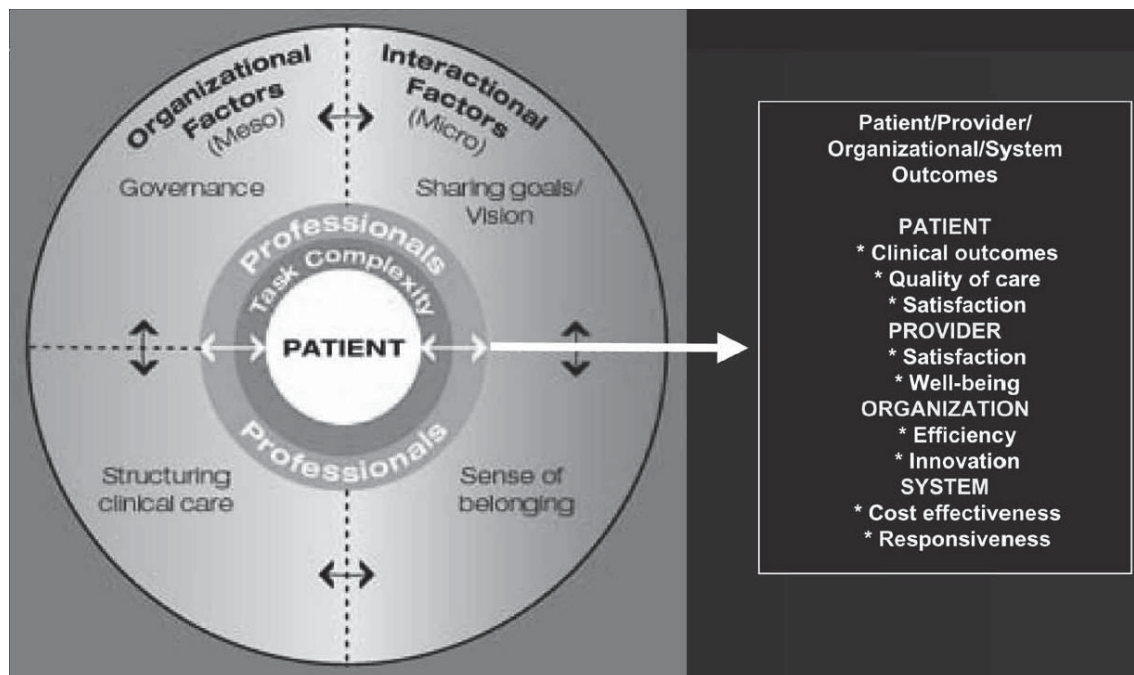
4.2.2 Collaborative Practice to Enhance Patient Care Outcomes framework

The Collaborative Practice to Enhance Patient Care Outcomes framework was developed to explore the key elements of interprofessional collaborative practice in healthcare (Figure 4.2). The framework's focus on exploring collaboration within an ecological systems context made it especially suitable to the focus of the project. D'Amour and Oandasan [4] define interprofessionality 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 [4](p. 9).

The framework depicts *"the interactional processes and organisational factors that have to be taken into account when professionals work collaboratively"* [4](p. 15). The patient is situated at the centre of the framework and conceptualised as in an interdependent relationship with providers, as the interactions between providers and the task complexity to be addressed through collaboration are determined by their needs [4]. Encompassing the interdependent relationship between patients and providers are four dimensions of collaborative processes between providers that mutually influence each other. Two dimensions are related to interactional processes between providers, and two dimensions related to organisational factors. Interactional processes are related to 1) Sharing common goals and vision, and 2) Sense of belonging. While Sharing common goals and vision for patient care is important to interprofessional collaborative practice, within this dimension it is equally important to *"recognise the diverse interests and the asymmetry of power of the various partners in care and the negotiations that result"* [4](p. 16). Sense of belonging *"refers to the bonds that develop between team members and their willingness to work together, elements that contribute to a sense of mutual trust among health professionals working in a team"* [4](p. 16). Organisational factors are related to 1) Governance, and 2) Formalisation. Governance relates to the important role of leadership in interprofessional collaborative practice and the need to consider different levels and types of leadership [4]. Formalisation relates to *"structuring clinical care in a more systematised way...[through] the development of information exchange, protocols, procedures"* [4](p. 16). The processes of interprofessional collaborative practice are

managed within, and influenced by, systemic factors related to policies, funding, and professional socio-cultural values [4].



Source: D'amour D and Oandasan I. 2005, 'Interprofessionality as the field of interprofessional practice and interprofessional education: An emerging concept', *Journal of Interprofessional Care* [4], reprinted by permission of copyright holder Taylor & Francis LLC, (<http://tandfonline.com>).

Figure 4.2 Collaborative Practice to Enhance Patient Care Outcomes framework

4.3 Conclusion

As a guiding conceptual framework, ecological systems theory [2] facilitates a holistic understanding of service provision to Aboriginal children with a disability and their families. This includes the perceptions, understandings, and experiences of non-ACCHO providers from the health, education, and social service sectors, working together in this space. The frameworks of Candidacy [3], and Collaborative Practice to Enhance Patient Care Outcomes [4] further elucidate the application of ecological systems theory [2] principles to explain how multidimensional factors interact as barriers and enablers to influence service access. Understanding the barriers and enablers to effective service delivery across sectors existing at the meso, exo, and macro levels, the interdependence of these factors, and how they both influence, and are influenced by, families at the center, is important in addressing issues related to a complex and fragmented service landscape.

4.4 References

1. Green A, Abbott P, Delaney P, Patradoon-Ho P, Delaney J, Davidson PM & DiGiacomo M. 2016, 'Navigating the journey of Aboriginal childhood disability: a qualitative study of carers' interface with services', *BMC Health Services Research*, vol. 16, no. 1, p. 680.
2. Bronfenbrenner U. 1979, *The ecology of human development: experiments by nature and design*, Harvard University Press, Cambridge, Mass.
3. Dixon-Woods M, Cavers D, Agarwal S, Annandale E, Arthur A, Harvey J, Hsu R, Katbamna S, Olsen R, Smith L & Riley R. 2006, 'Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups', *BMC Medical Research Methodology*, vol. 6, no. 1, p. 35.
4. D'amour D & Oandasan I. 2005, 'Interprofessionality as the field of interprofessional practice and interprofessional education: An emerging concept', *Journal of Interprofessional Care*, vol. 19, no. Suppl. 1, pp. 8-20.
5. Bronfenbrenner U. 1977, 'Toward an experimental ecology of human development', *American psychologist*, vol. 32, no. 7, pp. 513-531.
6. Santrock JW. 2007, *Child development*, 11th edition, McGraw-Hill, Boston.
7. Llewellyn A & Hogan K. 2000, 'The Use and Abuse of Models of Disability', *Disability & Society*, vol. 15, no. 1, pp. 157-165.

Chapter Five: Methodology and methods

5.1 Introduction

Chapters One, Two and Three have established the need to explore non-ACCHO health, education, and social service provider perceptions, understandings, and experiences of service provision to Aboriginal children with a disability and their families in Western Sydney. The purpose of this chapter is to describe the epistemology, methodology, and methods of the Phase three qualitative study.

5.2 Research design

5.2.1 Epistemology

The research design for this qualitative study was influenced by the epistemological assumptions of pragmatism. Pragmatism overcomes the binary argument between positivism and constructivism over whether or not objective true knowledge exists. The debate over this question on the nature of knowledge is merely one philosophical view among many others, the fact that it has been a dominant discourse does not mean that it is the only way to view knowledge [1]. Pragmatism provides an alternate view that bypasses the limitations of the perpetual debate between constructivism and positivism [2, 3]. Pragmatism asks the question of whether or not knowledge has served a purpose rather than whether or not knowledge mirrors an objective reality [1, 2, 4]. It is the consequences of knowledge in action that is the important focus for pragmatists as this is how human beings carry out their day-to-day lives [1, 4, 5]. As Cornish and Gillespie [4] argue, *“lay people and scientists alike construct knowledge in the context of action: knowledge guides action and action feeds back into knowledge construction”* [4](p. 802). In asserting that knowledge is constructed, pragmatism acknowledges the existence of multiple realities [6]. However pragmatism avoids inaction by asserting that knowledge can be judged on whether or not it has served a purpose thereby focusing on the consequences of knowledge in action [4]. A criticism of pragmatism is that it reduces the view of knowledge to a narrow focus solely on action [4]. According to noted

pragmatist Dewey [7] this is a misrepresentation; instead, action is viewed by pragmatists as playing the mediating role between how knowledge is applied meaningfully in people's daily lives rather than being a "*glorification of action for its own sake*" [7](p. 25).

The application of pragmatism as an epistemology in health research is still in its early stages [4]. Two key pragmatic principles influence how to conduct health research guided by this epistemology. First, the acknowledgment of multiple realities leads to recognition of the existence of multiple interests and the issue of how to choose which interest to pursue. Researchers are required to choose whose interests the research will serve and it is this choice which informs the selection of methodology and methods. Cornish and Gillespie [4] propose that one way to determine whose interest to pursue is to "*tackle problems defined by people's experience*" [4](p. 806). Second is the recognition that different methodologies and methods will suit different purposes. Unlike positivism and constructivism, pragmatism is not limited by allegiance to specific paradigms [5]. Selection of methodologies and methods should be carried out according to what will best suit the purpose of the research [2, 8]. In this sense, pragmatism provides a critique of the notion of gold standard and a hierarchy of evidence in health research as belittling alternative methods which should be legitimised as most suited for achieving specific purposes [4].

Pragmatism is the epistemology informing this research design. The interests of the partner ACCHO who identified the need to explore non-ACCHO provider perceptions, understandings, and experiences of service provision as important and appropriate, guide the research. The selection of whose interest to pursue was decided by consulting with the community who identified the need to improve service access for Aboriginal families with a child with a disability in Western Sydney. Having established whose interests were being pursued, the methodology and subsequent methods were selected according to what best suited the purpose of the research.

The research design is informed by principles of the general inductive approach [9] as a methodology, which is influenced by some of the principles of grounded theory [10]. Key principles informing the approach is that the preliminary approach to data analysis is inductive and that the research is interested in exploring perceptions,

understandings, and experiences and therefore utilises qualitative methods. The general inductive approach advocates that theory emerges from the data guided by the research objectives [9]. As the purpose of the research was to explore non-ACCHO provider perceptions, understandings, and experiences of service provision in pursuit of the research objectives, without applying a preconceived theory or model at the beginning of data analysis, the general inductive approach as a methodology was selected. The use of qualitative sampling and data collection methods as well as inductive analysis was therefore guided by the general inductive approach [9] as the methodology, which was chosen because it was important that the findings were useful according to the research objectives, as defined in consultation with the partner ACCHO.

5.2.2 Data collection

A qualitative approach to data collection was chosen as it facilitates exploration of the meanings of complex concepts for service providers through their own experiences in a specific context [11, 12]. Semi-structured in-depth interviews were chosen to explore the perceptions, understandings, and experiences of non-ACCHO providers. As a data collection technique, interviews were used because they facilitate the researcher's ability to access the providers' perspectives [8]. The interviews were designed to be semi-structured as this approach best aligned with the general inductive approach as a methodology that aims to address specific research objectives. Although semi-structured, the interview questions were open ended and the interviews were designed to elicit in-depth data in order to gain an in-depth understanding of provider perceptions, understandings, and experiences. The interviews were recorded using a digital audio recorder. Recorders allow the interviewer to focus on the participant and the data being collected while providing an objective record of the interview [8]. Data was collected from 16 June 2015 to 22 July 2016. All of the semi-structured in-depth interviews were conducted as an iterative process in conjunction with data analysis by the researcher. Interviews were stopped once no new issues emerged. Thorne [13] argues that it is not possible to achieve pure data saturation despite it often being employed in qualitative research as a key principle guiding data collection and analysis [13]. Data analysis was conducted as an

iterative process with data collection through preliminary analysis after each interview, creation of summary sheets, and reflexive journals [14]. This process, combined with the specific focus of the interview topic guide and the size of the sample, was sufficient to reveal recurrent themes in information about barriers and enablers and participant experiences that is consistent with findings from similar studies. The full process of analysis is detailed in Section 5.4.1. Following review of the first 21 interviews, additional participants were recruited from the education sector to ensure saturation. Three more education providers were recruited and data saturation was reached.

5.2.3 Sampling strategy

A purposive sampling strategy stratified by non-ACCHO health, education, and social service sectors was used for this qualitative study. Purposive sampling was selected as it allows for the selection of information-rich cases, which facilitates in-depth exploration of the research area of interest [8, 15, 16]. Unlike random sampling which aims to be representative of a large population, the aim of purposive sampling in qualitative research is investigative [17] and facilitates the exploration of provider perceptions, understandings, and experiences. The decision to target non-ACCHO providers in the sampling strategy and not ACCHO providers was made in consultation with the researcher's cultural mentors who advised that this population would be of most interest in relation to the aims of the larger LP120200484 project, discussed in Chapter One Section 1.2. It was important to explore the perspectives of mainstream providers in working with Aboriginal and Torres Strait Islander people, as their positions have the potential to obstruct or facilitate progress [18]. Also important was the influence of specific contexts when looking at partnerships between ACCHO and mainstream providers [19]. All these considerations influenced the decision to sample non-ACCHO providers in the Western Sydney area. For the purpose of this project, Western Sydney is defined by the area covered by the Deerubbin Local Aboriginal Land Council as serviced by the partner ACCHO. This area extends from around Lithgow in the West to as far East as Auburn, and from around Liverpool in the South to Windsor in the North (Figure 5.1).



Source: New South Wales Aboriginal Land Council
<http://www.alc.org.au/media/119304/state%20alc%202013.jpg>, reprinted by permission of copyright holder New South Wales Aboriginal Land Council.

Figure 5.1 Deerubbin Local Aboriginal Land Council boundary

The sampling strategy was stratified by non-ACCHO health, education, and social service sectors. Coyne [15] argues that there is no perfect way of designing a sampling strategy, but what is important is that strategies “*meet the information needs of the study*” [15](p. 630). This strategy aligns with pragmatism. As early intervention to address disability in Aboriginal and Torres Strait Islander children requires the involvement of providers from the health, education, and social service sectors, it was important that the sampling strategy be stratified according to sectors to encourage adequate participation from all providers. Stratification also helps to facilitate comparisons between cases relevant to the research question that are informationally representative [20-22].

While a purposive sampling strategy stratified by sectors facilitated the selection of an in-depth information-rich sample relevant to the research purpose, there are potential limitations of the strategy. As the sample was purposive, the

qualitative study findings may not be generalisable to other populations [8]. A clear and detailed description of the strategy and resultant sample has been provided to allow researchers to interpret how transferable the findings may be to other populations. Another potential limitation is that the selection of non-ACCHO sectors to stratify the sample strategy may have excluded other providers outside these sectors who might also play a role in early intervention. To mitigate this possibility, consultation with members of the project team with extensive experience in providing services within the Western Sydney area to this population was undertaken to ensure that the sectors chosen represented the relevant non-ACCHO sectors involved. The Phase one integrative literature review detailed in Chapter Three also demonstrated that the health, education, and social service sectors were relevant for this sampling strategy. The selection of sectors rather than professions was deliberate to ensure the broadest range of relevant providers were included. Further considerations related to sample size are discussed in Chapter Eight Section 8.5.

5.2.4 Recruitment

5.2.4.1 An asset-informed approach to service mapping

As Phase two of this project, an asset-informed approach to mapping services relevant to Aboriginal childhood disability for carers in Western Sydney was undertaken [23]. The purpose of this service map was twofold. Previous community forums and carer interviews identified the need for a directory of relevant services for carers to help address barriers to service access caused by service fragmentation and a lack of awareness of available services. As a research tool, it was an inexpensive and comprehensive way to inform recruitment for the qualitative study by identifying potential contacts and services, which due to the complex service landscape, may have been overlooked.

As there are no universally accepted guidelines for how an asset-informed approach to service mapping should work [24, 25], a systematic integrative literature review was undertaken to identify and summarise methods for asset-informed approaches to service mapping of formal institutions in health [23]. Findings from the review supported and extended existing generic tools for community asset mapping

for the healthcare context, notably the community asset mapping stages developed by Berkowitz and Wadud in The Community Tool Box [26], an online resource. The review generated a framework for conducting an asset-informed approach to service mapping of formal institutions consisting of four key stages: (1) defining the parameters of the service mapping process; (2) identifying services; (3) mapping services; and (4) consultation and implementation (see Appendix 3 for accepted publication). The framework guided the service map undertaken in this project (see Figure 5.2). The service map produced a directory of relevant services for carers of an Aboriginal child with a disability in Western Sydney. As a result of dissemination of the directory to the community, WentWest Primary Health Network requested, and was granted, permission to post the directory as a resource for the National Disability Insurance Scheme on their website for carers and providers.

Stage 1 – Define the parameters of the service mapping process	Stage 2 – Identify services	Stage 3 – Map services	Stage 4 – Consultation and implementation
<i>[Report defined outcome, size and scope of area to be mapped, what assets will be mapped, who will undertake the work, timeframe, required financial/human resources, what will be done with results etc.]</i>	<i>[Report data collection techniques, detailed record of information sources including date searched/accessed ect.]</i>	<i>[Report process used to map collected information to defined outcome]</i>	<i>[Report how results of the service map were made available to community members / key stakeholders]</i>
Example - Parents of Aboriginal and Torres Strait Islander children with a disability needed to understand what services were available and what these could offer. Relevant services were services from the health, education and social service sectors within a metropolitan region of a city. A researcher undertook the service map with the support of a core team of key stakeholders over a three-month period. No financial resources were required. The service map would form a directory of services to be provided to parents.	Example - Sources of information used to identify services included: a list of community resources; a continuous process of service identification by the key stakeholders including local government directories of services and agencies; a desktop review of websites and online resources; and discussions with community members. A detailed record was kept of where each source came from, the date it was searched and the services identified.	Example - Once the services had been identified, they were divided into groups based on their primary relevance for parents. The diagram was designed to present the list of services in the easiest way possible for families to understand. Groups were presented in table format with details under descriptive headings.	Example - The service map formed a directory of services provided to parents and a local community health service to use. Parents and health professionals were encouraged to use the map as a basis for discussion of different service needs and how they might be met.

Source: Green A et al. In press, 'Developing a framework for undertaking an asset-informed approach to service mapping: a systematic integrative review and synthesis', *Nurse Researcher* [23], reprinted by permission of copyright holder Royal College of Nursing Institute.

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

5.2.4.2 Recruitment plan

A recruitment plan informed by the three stage recruitment plan by MacDougall and Fudge [27] was developed to guide recruitment. The three stages to guide recruitment for focus groups and interviews are to 1) Prepare, 2) Contact and 3)

Follow-up. This recruitment guide was selected for its relevance to the context of the qualitative study as it was:

designed to address some of the common recruiting problems, especially when the research deals with sensitive issues and is part of a research agenda that values action and advocacy as a result of, or in association with, research [27](p. 124).

Stage one of the recruitment plan included a description of the sample and a table of information sources and contacts divided into health, education, and social service sectors. To be included in the qualitative study providers had to be health, education, and social service providers from the Western Sydney Area (excluding ACCHO providers). Providers must have had experience with service provision for Aboriginal and Torres Strait Islander children with a disability and their families. There were a number of different information sources from which potential contacts were derived. These sources included the Phase two service map, an existing database of providers who expressed interest in further involvement from the community forums (included casework managers, family support workers, speech pathologists, special educators, occupational therapists, early childhood educators, child and family health nurses, and itinerant support teachers), preliminary analysis of LP120200484 carer interview data, the partner ACCHO early childhood intervention contact lists, discussions with the partner ACCHO Child and Family Health team members and other staff, contacts of chief investigators involved in the project, and informal networking at a primary healthcare research conference. A local children's hospital provides a range of specialist services and is a key part of the service provision network. Recruitment of health providers, therefore, specifically targeted this setting through contacts of chief investigators. The plan for Stage one was circulated to the LP120200484 project team for their input into potential information sources and contacts.

Stage two involved contact with potential participants guided by the plan for initial approach, confirmation and involvement. Initial contact was established by inviting contacts derived from Stage one to participate via an email invitation and were asked to forward the invitation to any other contacts who may be relevant following a snowball approach. The invitation email emphasised that they had valuable experience, knowledge and insights that were important for the qualitative study and the overall

LP120200484 project (Appendix 4). The participant information sheet was attached to the email which also had a notification that the email will be followed up with a phone call in a week if there was no reply. Contacts without an email address were invited to participate via a phone call and were then sent additional information via email if they were interested. A detailed log of date of initial contact and response, as well as follow-up contact and response, if required, was kept. If no response was provided after follow-up contact, the contact was no longer approached. Providers contacted by email who replied that they were unable to participate in the qualitative study listed a number of reasons. The majority of these providers replied that they were either at a new organisation and no longer working within the area, on leave, or unable to participate due to staffing constraints. Two providers replied that they were not interested in participating in the qualitative study. A number of the email addresses were also no longer active and were not delivered. Once a provider confirmed that they would participate, a suitable time and place for the interview was arranged. The participant was then followed up again with a confirmation prior to the scheduled date. If possible, attempts were made for the interview to take place in a participant's office or another suitable location at their place of work. Participants were also given the option for the interview to take place at the University of Technology Sydney or via telephone.

At the beginning of each interview, the researcher introduced herself as the project manager for the LP120200484 project who was undertaking these interviews as part of a postgraduate research project to inform the aforementioned project. The researcher had no prior relationship with any of the participants. At the end of the interview, the participants' interests in further involvement with the project was ascertained. Participants were asked whether they would like to be kept updated on the outcomes of the LP120200484 project as well as whether they would like to receive the final project report which would include findings from the interviews.

Snowball sampling was also employed as participants were asked whether they knew any other relevant contacts who may be interested in participating. Initially, it was difficult to recruit health providers to the qualitative study. One of the supervision team members, who was a General Practitioner (GP), observed that the use of the

word ‘experiences’ in the qualitative study invitation material could potentially make some health providers who do not perceive themselves as experts in the area feel as though they did not know enough to participate. It was also suggested that some health providers may feel as though they do not differentiate between patients, in efforts to provide equal treatment, so exploring their experiences separately for Aboriginal children and their families was irrelevant. To address these observations, the researcher changed the wording from ‘experiences’ to ‘thoughts on’ or ‘ideas about’. This was important in capturing the perceptions, understandings, and experiences of mainstream providers whose clinical focus may not be specifically on Aboriginal children, but whom carers would inevitably come into contact with in navigating the mainstream service system. Interestingly, the majority of health providers were recruited after these adjustments to the qualitative study invitation material was made.

Stage 3 involved follow-up with the participants. All participants were sent the qualitative study findings with a request for their feedback. Further detail on this stage is provided in Section 5.4.2. Any feedback was incorporated into the findings.

5.2.5 Participant characteristics

Twenty-four providers participated in the qualitative study from the non-ACCHO health, education, and social service sectors. Ethically, researchers should only collect demographic details required for the research purpose and data analysis, while collecting extensive demographic details that are not relevant should be avoided [28]. The relevant demographic details collected for this qualitative study were the sectors (health, education, or social services), type of organisation (Government, Non-Government Organisation (NGO), or private practice), whether providers worked in administrative or practice roles, and gender (see Table 5.1). Thirteen providers were from the health sector, eight from the education sector, and three from the social service sector. The education sector was inclusive of both early childhood education and early school education. Additional relevant background facts provided during interviews by participants were also recorded to aid in-depth description of the sample for transferability [11]. For example, three providers also had experience as carers, or

were family members, of a child with a disability, two providers identified as Aboriginal, and two non-Aboriginal providers reported having a current or past partner who was Aboriginal. The sample included social service case managers, early childhood education support workers, disability support workers, a special educator, allied health workers, early intervention teachers, Aboriginal health managers, GPs, nurses, and a paediatrician.

Table 5.1 Participant demographics

Pseudonym	Sector	Organisation	Role type	Gender
Amanda	Education	Gov	Practice	F
Belinda	Health	Gov	Practice	F
Beverly	Health	Gov	Administrative	F
Brenda	Education	Gov	Practice	F
Brian	Health	Private	Practice	M
Charmaine	Education	NGO	Administrative	F
Christine	Health	Private	Practice	F
Colleen	Education	NGO	Practice	F
Curtis	Health	Gov	Practice	M
Dana	Education	NGO	Practice	F
Danielle	Social services	Gov	Practice	F
Ella	Social services	Gov	Practice	F
Frank	Health	Private	Practice	M
Lydia	Education	Gov	Practice	F
Madeline	Health	NGO	Practice	F
Mark	Health	NGO	Administrative	M
Martin	Health	Private	Practice	M
Mary	Education	NGO	Administrative	F

May	Education	NGO	Practice	F
Rachel	Health	Gov	Practice	F
Sally	Health	Private	Practice	F
Shelley	Health	Gov	Practice	F
Simon	Health	Private	Practice	M
Tracy	Social services	Gov	Practice	F

5.2.6 Ethical considerations

The Aboriginal Health and Medical Research Council (AH&MRC) (Ref 762/10) approved this research and it was ratified by the University of Technology Sydney Human Research Ethics Committee (Ref 2011-417R). Amendments to the original LP120200484 ethics application were approved to include the researcher as a team member as well as the interviews with non-ACCHO providers. The amended application was also approved by the Sydney Children's Hospital Human Research Ethics Committee (LNR/15/SCHN/445) and site-specific approval for the Children's Hospital at Westmead was also obtained (LNRSSA/15/SCHN/469) (Appendix 5).

The research adhered to key principles for research with Aboriginal and Torres Strait Islander peoples as espoused by the AH&MRC [29]. Historically, research on the health and well-being of Aboriginal and Torres Strait Islander peoples positioned the population as the subjects of research *"to be seen but not asked, heard nor respected"* [30](p. 203). The values detailed in the AH&MRC guidelines developed as a response to the past direction much of the research had taken. This qualitative study implemented a number of measures to ensure key principles were met. Measures included: outcomes to inform the design and delivery of needed culturally appropriate services for children and their families (Net Benefits for Aboriginal peoples and communities); research development in close consultation with partners from the ACCHO and guided by what they identified as important and appropriate (Aboriginal Community Control of Research); direct consultation with members of the community affected by the research (Cultural Sensitivity); and outcomes aimed at increasing the community's knowledge of and ways to access services and support (Enhancing Aboriginal skills and

knowledge). All publications and conference abstracts resulting from this research were approved for publication by the partner ACCHO representatives and the AH&MRC. Partners from the ACCHO made authorship contributions on all publications and abstracts.

Prior to the interviews the participant information sheet and consent form (Appendix 6) were provided to the participants via email. At the start of each interview a standard introduction template briefly discussing the content of the consent form and participant information sheet was used. Participants were informed that all the data from the interview was confidential with the supervision team as the only people with access to their personal details, data would be de-identified, participation was voluntary so that they could withdraw from the study at any time and their data would be deleted, any relationships with the researchers or relevant organisations would not be affected by withdrawal, and if they did become distressed at anything that came up, the researcher would help to arrange appropriate care. All participants signed a consent form at the start of each interview. Transcription of digital audio files and project notes were stored on a secure password protected network drive at the University of Technology Sydney. Hardcopy project documents, including signed consent forms, were locked in a cabinet in the secure Centre for Cardiovascular and Chronic Care office at the University of Technology Sydney. Any identifying information relating to participants was removed and names were replaced by pseudonyms on all transcriptions and publications.

5.3 Research process

5.3.1 Context

During the process of data collection, government de-funding of the partner ACCHO led to its closure and subsequent change of management. This required amendments to the original LP120200484 AH&MRC application around personnel and data storage. In relation to this qualitative study, recruitment and data collection were suspended for 6 months until the ethics amendments had been approved. The first nine participants received the first version of the participant information sheet while subsequent participants received the amended sheet. Once the AH&MRC approved

the amended sheet it was sent to the first nine participants to update them on changes to the qualitative study as a result of what had happened. Despite the closure of the organisation, LP120200484, and this project, proceeded in consultation with Aboriginal community members in Western Sydney who were part of the research team.

5.3.2 Cultural mentorship

The project was guided by the cultural mentorship of Patricia and John Delaney, respected elders in the community. Regular face-to-face meetings between the researcher and cultural mentors were held throughout the project. This cultural mentorship was essential in ensuring all stages of the research aligned with the identified needs of the community and was conducted in a culturally appropriate manner. Advice was sought on areas including determining the study sample, wording of interview questions, researcher reflexivity, and data analysis. Specific detail on the influence of cultural mentorship on the research stages is provided in Sections 5.2.3, 5.3.4, 5.3.5, 5.3.6, and 5.4.1.

5.3.3 Interview settings

Interviews were conducted face-to-face at participants' place of work, or via the telephone. Most face-to-face interviews took place in either the participants' offices or in an alternate private room with only the researcher and participant present. Due to workplace space restraints one interview was held in the middle of an open workspace where another colleague was working at the time. In this instance the researcher received permission from both parties to proceed with the interview. Data collected during this interview was particularly in-depth suggesting that this setting did not adversely affect the participants' responses. As participants were sampled across sectors, the workplace settings for the interviews included schools, government offices, non-government offices and a local children's hospital. Although participants were offered the option for the interview to take place at the University of Technology Sydney, it was decided that due to significant provider time constraints, it would be most effective to conduct interviews at the participants' workplaces. For interviews conducted over the telephone, the researcher sat in a secure meeting room at the

University of Technology Sydney. Each participant was asked for permission to be recorded.

5.3.4 Topic guide

Interview topic guides are a practical way to make the best use of the time available during an interview and help to refine interview questions [8, 31]. The semi-structured interviews covered the topics developed in the guide to ensure that information relevant to the research question and purpose was collected. The questions within the topic guide were designed to be open ended to elicit in-depth data and facilitate the exploration of new concepts.

Development of the topic guide involved two stages. The first stage involved development of a brainstorm map reflecting the findings of the Phase one integrative literature review, detailed in Chapter Three, and previous community forums, discussed in Chapter One Section 1.2 (Appendix 7). The findings were grouped under key categories. The key categories were perceptions, understandings, and experiences of working together, system issues, sustainable collaborative practice, policy, communication/awareness, relationships, service delivery settings, concept of disability, cultural issues, and way forward. The brainstorm map was circulated to all members of the supervision team for their feedback. The second stage was development of the topic guide (Appendix 8). From the brainstorm map and supervision team feedback, four key topic areas emerged. The topic areas were 1) background and contextual information, 2) health, education and social service systems, 3) acceptability issues, and 4) future outlook. Open-ended questions were developed and refined under each topic area in consultation with all members of the supervision team. Not all questions were asked during the interviews as participants sometimes inadvertently answered a question without being asked. The order of questions also varied according to the flow of each interview however each interview covered the four topic areas [32]. Following the recruitment of two Aboriginal providers working in non-ACCHO sectors, the researcher consulted with one of the cultural mentors on the project as to whether it was necessary to reframe how questions around the topic of acceptability issues were asked for these participants.

Following the cultural mentors' advice, the topic guide was amended to ask two participants the following questions related to acceptability issues: 1) thinking about your experiences of interactions with other services and providers, are there any differences you would like to see in terms of addressing acceptability issues?, and 2) what could be improved? Apart from this amendment, the topic guide was the same for all participants.

5.3.5 Positioning statement

I approached this qualitative study influenced by an intersection of different identities. Reflecting on how these identities shape my ontological assumptions is an essential step in recognising the influence they may have had on this research. Prior to starting the project I had completed a 20-hour Qualitative Research Masterclass Series on maintaining rigor in research with vulnerable populations which increased my confidence to undertake and manage data collection and management. Having completed a Bachelor of Social Sciences and Master of Development Studies, I approached the research process with a background in social science research, as a female researcher in my late twenties, external to the Western Sydney community. One day per week during the project I was also research assistant and project manager for LP120200484, which provided a valuable context to the research. I conducted all of the interviews, which ranged from 20 minutes to 1 hour 20 minutes. One group interview comprised three participants, as requested by the participants. Prior to my involvement in LP120200484, I had no experience in the area of disability. I also come from a privileged middle-class Anglo-Saxon Australian background. This latter identity has perhaps generated the most reflection in positioning myself in relation to this research.

It was through conducting interviews with non-ACCHO providers for this qualitative study that I was conscious of how having no previous experience in the area of disability and being a young female potentially influenced the dynamics between participants and myself. Awareness of my relative lack of experience led to a lack of confidence in the initial stages of interviews. As the data collection stage progressed,

however, my level of confidence increased. Further reflection on the dynamics of interviews and rapport is discussed in Sections 5.3.6 and 5.3.7.

As an Anglo-Saxon Australian with a strong social conscience in relation to the uneven power relations between white Australia and Aboriginal and Torres Strait Islander peoples, I have for a long time been conscious of what Cowlshaw [33] has described as *“the shame of belonging to the privileged segment of a cultural hierarchy”* [33](p. 126). My social consciousness around the need for social justice and equity for Aboriginal and Torres Strait Islander peoples has been largely developed through secondary and tertiary education which supported reflexivity of my privileged position, and being surrounded by family members and friends who share similar values. However, I had long felt a distinct unease that throughout my life I had little contact with Aboriginal and Torres Strait Islander peoples in my day-to-day life. I was aware that I had lived almost exclusively within a privileged white Australian context. As Cowlshaw [33] points out *“the lives of Aboriginal Australians are largely concealed from the urban majority”* [33](p. 3). In becoming involved with LP120200484, and this subsequent project, I was aware of the need to be reflexive on how this inner contradiction, and what might be termed white guilt, may influence this research. Haynes et al. [34] assert that *“naming and understanding the reasons for guilt can provide individuals with an opportunity to work through feelings of shame and distress over Australia’s historical and current relationship with Indigenous people”* [34] (p. 5). I was aware during the stage of data analysis that I needed to be particularly reflexive in not projecting my own feelings when interpreting what providers were saying in relation to their own perceptions, understandings, and experiences of interacting with Aboriginal and Torres Strait Islander families. The most rewarding aspect of this project for me personally has been the ongoing cultural mentorship from my cultural mentors, which has led me to embrace continual reflexivity rather than a need to reconcile my inner contradictions identified above. I believe continual reflexivity to be an essential part of being involved in research in this space as an Anglo-Saxon Australian.

5.3.6 Reflexive account

It is inevitable that researchers' characteristics and position in relation to research will have an effect on the research process [11]. To address this impact, I ensured that strategies were put in place to facilitate reflexivity. A self-care plan (Appendix 9) was developed with members of the supervision team to establish ways to mitigate potential risks to myself as a researcher. Development of the self-care plan was also a helpful reflexive process to undertake as it forced reflection on potential risks and self-care strategies. The potential risks centred on the impact of research involving sensitive cultural issues on myself as a non-indigenous Australian and how to handle expressions of racism during interviews. Self-care strategies included drawing out meanings behind racist comments, ongoing de-briefing sessions with supervisors and cultural mentors, being aware of having access to the free counselling service offered at the University of Technology Sydney, and keeping a reflexive journal throughout the research. Templates for a summary sheet and reflexive journal were also developed. Following each interview, the first action I took was to complete a summary sheet and reflexive journal for that interview. The summary sheet recorded demographic information, the interview setting, and a summary of the key concepts raised in the interview along with noting similarities or differences with previous interviews. The reflexive journal recorded information on interaction flow, rapport, technique, and other relevant observations related to the interaction between myself and the participant. Reflecting on each interview in this manner was important in recording external factors that may have influenced the data as well as being a useful tool to develop my technique.

At the start of each interview, I introduced myself as the LP120200484 project manager who was undertaking the interviews as a postgraduate research student. The rationale behind the interviews were linked to the LP120200484 project in my introduction. Each interview began with an introduction to the aims of the LP120200484 project and a summary of the key findings from the LP120200484 community forums. The aim of the interview was explained in terms of how it evolved from previous stages of the LP120200484 project. Positioning my research in this way may have engendered confidence that this was a project with funding and could have

influenced their willingness to participate. Qualitative research involves a balance of power between the researcher and participants [35]. Positioning myself as an outsider with no clinical/practical background in the area, no allegiance to a specific sector, and who is not a member of the Western Sydney community, may have allowed participants to speak more freely [36]. This was particularly evident in the in-depth data that was provided around some negative systems issues. As a researcher, however, without the clinical/practical background, I sometimes felt intimidated by the participants given their perceived level of expertise/authority. It was important to acknowledge this reflection so that I could monitor its potential impact on data collection and analysis.

5.3.7 Rapport

The influence of rapport on interviews is particularly important. Establishing an enabling rapport necessarily involves the researcher opening up and investing personal characteristics in building a relationship with the participant [8]. It became evident during data collection that rapport seemed to be most easily established with female participants who were similar to myself in being predisposed to communicate in an informal and friendly manner. Another element that seemed to influence establishing rapport were the few shorter interviews in which the providers were friendly, but formal. The group interview with three participants was one of the most welcoming and easiest to establish rapport. All three participants were so passionate about the research topic that I needed to be mindful of not inserting my own perspectives and interest. However, this was difficult as at the time it felt that I might affect the dynamic if I did not also invest my own interest in the area. There was also an evident difference in rapport with providers involved only in practice and those providers in high level administrative positions (ie heads of departments). Rapport with those participants in senior positions was noticeably more formal and slower to establish rapport than with other participants. The start of these interviews were very descriptive with participants articulating generic information and processes. It was only as interviews progressed that they began providing more in-depth personal opinions and understandings. The physical settings of these interviews may have also contributed to the more formal interactions. One interview with a social service

manager was conducted in an office with the participant sitting behind their desk and I sat opposite. This created a more formal dynamic compared with other interview settings where the seating positions were less formal.

Establishing rapport with male participants was variable, highlighting the role that gender plays in influencing rapport between a researcher and study participants [37]. In one interview with a male health provider with decades of clinical experience, rapport seemed to be characterised by myself as the young postgraduate student and him as the expert with extensive experience. The participant was not patronising, but rather imparting his knowledge. There was only one interview where it was very difficult to establish a good rapport. One male health provider with extensive experience seemed very wary and defensive throughout the interview. My perception was that being a young female without a clinical health background impeded establishing good rapport with this participant. The variable experiences with male participants may have been influenced by my own level of comfort interacting with males in this context. However, on the whole these were useful interviews.

5.3.8 Data management and storage

Signed consent forms were locked in a cabinet in the secure Centre for Cardiovascular and Chronic Care office at the University of Technology Sydney. After each interview, the recording was uploaded to a secure professional transcription service. A copy of the recording was saved to a secure password protected network drive at the University of Technology Sydney. Once the researcher received a transcript, they listened to the recording while reading the transcript to ensure accuracy as part of ensuring rigour. This step of data management was important, as some words had been transcribed incorrectly. Potentially this indicates that while a recording can be objective, once the process of transcribing is applied human error may influence the interview transcript and strategies to address this need to be put in place. After cross-checking the transcript with the recording, the recording was deleted. During this process, the digital audio recorder was kept locked in a cabinet in the secure Centre for Cardiovascular and Chronic Care office at the University of Technology Sydney, unless used for another interview. As introduced in Section 5.2.6,

transcripts were saved under a pseudonym and stored on a secure password protected network drive at the University of Technology Sydney. The legend linking participants' details with their pseudonym was also stored on the password protected network drive in a separate folder. All identifying details, such as names and workplaces, were removed from the transcripts. Microsoft Word software was used for data management and analysis. As per the National Health and Medical Research Council guidelines for storage of data, data will be securely stored for a minimum of 7 years and then disposed of according to the University of Technology Sydney guidelines.

5.4 Research analysis

5.4.1 Data analysis

Data analysis was informed by some of the principles of the general inductive approach. This qualitative approach analyses data inductively so that categories emerge from the raw data to form a model or framework [9]. A guiding principle of this approach in comparison with the inductive approach of grounded theory, which it is most similar to, is that data analysis is guided by the research objectives. Thomas [9] emphasises that the research objectives *"provide a focus or domain of relevance for conducting the analysis, not a set of expectations about specific findings"* [9](p. 239). The general inductive approach was selected as the methodology best suited to the purpose of the research as guided by pragmatism. The principle of data analysis guided by the research objectives underpinned the rationale for selection of the approach. It was important that data analysis was guided by the research objectives so that the findings could assist as part of the overall LP120200484 project in addressing the problem of access to services and support as identified by the partner ACCHO. Data analysis was guided by the research aim, objectives and questions outlined in Chapter One Section 1.3.

Employing an inductive approach to preliminary data analysis was important in facilitating exploration of provider perceptions, understandings, and experiences and what the important categories were without the influence of a priori assumptions or frameworks [8]. Although findings of the Phase one integrative literature review into the important components involved in inter- and intra- sector collaboration were

explored using ecological systems theory, a key overall finding was that collaboration needed to be explored in specific contexts so that solutions are sustainable and responsive to local needs. It was decided that deductively applying the theory to the data analysis a priori might hinder important contextual issues. As each community is unique, it was important that an inductive approach be used. A suggested limitation of the general inductive approach is that it is not as strong in model and theory development as other approaches to data analysis [9]. The benefit of the data analysis generating useful findings relevant to the research objectives in this case, however, overrode this consideration in light of the purpose of this research.

Preliminary analysis of each interview transcript was undertaken by the researcher and involved the four following steps. First, close reading of the transcript multiple times was undertaken before applying codes. The summary sheet and reflexive journal for the interview were also read. Immersing the researcher in the data in this way was important in generating preliminary ideas and *“getting a sense of the whole”* [38](p. 371). This stage also facilitated conceptual links between interviews. Second, line-by-line coding of the transcript was conducted. The codes closely reflected what the participant was describing at this stage and sections of text could be assigned more than one code. The codes and their corresponding text were inserted into a Microsoft Word document table under the headings code and text. Third, after the transcript had been coded the coded text was grouped together under the same codes. Codes that were describing the same thing but which had been labelled differently were collapsed into the code name that fit the best. Fourth, the codes and associated text were then compared with each other and grouped into preliminary categories in a table format. The categories listed in the table were then developed through being written up using thick description in relation to contextual factors of the participant.

Independent parallel coding by two supervisors and the researcher was carried out on the first two transcripts to crosscheck the preliminary codes and categories. Without seeing the researcher’s preliminary codes and categories, these two supervisors each independently coded an entire transcript. Once coding had been completed, they met as a team to compare their preliminary codes and categories and

discuss similarities and differences. Although no major variations in interpretations emerged, the value of this stage was in the discussion of codes and categories between the researchers and the insights generated [39]. It was not possible to cross-check the coding of each transcript but this stage was an important part of ensuring credibility of the preliminary analysis.

Preliminary analysis of the data reflected two main areas: 1) provider perceptions, understandings, and experiences related to direct service provision to families, and 2) provider perceptions, understandings, and experiences of working together with other providers across the health, education, and social service sectors. At this stage, the researcher met with members of the supervision team to discuss whether further condensing of codes should be carried out within these two areas. It was agreed that analysis should continue as is due to relevance to the research objectives, and no obvious crossovers justified merging the two areas. Following preliminary analysis, categories were compared in an iterative process to develop links and uncover disconfirming evidence. This stage led to some categories to be collapsed into others and other new overarching categories to be created guided by what were the most important categories for the research objectives. Key categories related to direct service provision to families included the perception that Aboriginal families of a child with a disability do not want the help of non-Aboriginal providers, factors that influenced interactions with families, factors that influenced the ability of families to access services, and the influence of macro factors such as socio-political context, and policy and funding directives. Key categories related to provider perceptions, understandings, and experiences of working together included factors that either impeded or enabled the ability of providers to work effectively together, the important role of effective communication and sharing of information, and unlocking the strength of schools as settings for early intervention. Quotations from the raw data that best demonstrated the categories were selected. Following preliminary analysis, two conceptual frameworks were chosen to further explore the data.

5.4.1.1 Candidacy framework

It was evident that the categories emerging in the area of provider perceptions, understandings, and experiences of direct service provision to families related to providers' perceptions of the process of families accessing services. Underlying the process of accessing services were issues of trust and power relations between providers and families. Following discussion with the supervision team, the Candidacy framework by Dixon-Woods et al. [40], introduced in Chapter Four, was chosen as a suitable model to further explore the data. Suitability of this model was confirmed as all preliminary categories fit within the framework. The concept of candidacy in relation to this qualitative study describes the joint negotiation between families and providers of the eligibility of Aboriginal children with a disability and their families for services. The model, explored in Chapter Six, explores provider understanding of candidacy for Aboriginal children with a disability and their families accessing services.

5.4.1.2 Collaborative Practice to Enhance Patient Care Outcomes framework

It was evident that the categories emerging in the area of provider perceptions, understandings, and experiences of working together with other providers across the health, education, and social service sectors related their perception of factors that either impeded or enabled collaboration. Following discussion with the supervision team, it was decided to further explore the data using the concept of interprofessionalism. D'Amour and Oandasan [41] define interprofessionalism 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 [41](p. 9).

The Collaborative Practice to Enhance Patient Care Outcomes framework, introduced in Chapter Four, was developed to explore the key elements of interprofessional collaborative practice in healthcare and an adaptation of this framework is used to explore interprofessionalism in the context of Aboriginal childhood disability. The concept of interprofessionalism in relation to this qualitative study describes the processes and determinants of interprofessionalism in the specific context of service provision to Aboriginal children with a disability and their families. The model,

explored in Chapter Seven, explores provider understanding of factors influencing interprofessional collaborative practice in this area.

A reflexive journal of the data analysis process was kept throughout the process to record formative ideas and areas for further pursuit in subsequent interviews. Regular monthly peer debriefings with members of the supervision team were held to discuss and refine emerging findings throughout the process. The different expertise and backgrounds of these supervision team members provided invaluable interpretations and insights to data analysis. The team included researchers with expertise in qualitative research methods, clinical backgrounds in general practice, nursing, psychology and speech pathology, and cultural mentors with extensive experience in ACCHOs who were also community stakeholders.

5.4.2 Rigour (credibility, transferability, dependability, and confirmability)

Similar techniques used to assess the trustworthiness of findings in other qualitative analysis approaches can be applied to the general inductive approach [9]. To ensure trustworthiness, measures were taken to address credibility, transferability, dependability and confirmability [42]. The independent parallel coding by the researcher and two other members of the supervision team during the preliminary data analysis stage and regular peer debriefings with the LP120200484 project team to discuss emerging findings was undertaken to ensure credibility [5, 9, 11]. Member checks were carried out with the participants in the form of providing them with the study findings for their feedback [42], yet, none of the participants provided feedback on the findings. Members of the supervision team who were part of the community and who worked in Western Sydney also provided valuable insights and guidance to the findings. Two members were carers of an Aboriginal child with a disability living in Western Sydney and another member was a GP who provides services for Aboriginal children with a disability and their families.

Transferability was addressed through the use of thick description when reporting data [43]. The use of thick description in reporting data was selected so that external parties can assess the transferability of findings [42]. This was applied not only to the reporting of findings but also in the provision of a detailed description of

relevant participant demographics and study settings [11]. The summary sheet and reflexive journal written up following each interview assisted in recording the context of the interview to inform the thick description of data [8]. These resources were particularly valuable as a number of participants continued to discuss issues relevant to the interview after the recording had stopped. When this happened, notes were written immediately following the interview in a field journal. The physical descriptions of places by two participants were also cases where it was valuable to have the summary sheet and reflexive journal to record additional contextual data. One participant felt that the physical set up of her office where the interview took place isolated her from collaborating with the Aboriginal Education Workers in the opposite building. Describing the setting in the summary sheet was an important part of data collection for this participant. While describing why services in Western Sydney were perceived as inaccessible to some families, another participant drew a map of the physical placement of services in a spoke-wheel shape to illustrate their meaning, which was important to record in the summary sheet.

In this chapter, the stages of data collection and analysis were clearly defined and documented to facilitate transparency and dependability. Leaving a detailed audit trail of the research processes importantly allows for external parties to assess dependability of the findings [42]. Field notes in the form of summary sheets and reflexive journals were kept to ensure confirmability as additions to an audit trail [44]. It is recognised that no researcher is able to come to the research process with an objective clean slate [31, 45]. As introduced in Section 5.3, the summary sheets and reflexive journals for both individual interviews and the overall data analysis process were used as checks to ensure the researcher reflected on how their subjectivities might influence the research process and findings. As this project is generally informed by Bronfenbrenner's ecological systems theory [46], it was particularly important that these checks were in place during preliminary data analysis as inductive analysis was selected as the most suitable data analysis approach to address the purpose of the research. It is argued that the inductive approach to data analysis can never truly be separated from all theory [5, 11]. A research project is always situated in the context of knowledge of relevant scholarship in the chosen area either through a literature

review or general discipline background which can affect choices regarding the research design, process and analysis [39, 45]. In selecting the general inductive approach as best suited to the research purpose, it was important that these checks were in place so that the researcher could reflect on the data analysis process and ensure that the theory was not inadvertently applied a priori.

5.5 Conclusion

Phase three of this PhD project used a qualitative research design influenced by the epistemological assumptions of pragmatism to explore non-ACCHO provider perceptions, understandings, and experiences of providing services. Both Phase one and Phase two of the project informed the research design in the development of the topic guide and the recruitment strategy, respectively. The Phase three data is explored using the Candidacy [40], and Collaborative Practice to Enhance Patient Care Outcomes [41], frameworks in the following two chapters.

5.6 References

1. Rorty R. 1999, *Philosophy and Social Hope*, Penguin Books, England.
2. Cherryholmes CH. 1992, 'Notes on Pragmatism and Scientific Realism', *Educational researcher*, vol. 21, no. 6, pp. 13-17.
3. James W. 1982, 'What Pragmatism Means'. In: Thayer HS (ed.) *Pragmatism: The classic writings*, Hackett Publishing Company, Indianapolis, pp. 209-226.
4. Cornish F & Gillespie A. 2009, 'A Pragmatist Approach to the Problem of Knowledge in Health Psychology', *Journal of Health Psychology*, vol. 14, no. 6, pp. 800-809.
5. Creswell JW. 2014, *Research Design Qualitative, Quantitative, and Mixed Methods Approaches*, SAGE Publications, United States of America.
6. James W. 1982, 'An Interview: Pragmatism - What It Is'. In: Thayer HS (ed.) *Pragmatism: The classic writings*, Hackett Publishing Company, Indianapolis, pp. 131-134.
7. Dewey J. 1982, 'The Development of American Pragmatism'. In: Thayer HS (ed.) *Pragmatism: The classic writings*, Hackett Publishing Company, Indianapolis, pp. 23-42.
8. Patton MQ. 2015, *Qualitative Research and Evaluation Methods*, 4th, SAGE Publications, United States of America.
9. Thomas D. 2006, 'A general inductive approach for analysing qualitative evaluation data', *American Journal of Evaluation*, vol. 27, no. 2, pp. 237-246.
10. Corbin J & Strauss A. 2015, *Basics of qualitative research*, 4th, Sage, Newbury Park, CA.
11. Malterud K. 2001, 'Qualitative research: standards, challenges, and guidelines', *The Lancet*, vol. 358, no. 9280, pp. 483-488.
12. Pope C & Mays N. 1995, 'Reaching parts other methods cannot reach: an introduction to qualitative methods in health and health services research', *British Medical Journal*, vol. 311, no. 6996, p. 42.
13. Thorne S. 2016, *Interpretive description: Qualitative research for applied practice*, 2nd, Routledge, New York
14. Fusch PI & Ness LR. 2015, 'Are We There Yet? Data Saturation in Qualitative Research', *The Qualitative Report*, vol. 20, no. 9, pp. 1408-1416.
15. Coyne IT. 1997, 'Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries?', *Journal of Advanced Nursing*, vol. 26, no. 3, pp. 623-630.
16. Teddlie C & Yu F. 2007, 'Mixed Methods Sampling: A Typology With Examples', *Journal of Mixed Methods Research*, vol. 1, no. 1, pp. 77-100.

17. Carter, S. & Little M. 2007, 'Justifying knowledge, justifying method, taking action: Epistemologies, methodologies, and methods in qualitative research', *Qualitative Health Research*, vol. 17, no. 10, pp. 1316-1328.
18. Herring S, Spangaro J, Lauw M & McNamara L. 2013, 'The Intersection of Trauma, Racism, and Cultural Competence in Effective Work with Aboriginal People: Waiting for Trust', *Australian Social Work*, vol. 66, no. 1, pp. 104-117.
19. Tsou C, Haynes E, Warner WD, Gray G & Thompson SC. 2015, 'An exploration of inter-organisational partnership assessment tools in the context of Australian Aboriginal-mainstream partnerships: a scoping review of the literature', *BMC Public Health*, vol. 15, no. 1, p. 416.
20. Miles MB & Huberman AM. 1994, *An Expanded Sourcebook Qualitative Data Analysis*, Sage Publications, United States of America.
21. Onwuegbuzie AJ & Leech NL. 2007, 'Sampling Designs in Qualitative Research: Making the Sampling Process More Public', *The Qualitative Report*, vol. 12, no. 2, pp. 238-254.
22. Sandelowski M. 2000, 'Combining Qualitative and Quantitative Sampling, Data Collection, and Analysis Techniques in Mixed-Method Studies', *Research in Nursing & Health*, vol. 23, no. 3, pp. 246–255.
23. Green A, Luckett T, Abbott P, DiGiacomo M, Delaney J, Delaney P & Davidson PM. In press, 'Developing a framework for undertaking an asset-informed approach to service mapping: a systematic integrative review and synthesis', *Nurse Researcher*, accepted 06/10/2016.
24. Whiting L, Kendall S & Wills W. 2012, 'An asset-based approach: an alternative health promotion strategy?', *Community Practitioner*, vol. 85, no. 1, pp. 25-28.
25. Whiting L.S., Kendall S & Wills W. 2013, 'Rethinking children's public health: the development of an assets model', *Critical Public Health*, vol. 23, no. 2, pp. 146-159.
26. Berkowitz B & Wadud E 2015, *Community Tool Box: Chapter 3 Section 8. Identifying Community Assets and Resources*. Available: <http://ctb.ku.edu/en/table-of-contents/assessment/assessing-community-needs-and-resources/identify-community-assets/main> [Accessed 16/04 2015].
27. MacDougall C & Fudge E. 2001, 'Planning and recruiting the sample for focus groups and in-depth interviews', *Qualitative Health Research*, vol. 11, no. 1, pp. 117-126.
28. Gibbs L, Kealy M, Willis K, Green J, Welch N & Daly J. 2007, 'What have sampling and data collection got to do with good qualitative research?', *Australian and New Zealand Journal of Public Health*, vol. 31, no. 6, pp. 540-544.
29. Aboriginal Health & Medical Research Council Ethics Committee 2013, *AH&MRC Guidelines for Research into Aboriginal Health: Key Principles*, Aboriginal Health & Medical Research Council of New South Wales, Sydney.

30. Martin K. 2003, 'Ways of Knowing, Ways of Being and Ways of Doing: a theoretical framework and methods for Indigenous re-search and Indigenist research', *Journal of Australian Studies*, vol. 27, no. 76, pp. 203-214.
31. Charmaz K. 2014, *Constructing Grounded Theory*, SAGE Publications, United States of America.
32. Turner D. 2010, 'Qualitative Interview Design: A Practical Guide for Novice Investigators', *The Qualitative Report*, vol. 15, no. 3, pp. 754-760.
33. Cowlshaw, G. 2009, *The city's outback*, NewSouth Publishing, Sydney.
34. Haynes E, Taylor K, Durey A, Bessarab D & Thompson S. 2014, 'Examining the potential contribution of social theory to developing and supporting Australian Indigenous-mainstream health service partnerships', *International Journal for Equity in Health*, vol. 13, no. 1, p. 75.
35. Orb A, Eisenhauer L & Wynaden D. 2001, 'Ethics in Qualitative Research', *Journal of Nursing Scholarship*, vol. 33, no. 1, pp. 93-96.
36. Minichiello V, Madison J, Hays T, Courtney M & St.John W. 1999, 'Qualitative interviews'. In: Minichiello V, Sullivan G, Greenwood K & Axford A (eds.) *Handbook of Research Methods in Health Sciences*, Addison-Wesley, Sydney, pp. 395-418.
37. Pini B. 2005, 'Interviewing men: Gender and the collection and interpretation of qualitative data', *Journal of Sociology*, vol. 41, no. 2, pp. 201-216
38. Sandelowski M. 1995, 'Qualitative Analysis: What It Is and How to Begin', *Research in Nursing & Health*, vol. 18, no. 4, pp. 371-375.
39. Barbour RS. 2001, 'Checklists for improving rigour in qualitative research: a case of the tail wagging the dog?', *British Medical Journal*, vol. 322, no. 7294, pp. 1115-1117.
40. Dixon-Woods M, Cavers D, Agarwal S, Annandale E, Arthur A, Harvey J, Hsu R, Katbamna S, Olsen R, Smith L & Riley R. 2006, 'Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups', *BMC Medical Research Methodology*, vol. 6, no. 1, p. 35.
41. D'amour D & Oandasan I. 2005, 'Interprofessional practice and interprofessional education: An emerging concept', *Journal of Interprofessional Care*, vol. 19, no. Suppl. 1, pp. 8-20.
42. Lincoln Y & Guba E. 1985, *Naturalistic inquiry*, Sage Publications, Newbury Park.
43. Lincoln Y & Guba E. 1986, 'But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation', *New Directions for Program Evaluation*, vol. 30, pp. 73-84.
44. Jeanfreau S & Jack L. 2010, 'Appraising qualitative research in health education: Guidelines for public health educators', *Health Promotion Practice*, vol. 11, no. 5, pp. 612-617.
45. Sandelowski M. 1993, 'Theory Unmasked: The Uses and Guises of Theory in Qualitative Research', *Research in Nursing & Health*, vol. 16, no. 3, pp. 213-218.

46. Bronfenbrenner U. 1979, *The ecology of human development: experiments by nature and design*, Harvard University Press, Cambridge, Mass.

Chapter Six: Provider understanding of candidacy for Aboriginal children with a disability and their families accessing services

6.1 Introduction

Providers' perceptions, understandings, and experiences of direct service provision to families centred on their perceptions of factors which either impeded or enabled families' access to their services. These are explored in this chapter through an adaptation of the Candidacy framework [1], introduced in Chapter Four Section 4.2.1. 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. It is a *"dynamic and contingent process"* (p. 7) in a constant state of being *"defined and redefined"* (p. 7) through interactions between families and providers [1]. Candidacy is influenced by interactions through the stages of 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 (Figure 6.1).

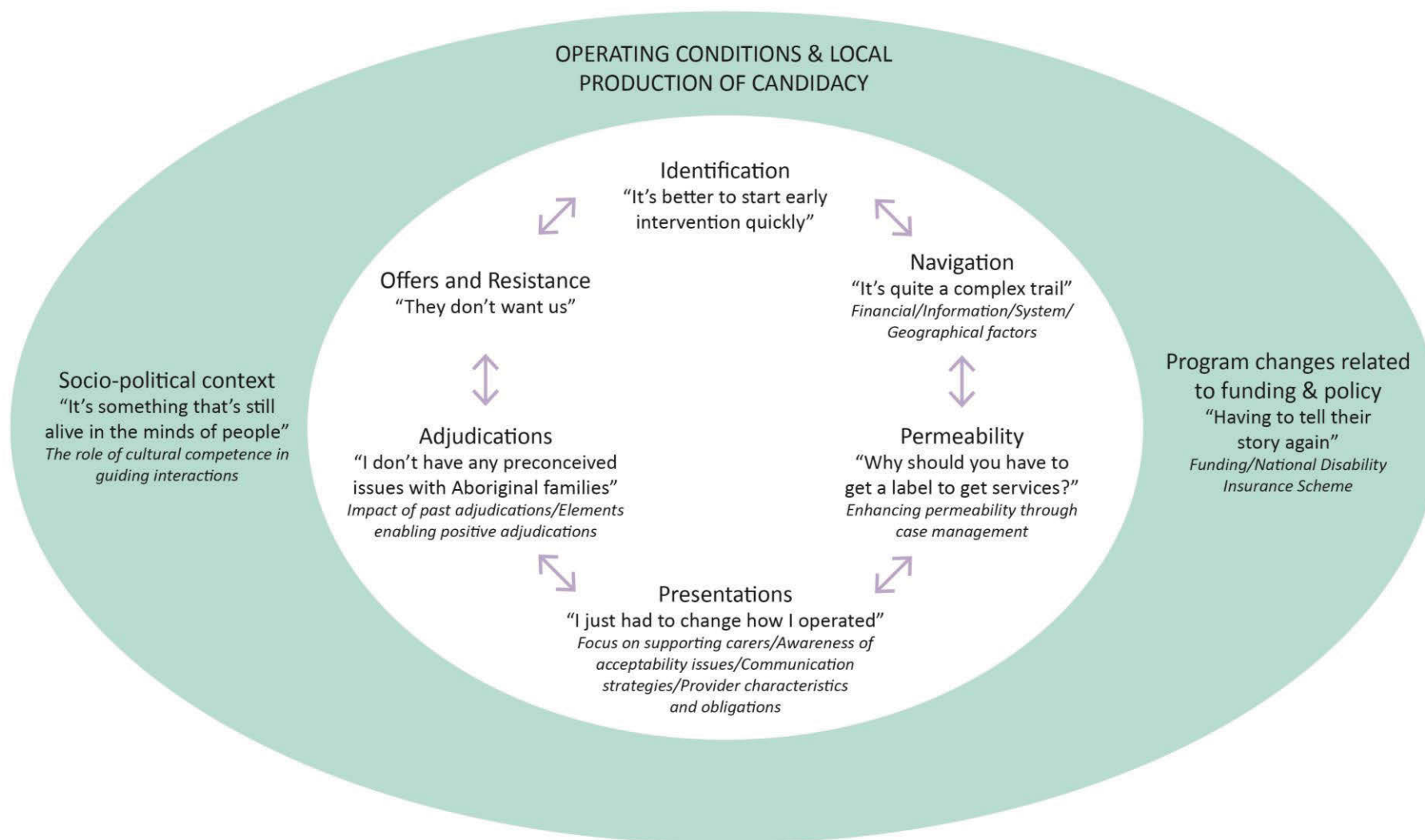


Figure 6.1 Provider understanding of candidacy for Aboriginal children with a disability and their families accessing services

6.2 Identification of candidacy – “It’s better to start early intervention quickly”

Identification that a child might have a condition requiring assessment and treatment required families to both recognise their child as a candidate for services and act on this knowledge. Some providers perceived that some families may have not been aware of developmental issues with their children due to family systems being “fluid” and advice provided by members of their community. Some providers described some families as “easy going” and accepting of a range of behavioural issues, which may influence issues not being identified at an early stage.

“Because Aboriginal families have that greater, you know, they don’t necessarily always – the kids don’t necessarily stay with the parents all the time, you know, they might be living for a period of time with aunt and uncle or with grandma, grand pop. You know, it’s more fluid. That whole system is more fluid with Aboriginal families. So yeah, they could be missed in the big scheme of things.” (Tracy - social service provider)

Rachel (health provider) explained her perception that some kinship carers caring for Aboriginal children in out-of-home care (OOHC) could be “lax” about identifying that there may be an issue and acting on this knowledge.

“As the Aboriginal culture sort of does, it’s a lot more lax. So if there’s a speech issue they might just say oh, so and so did that at three years old and now they’re talking fine too.” (Rachel - health provider)

In these cases, it was described as important for providers to support carers by providing access to information around why a child required access to specific services.

“So I guess it’s supporting the carers, the kinship, guardianship carers that it’s okay, ‘I know that this probably wasn’t done sort of 30 years ago, but now we have evidence to say, no, it’s better to start early intervention quickly’.” (Rachel - health provider)

This participant perceived that there had been a shift over decades towards the current recognition of the importance of early intervention. Kinship carers from older

generations were perceived as potentially requiring information around the importance of early intervention, which may not have been prominent when they were younger.

6.3 Navigation of services – “It’s quite a complex trail”

Providers across all sectors perceived that once families had identified the need for assessment and treatment they faced navigating a complex service landscape to access services. The ability of families to mobilise the competencies and resources required to navigate services was influenced by four factors. 1) Financial, 2) Information, 3) System, and 4) Geographical factors were identified by providers as influencing the successful navigation of services and are explored in further detail below.

6.3.1 Financial factors

The cost of accessing private providers in the context of long waitlists in the public system, and additional costs associated with accessing services, was perceived to impede the ability of some families to navigate services. The cost of private providers was identified as prohibitive to families without access to the financial resources required to access their services. Providers identified that for families with the financial resources to access the private system, there was no issue referring them and getting those families the support that they need. However, families unable to afford private providers faced long waitlists and few providers who bulk bill in the public system.

“Well, I mean, the current, ah - how to say it - the problem with the public system is long waiting lists. So currently speech pathology at the [Community Health Centre] has a two-year waiting list. So, ah, there’s clearly a problem for those who believe in the importance of early intervention.” (Frank - health provider)

Ella (social service provider) identified that families waiting for assistance from relevant funding packages may still have had to access private providers in the

meantime. Even with the assistance of universal health cover, she perceived that the gap payments for private providers could be too much for families who were struggling.

"I think, with funding, like, if, for example, with families, Aboriginal families are struggling already, even paying a gap of \$20 is too much for them." (Ella - social service provider)

The additional costs associated with accessing services, even free services, were also perceived as being prohibitive for families. Providers identified that covering the cost of food and transport to services was difficult for some families. The cost of parking and food was described as exacerbated for families accessing assessment services as an assessment could take all day.

"The only thing we have had in the past with some of the Aboriginal families who have come who have a lot of difficulty with the parking and food while they're here. So, we often need to go and get food vouchers...sometimes they would have come without having the ability to, I don't know, without food and without finance to be able to get it from the shopping centre." (Shelley - health provider)

"Food, if they're here all day you know, food. You know, we do have, the specialist department do have food vouchers, but it's very hard, it's like you have to make an argument just to get, you know, the food vouchers." (Ella - social service provider)

The cost of food in these situations was identified as compounded for carers who, without alternate childcare arrangements, may have had to bring other children along to a child's assessment.

Financial barriers were also perceived to impede some services and providers in providing outreach services. Some private providers identified that while they wanted to assist families struggling financially to access their services, it was not financially feasible in terms of the operating costs of running a practice and the lack of government assistance in covering the cost of providing services in free clinics. Providers perceived that services that bulk billed and free clinics were key enablers to families' navigation of services. Curtis (health provider) identified, in relation to a free

hospital outreach clinic run at a local Aboriginal health service, that although from “an organisation point of view, the clinic is financially inefficient”, yet, from an access point of view children were more likely to be seen and treated.

6.3.2 Information factors

Lack of available information about, and education on how to access services were perceived to impede the ability of families to enhance their competency to navigate services. Some providers identified that they themselves were unsure of how to find relevant services to refer families for support. They perceived that for families, the lack of information and education made navigating services even more stressful and difficult.

“I’m a health professional, even for me sometimes when I’m thinking, oh, where do I go about particular things, so there’s so many different services but how do you know which service you need for your child, and if you’re in a very stressful situation and then you were trying to find a service and you’ve rung five and they’ve all said, ‘well, not us, do you want to try them?’ I mean you’re going to give up.” (Madeline - health provider)

Mark (health provider), an Aboriginal provider, described that he had experienced this confusion on a personal level both in his role as a provider and as a relative of children with a disability.

“From a personal point of view, like, I’ve got my [child relatives] that are through community services, and, sort of, my own personal experience is, yeah, there is not enough information out there, or sometimes, it’s the way you try and get through the systems, and, yeah. So I’ve experienced it on a personal basis...I think it’s hard, because even myself, working as a health professional, I know how to navigate the system. I still find it hard ‘cause, it’s hard to find where, who do you communicate this to? Who do you provide feedback to, and stuff like that. There’s no clear direction to say, ‘Well, if you have any issues, and stuff, who do I contact?’.” (Mark - health provider)

While Aboriginal health services were perceived as helping to address access issues, providers identified that it was inevitable that families would have to engage with

mainstream services in seeking care and support. Increased information and education on how to work with mainstream systems, rather than avoiding them, was perceived by providers as key to empowering families to understand how to navigate services.

Some providers identified a number of potential strategies to increase the access of families to information. These included a central online information system specific to Western Sydney, an electronic service map compiled and disseminated by lead government departments, such as the Department of Family and Community Services (FACS), and advertising services in the newsletters or Facebook pages of preschools and schools.

“A map or something like, a navigation thing for people where they can say, ‘Well, if you’ve got, for example, you’ve got a child with disability these are the types of services in your community’. I haven’t seen one around though where people can just pick something up and say, these are the people I contact.”

(Mark - health provider)

Several providers confirmed it was important that disseminated information be written in easy to understand language for families.

“I think that’s what we need – and it’s got to be in a language that people understand too...Stop the jargon.” (Madeline - health provider)

Increasing education and awareness in the wider community was also identified by several providers as a key element to enabling families to navigate services. Some providers described the need for providers and their services to link closer with Aboriginal community groups. This was identified in the context of recognition of the role of community groups’ in guiding families’ around navigating services.

6.3.3 System factors

Providers across all sectors identified that the complex service landscape impeded the ability of families to successfully navigate services. A key issue raised by providers was the confusion caused by the multiple early intervention services encountered by families. Some providers perceived that frustration associated with this confusion influenced the willingness of some families to navigate services.

“Because, um, it’s hard for families to have 20 service providers asking them the same questions over and over. Um, and, you know, it frustrates them.”

(Danielle - social service provider)

Providers described the number of services involved in early intervention as having changed overtime. They perceived that the service system has become more complex for families.

“But families have got no chance, there’s so many different people working with children...you know, 15 years ago they’d come to me and there’d be nobody else, but now there’s so many agencies out there putting their hands up, or children on waiting lists and parents can’t remember which waiting list they’re on, and someone contacts them and they say, oh, no, I’m already getting that, when they’re actually not...It’s quite a complex trail for families now.” (Brenda - education provider)

For Tracy (social service provider), the emergence of more NGOs working in the area of early intervention may mean vulnerable families, in particular, miss out on available support services. This was due to her perception that, in general, NGOs were reluctant to take on complex cases.

“The NGO disability services, I mean I’m making a blanket statement and I could be totally unfair to some organisations, and I grant that that’s the case but generally they were able to pick and choose who they saw and who they didn’t see. So very complex families, very complex clients tended not to receive services through the non-gov sector.” (Tracy - social service provider)

Within the complex service landscape, providers identified that first-port-of-call providers could potentially play an important role in enabling families to access services. First-port-of-call providers were defined as those providers working in the health, education, and social service sectors who were most likely to come into incidental contact with families who were not already engaged with the service system. Key points of contact included preschool teachers, kindergarten teachers, and general health providers such as GPs and Aboriginal Health Workers. First-port-of-call

providers were perceived as having the potential to identify children with issues and link them and their families into the service system.

“I don’t know, maybe if GPs knew more, because if you’re not going to go anywhere you’ve at least got to see your doctor at some point...the GP and the preschools or schools are the places that most families go to. I know there are Aboriginal families that don’t necessarily go to preschool, but in [suburb] they definitely do with the preschool there. But at those type of places because that’s where people go...Everyone at some point goes to the GP, you know, all children, at some point, go to school.” (Madeline - health provider)

“Yeah ‘cause when you think about it, perhaps some of our families – it’ll be [child services] that identifies the families and they may be the ones who plug them into [National Disability Insurance Scheme] or it might be housing who identify that there’s a child in the household that looks like they could have a disability and there’s nothing in place for them...Whoever they think might be the first port of call for that family. Local GPs. You know, anybody who’s going to be that first port of call.” (Tracy - social service provider)

Providers identified that increasing first-port-of-call providers’ awareness and knowledge of how to identify a child who requires support, the services available, and make appropriate referrals were key to improving access to services for families.

6.3.4 Geographical factors

Some providers identified that the geographical location of Western Sydney influenced the ability of families to navigate services. Tracy (social service provider) perceived that in Western Sydney, the locations where services were concentrated, combined with a lack of public transport infrastructure and the prohibitive cost of transport for carers, influenced service access. In describing a central area of Western Sydney, Tracy depicted the location of services in relation to families in terms of a hub and spoke model. The hub and spoke model included the majority of services located in a central suburb, with families living in outer suburbs without adequate transport infrastructure and financial support to get them to and from services.

“The problem with [central suburb] is it’s a difficult place for families to actually travel in...all the suburbs come out of [central suburb] like this. If you lived here and you wanted to go here, you have to go in there and out there, you know, there’s no sort of way of getting amongst those suburbs and that makes it difficult and because of the financial situation, they don’t have money for the bus fares.” (Tracy - social service provider)

Some providers also identified that compared to other areas of Sydney; Western Sydney does not have enough services for the Aboriginal population. For Danielle (social service provider), compared with the amount of services offered in the inner city area of Redfern for the Aboriginal population residing there, there was a lack of similar services offered in Western Sydney. This may have been in part due to her perception that some members of the Aboriginal community in the inner city are better educated on how to navigate advocacy for services and using prominent government contacts to their advantage.

“Because people in the city can fight for their rights. There’s a lot of very educated families who know how to get what they want. They have contacts with the minsters; they’re the first ones to get all these services whereas a lot of people in the [Western Sydney suburb] area, um, you know, they struggle to have, um, those kind of conversations; they don’t have enough contacts they don’t have enough people to advocate on their behalf. Um, so their children miss out on services.” (Danielle - social service provider)

6.4 Permeability of services – “Why should you have to have a label to get services?”

In the context of the high proportion of Aboriginal and Torres Strait Islander people residing in Western Sydney, providers identified low numbers of families who accessed their early intervention services.

“I actually don’t understand why is it that we’re not seeing more Aboriginal families...we just seem to see so very few and I don’t quite understand why. So

there may be reasons that they are not accessing our services...I'm not sure why they're not finding their way here.” (Shelley)

Non-attendance of families at services is an indication of low permeability. A key issue identified by providers that influenced low permeability of services was the need to medically label a child through diagnosis to gain access to services, which was perceived as incongruous with the preferences of some families. Providers observed that some families did not necessarily want to label their child as having a disability.

“what I think would be the way forward is because families often don’t see the value in their child having the label and I totally agree with them. Why should you have to have a label to get services?...So therefore, we shouldn’t be hounding the families to get a label on their child.” (Charmaine - education provider)

The reluctance to label a child through diagnosis was perceived as incongruous with many mainstream service requirements for children to have a diagnosis in order to access services and support.

“We had, like, an exit plan for our service, and for each family, and for the kids who didn’t have a diagnosis, or possibly had just a mild intellectual disability, we struggled to find people to refer them on to because they didn’t fit anyone’s criteria and that’s one of the things that I think in Aboriginal communities, if someone who doesn’t have a diagnosis, I’m not sure what’s going to happen.” (Madeline - health provider)

As demonstrated in the excerpt above, the requirement of labelling a child through diagnosis to gain access to services was identified by some providers as needing to be addressed to overcome the impediment to service access for children without a diagnosis. A key element of the school readiness program that Madeline (health provider) had been involved in was that children did not require a diagnosis to be eligible. Through this approach, the program was able to identify and support children who did in fact have mild disabilities that were not diagnosed. An issue with this approach was that when the program ended, it was difficult to find providers to refer these children to due to strict eligibility requirements. Providers identified that

services that took a holistic approach and addressed specific acceptability issues, such as culturally acceptable models, in their design, were more permeable for families to access. Tracy (social service provider) described an instance where her service offered to run the Positive Parenting Program (PPP) for carers at a local Aboriginal health service. The program aimed to provide carers with the tools to support them to develop skills and strategies to handle behavioural issues. However, staff at the Aboriginal health service explained that as a cumulative model guided the program it would not be suitable for their carers who would benefit more from stand-alone units of training.

“[Aboriginal health service staff] said, ‘Look the style of PPP isn’t suitable for our clientele because they need to have standalone units of training because they can’t always turn up for a period of six or seven weeks.’... As you would in a PPP program and when we went back and looked at PPP, there was no way to actually encapsulate it because the skills were cumulative and you needed to have done the pre cursor before you could move on.” (Tracy - social service provider)

Several providers stated that taking a holistic approach involved not solely focusing on supporting children with diagnosed disabilities. This approach assisted with providing support to children with disabilities without diagnoses that were ineligible for certain support services.

“You didn’t have to have a diagnosed disability to participate [in the program], which, I think, helped a lot of families because a lot of the children didn’t have a diagnosis...Some of the children we helped to possibly get it, because that was part of the program, obviously, was just families to get a diagnosis if that’s what they wanted. Even if we did, sometimes the children came out as having mild developmental disability, which still means they can’t access all the services anyway, but it was impacting greatly on their lives.” (Madeline - health provider)

It was important for these providers that services addressed permeability through taking a holistic approach in the design of their service provision models to Aboriginal children with a disability and their families.

6.4.1 Enhancing permeability through case management

The majority of providers identified the case management model as key to addressing the variable permeability of services for families. Case management was perceived to assist families to gather information to successfully access services as well as providers to coordinate care for a child with other providers.

“I think case management roles would be so much better. I think, you know, even from my perspective, and, you know, from what I'm hearing back from parents, this would be a thing - you know, I've got parents who see, you know, four or five doctors and specialists and therapists and things like that, and then, you know, trying to get all that information together in one place and, you know, have it all being communicated across the board, so we're all doing the same things and working together is the biggest thing.” (Lydia - education provider)

Belinda (health provider) perceived that for Aboriginal families, case management would be important to ensuring consistency of care whereby families do not need to tell their stories repeatedly to different providers, and do not have to start from scratch to build trust.

“Because of those challenges around developing rapport and trust, that if [case management] was to be developed with Aboriginal families, so if they had someone that was there, you know, sort of consistent go-to person that knew their health journey, knew as they moved through the system, they wouldn't be starting each time they presented somewhere to re-establish trust, re-tell stories of how we've come to be where we are. So you know, that would really make sense, to have the capacity to have that link.” (Belinda - health provider)

Although providers identified case management as important, they described it as not currently implemented well. Reasons for this were a lack of financial and human resources, and uncertainty over how best to implement the model and what it should

look like. For Mary (education provider), a case management model which involves a central provider trusted by a family who sits down with them to map out what the needs of the child and family are, and then helps to implement an action plan, would address many of the factors around service provision for families. However she identified that this type of case management was missing from service provision.

“What all families need is a go-to person that they trust that with okay, this is it, this is our plan of action, let’s go suss out a really good GP, right. That case management does not exist.” (Mary - education provider)

Providers identified that potential effective models of case management would include the importance of considering the characteristics of a case manager, and elements such as the need for it to be a dedicated role, and establishing systems around relationships and communication. The effectiveness of a case management model was identified as dependent on the individual characteristics of the case manager. Providers perceived that a case manager needed to have good communication skills spanning across all levels and sectors involved in service provision, be able to build the capacity and skills of other providers to maintain the sustainability of relationships and connections, and have a wide range of knowledge to process information from different sectors.

“It depends on the person who is the case manager, doesn’t it? You know, the skills of that and the personality of that person being genuine in their interest in people, and interested in what they do, and that holds the key doesn’t it, you know, for everything else to fall into place, you know, that key person having really good communication skills to be able to talk on all different levels as well, you know, like because everyone has their own jargon and things like that, you need to sort of pull it all together.” (May - education provider)

Simon (health provider) identified that GPs in particular were competent in lots of areas but not experts in many. He perceived that having a case manager specifically trained in Aboriginal health would be important in raising awareness of available services and supports relevant for Aboriginal children with a disability and their families.

"I think one of the things that we lose sight of in general prac or primary care in general is that, we're providing care for absolutely everything under the sun, and then become, ah, competent at a lot of things but experts in not very many, and we also don't have the understanding of the services that are out there so myself or my colleagues won't actually know who to tap into when dealing with a particular patient...So having a case manager that's trained in Aboriginal health means that it makes our job as care co-ordinators a lot easier because we know what services are out there." (Simon - health provider)

Case managers from an Aboriginal background were also identified as potentially important in assisting families to better relate to the case manager and be more receptive to their assistance.

"I just think a familiar person. Like, you know, if there was an Aboriginal case worker that was like the one constant for that child's family...but they helped them with attendance to meetings and all of that sort of thing. I just sort of think often someone from their own culture they seem more, receptive to, if you know what I mean? And if it's a familiar person all the time, you know, it gives them confidence if they've got someone else that can ring them with the questions they forget to ask or remember information I've shared." (Amanda - education provider)

Several providers also identified a number of elements to consider in developing a case management model. A key element identified by providers was that it needs to be a dedicated role with dedicated funding, rather than an additional role for a health, education, or social service provider. For some GP providers, this was identified as important in moving away from the idea that GPs are the *"be all and end all"* in terms of coordinating services.

"It's something that doesn't need a GP to do, calling people does not need a GP to do it, and I think we need to get out of that mindset that the GP is the be all and end all...I know there's a lot of GPs out there who think that that's their job but you're preventing them doing a lot more for that patient by having them do the phone calls and running around." (Sally - health provider)

Lydia (education provider) identified that although early intervention teachers were in a good position in terms of ongoing contact with providers and families to undertake case management, their high workloads meant that they do not have the time to take on a case management role themselves.

“I think it's having that one person who can filter all that information and keep it all together and streamlined, is a very good idea. You know, it's very time consuming having a student with disabilities, a disability at all, and you know, to then try and jumble through all the pieces of documentation and, you know, funding and different things that they have access to is, you know, a whole other job on itself.” (Lydia - education provider)

Providers also identified the importance of establishing systems around relationships and communication. Relationships and communication were identified as two fundamental elements of case management. May (education provider) identified that the key was to build systems into a case management model that promote and develop relationships and communication, which could have positive ripple effects to service provision.

“So building people up about relationship and about building, you know, who - what relationships are about and how to be in tune with people...You know, those two key things I think affect everything. So if you are able to build that up as your core and then the rest will all filter in I think. That's my analogy of everything.” (May - education provider)

6.5 Presentation at services – “I had to just change how I operated”

Interactions between providers and families, once families had presented at services to make claims to candidacy, were influenced by four key factors. Presentation at services in this context included not just families' attendance at services, but also their active ongoing engagement with services and providers. A common theme underlying these factors was power in relation to providers' perceptions of their interactions with families. The four factors 1) Focus on supporting carers, 2) Awareness of acceptability issues, 3) Communication strategies, and 4) Provider characteristics and obligations, are explored in further detail below.

6.5.1 Focus on supporting carers

Providers across all sectors identified that maintaining a focus on supporting carers in providing services to children enabled effective interactions. Being mindful of the context within which carers were caring for their children, and the provision of supportive resources were perceived as key to supporting carers. For many providers, supporting carers and helping to strengthen their resilience was one of the most important things they could do to enable effective service provision to families. It was perceived to enhance carers' advocacy for their children and empower their ability to be involved.

"The most important thing that we can do for the Aboriginal community, um, for the whole community, um, of anyone who has a child with a learning need is to empower that parent - and to make that parent resilient." (Mary - education provider)

Supporting carers required providers to be mindful of the context within which they were caring for their children. Working with carers to strengthen their skills and knowledge of how to help their children through ensuring advice aligned with individual contexts was perceived as important. This was identified in contrast to a provider telling carers what they thought they should be doing. Colleen (education provider) described a case where she worked with a grandmother who was the carer of a child with autism and reconfigured her service provision techniques to accommodate the specific context of the family. In approaching Colleen for help with supporting her grandchild, this carer described the context within which the child was growing-up, which involved extended family members coming and going at different times of the day and night. While Colleen understood the context as *"culturally acceptable"* she could see as an autism expert that it would be a high stress environment for the child. Colleen identified that the child required more structure, but described initially being uncertain about how to convey this to the carer in light of the family's context. Within this context, Colleen encouraged and supported the grandmother to explain to other family members techniques that they could employ to provide more structure and support for the child.

"I said, 'You are allowed to say hey guys, can you take your football to cousin's place because little [child] really needs his time to defrag.'...I said to the grandma, 'You are allowed to say that, it's in his best interest'. Because she has picked up on it, she could see the distress of this child...I said, 'You can explain to your family, this child's struggling with these issues and we can support him, he just needs a bit of quiet time especially in the evening, let's have the party stuff wrapped up by nine o'clock so he can get to bed for school or whatever'. But it was very sensitive of her to really to make all those observations as well."
(Colleen - education provider)

Supporting carers to support their children was important for providers who identified that it required insight and empathy into the context of families. As demonstrated in this example, it was identified as important by Colleen to reconfigure her service provision techniques within the individual context of the family to achieve the best outcomes for the child. Providing support to carers before implementing programs for children was also perceived by some providers as important in supporting carers to participate and engage with programs. Madeline (health provider) was involved in implementing a school readiness program for children. She described needing to support the carers to feel empowered to take part in the program before they could support the children.

"We needed support for the parents so that they could support the children to be ready for school and if the parents weren't ready, or not able to for other reasons, then they're not going to be able to...we did a lot of other stuff first before we even got to school readiness for some families, and that's okay, because if we could get the families in a strong enough position they could look at that, well then that is an outcome that's good for that family." (Madeline - health provider)

In being mindful of the context within which carers were caring for their children, providers also identified the importance of recognising the different levels of competency in terms of understanding and advocacy among carers, and a need to increase provider skills in listening to the needs of both the child and family. Frank (health provider) identified that for carers at the lower end of the socio-economic

spectrum, being mindful of context was particularly important as they were exposed to more environmental factors competing with engaging in service provision for their children.

“And it’s not as though people don’t want the best for their children, but the lower down the social gradient you go, the more competing factors a family faces.” (Frank - health provider)

Providing access to supportive resources was perceived as another important element to supporting carers and enabling effective interactions. Supportive resources identified by providers included highlighting strengths and support networks, linking carers with other carers, and providing information and education. Some providers perceived that highlighting the strengths and support networks available to families helped to support carers.

“So, I guess, talking about their, you know, when they’re talking, like, they’re giving their family history, you know, everyone has got strengths, so just highlighting their strengths and their support network and where they can get help from you know. And just, sort of, teasing out where they can, sort of, go for support, and that you know, they are able to, sort of, you know, pick up that phone call or make that referral.” (Ella - social service provider)

Linking carers with other carers was also identified as important in supporting carers so that they did not feel as if they were navigating their journeys alone. Facilitating informal support groups for carers was perceived by some providers to have assisted carers to cope with stress related to caring, particularly for carers dealing with an initial diagnosis for their child which was perceived as often being an emotional and stressful time. Amanda (education provider) described setting up an informal support group for the carers of children on her caseload. These groups took the form of ‘coffee mornings’ after her classes twice a school term for carers to talk and support one another. Although Amanda would have preferred to hold more frequent groups, her workload imposed time limitations.

“I say to parents, you know, it’s nothing formal. It’s just really informal so that parents can meet other parents because often when they’re dropping off and

picking up they're in a hurry. But it's just really so parents can meet other parents and, you know, just - sometimes they just want to gossip about, 'oh, I've had a really crappy day'. And, you know, sometimes they will just burst into tears and go, 'You know what? I'm just overwhelmed with everything at the moment'." (Amanda - education provider)

Providing information and education to carers on how to assist their child with their needs and interact with the service system was another means of supporting carers identified by providers.

"So some families felt really, by the end [of the program], felt really empowered...they said they felt really comfortable going to the school now, but they didn't initially and they had the knowledge to know what to talk to the school about, because there are times when they felt like they couldn't approach the school." (Madeline - health provider)

Open days run by Aboriginal Community Controlled Organisations were identified as an effective delivery method of information and education.

6.5.2 Awareness of acceptability issues

Several providers identified the need for non-Aboriginal providers to bring an awareness of acceptability issues and their influence on power dynamics into their interactions with families presenting to their services. Acceptability relates to social or cultural factors influencing the extent to which services are acceptable to families. Taking a holistic approach, working with a key worker, and an awareness of the time required to build relationships with families were perceived as important factors in service provision for providers.

Service provision informed by providers taking a holistic approach was identified as key to enabling effective interactions. Understanding the complexities faced by some families, and adjusting service provision techniques to accommodate them, was perceived by providers as particularly important. Within this was an identified need to understand that families and the wider community may have had priorities that were different to those of providers. For providers, this involved the need to be flexible about families being on time for appointments, and addressing the

most pressing priorities for families, such as finances and housing, before implementing programs. Implementation of these approaches to service provision helped to ensure the ongoing engagement of families with services.

“If [a program’s] not the priority at that time for that community or those families it’s not going to happen...we were working on school readiness but we couldn’t get to work with the families on school readiness straight away because their biggest issue was they were actually going to be evicted and they had no money for food, so we had some experienced staff so they, you know, quickly picked that up and, ‘Okay, let’s work on this with you first’ and then – or even ‘if we can’t help you with that then let’s find someone else who can’.”
(Madeline - health provider)

Tracy (social service provider) described instances where therapists had called her to say that they were working with a family who were *“not engaging, answering calls, or at home”*. In these instances Tracy made the therapists aware that therapy sessions were not going to take priority if families were dealing with more pressing issues at home.

“It’s with families that have got so much going on in their lives that perhaps therapy may not be number one priority, you know, they’ve got no money to pay their bills. Housing are going to kick them out the door...And all those other things, they might be ill themselves, they’re trying to get treatment for themselves, you know, one of their other family members may be in the criminal justice system. So, you know, their court appearances, perhaps incarceration, all of these things and they’re just trying to battle through the best they can.” (Tracy - social service provider)

Providers identified that working with a key worker who a family was familiar with also enabled effective interactions. Providers who had worked with a key worker in their interactions with families observed that they were important in helping families have a voice, particularly in cases where they were interacting with multiple providers at the same time. Families were observed to be more comfortable with speaking up and asserting their needs if they had a key worker to whom they could direct questions.

“I think one of the things that I would probably note, to do with Aboriginal families is that if there’s a key worker or two in the room, that the family, you know, has bonded with or are comfortable with, have got some trust with. Even if you’ve got your group of you know, 10 people sitting in the room. They’re probably going to direct their questions or their responses to that person they feel the most comfortable with...which is – you know, it’s probably a reasonably clever way to manage that for yourself internally, rather than talking to you know, a big room or an audience. To be able to get that, almost closed loop communication. You know, you get the, reassurance in just talking to the one person where you’ve already established some rapport.” (Belinda - health provider)

Some providers identified that a key worker did not necessarily need to be another Aboriginal person. Commonly it was a social worker, doctor, or nurse who was closely involved in the care of a child with whom families were in frequent contact. Providers identified that this varied for individual families and was associated with who they had had enough contact with to have established a link. Shelley (health provider) identified that having access to a key worker was particularly important for Aboriginal families whom she observed disliked being passed over to multiple providers. She perceived that each transition to a different provider without the consistency of a key worker increased the risk of families withdrawing from the system.

“They don’t like it when they see a new face every time or when they’re handed - passed on from one person to another to another to another. Then every time you hand them on there’s the risk of losing them. Whereas if there was one consistent face or person involved that would be so much better.” (Shelley - health provider)

Providers also identified that time enabled effective interactions with families by enabling trust and building relationships. Providers observed that building effective interactions with families required a significant amount of investment in terms of long-term commitment from providers and their services. Individualising care so that providers were in tune with the needs of individual families was perceived as important but took time and perseverance. Colleen (education provider) described the

importance of maintaining a presence in the early childhood settings where she was implementing her program in the face of difficulties she encountered in accessing families.

“I mean I came back here many times going oh, I don’t know if this is working, I can’t see that I’m, you know, helping or making a difference or anything’s happening and [manager of the service] said and you know...on the literature research around how to make this successful and it’s just simply, you know, [manager of the service] said you need to go every week for the rest of the year before we pull out of this because that’s what the research is saying we have to have a presence.” (Colleen - education provider)

This sustained presence eventually led to Colleen being able to build a significant amount of engagement and openness with families where they would come to her for advice.

6.5.3 Communication strategies

The use of inappropriate communication strategies by providers impeded effective interactions with families. Inappropriate strategies identified by providers involved the impact of language used in communication, and lack of understanding of reasons why families may not disclose information. The language chosen by providers to communicate with families was perceived as having a key impact on interactions. The use of jargon in communicating with families was observed to be confusing for families. Several providers stated that sometimes they forgot the importance of using plain language when communicating with families and resorted to the use of professional jargon.

“I’m a therapist, I’m probably a lot better at it now than I used to be, but, you know, talking in plain English instead of jargon, therapists quite like the jargon, but I think also teachers can do the same and not speaking in a language that’s understandable for people.” (Madeline - health provider)

Belinda (health provider) perceived that the use of jargon by providers could emphasise a “knowledge deficit” for families. This was particularly evident in family

meetings where a number of different providers could be involved in communication, which she believed could cause families to feel overwhelmed.

“I think probably a lot of it is a knowledge deficit, that you’re in a room with a lot of health professionals, who are very comfortable with what their knowledge is, what their terminology is, and what their plan of care is...I imagine that knowledge and experience is quite overwhelming.” (Belinda - health provider)

Providers who lacked an understanding of reasons behind why families may not disclose information and failed to take these into account in their communication strategies with families were perceived by some providers to impede effective communication. Families who chose not to disclose information to providers were identified as posing a challenge to service provision. It was identified as important that providers increased their understanding of the reasons behind why this may have been the case and incorporate this into communication strategies to overcome the challenge. Providers identified that the emotional impact of discussing aspects of a child’s care could impede families opening up with providers. Confidentiality issues within the Aboriginal community were also perceived by some providers to influence families sharing information.

“Because with, you know, with different tribes they may come from the same tribe it might be that, you know, some families may not want to give much information, because of you know, in the Aboriginal community from - I’m just saying from more, you know, personal experience, there’s not a lot of confidentiality and it’s, sort of, like, information is just, sort of, shared loosely.” (Ella - social service provider)

Colleen (education provider) provided an example of the importance of providers understanding reasons behind why families may not disclose information, and the need to subsequently adjust communication strategies. Colleen described feeling annoyed when therapists interrupted play sessions to announce that they were there to assess children who might be having problems. In one instance she observed therapists directly approach a family using inappropriate communication strategies in

telling them that there was something wrong with their child. The family's response to this encounter was to withdraw and reject the assistance being offered.

"We get our back up and I would be annoyed by these other therapists...that sort of swarm in halfway through a session where we're already in play with their folders and just sort of go, 'Oh, we're here to assess any kids that might have troubles.' And I'll go well, you know, this little fellow over here is definitely delayed in language and they sort of go over approach the family like, 'oh hi, we're here to, you know, not fix your kid but you know, sort of do assessments if there's something wrong, we think there's a problem', and like I said to [colleague], the body language is just like nope, all good here, off you go, you know, there's no way that they were going to disclose." (Colleen - education provider)

Providers identified a number of elements related to communication that enabled effective interactions with families. It was perceived as important for providers to carefully consider their communication strategies with families to enable effective communication.

"I kind of train the staff to just use different language [with Aboriginal families], and to make sure that we're not talking about problems and difficulties and we make sure to explain the fact that, ah, we're looking at what children are good at and why we're looking at what they may be struggling with because it's, you know, to explain how we can help." (Shelley - health provider)

Several providers characterised effective communication strategies as offering the appropriate amount of time to families' needs, and being supportive. Offering the appropriate amount of time to their needs when communicating with families was perceived as key to enabling effective communication. This was identified as particularly important in the context of communicating with families who had just received a diagnosis in helping them to work through their initial reactions. It was also important in slowly building up a connection with families through conversing on subjects other than a child's diagnosis instead of starting communication by focusing on what is wrong with a child.

“In the playgroup, if I saw a child that I would see as sort of working differently like slightly differently, I’d sort of hone in on them and sit and play with them and start chatting with mum or grandma or dad or whoever and trying to make a connection with that family. Um, and just sort of wait for that conversation to begin because, you know, you can’t just go oh wow, you’re looking really unusual sort of thing.” (Colleen - education provider)

Taking a supportive approach to communicating with families was also identified as having enabled effective communication. For Amanda (education provider), her awareness of the importance of being supportive was influenced by her personal experience as a carer of a child with a disability. As a carer, Amanda experienced communicating with teachers about her child without understanding what they were trying to communicate. This awareness led her to adjust her communication strategy so that it was supportive for families in relation to communicating in a way they are able to understand.

“Even though my children were not Aboriginal they were, I had one daughter who had special needs, and I knew when I went to school, you know, when the teachers were talking to me often I had no concept of what they were talking about. I just didn’t understand the terminology...so when I talk with my parents I try really hard not to dumb it down, but just to explain if I use a terminology I always say, this means blah, blah, blah, blah, blah. You know, it’s just a word for - I try to talk where I think that their level of understanding is.” (Amanda - education provider)

6.5.4 Provider characteristics and obligations

Provider characteristics and obligations that impeded effective interactions with families were associated with the working style and role of some providers. Impeding elements for some providers included a bureaucratic style and roles as mandatory reporters, which were perceived to erode trust. Some providers perceived that some families’ association of a bureaucratic working style with government providers contributed to feeling *“policed”*. Elements of this working style that

contributed to this perception included providers attending meetings with lots of “books and papers”, and their obligatory roles as mandatory reporters.

“they always feel that we’re more like policing them, and that’s the impression I gave.” (Danielle - social service provider)

Being obligated by policy to enforce mandatory reporting was perceived to influence interactions with families for some government-employed providers. Mandatory reporting is a government requirement for providers in some occupations (e.g. police, doctors, nurses, and teachers) to submit a report to child protection authorities in cases where child abuse and neglect are suspected. Providers who had to disclose that they were mandatory reporters identified this as having influenced their ability to develop a working relationship with families who were fearful of the involvement of FACS.

“I mean generally I’d say that a lot of the difficulties we’ve had with Aboriginal children too is around perhaps child protection for a lot of families because that child protection may get involved and then there’s a whole new aspect of the service provision...we try and make sure families realise from day one that we get involved that we’re mandatory reporters. That’s part of the general script that we talk to families about, so it’s no surprise and we do tell families if we’re going to do it.” (Tracy - social service provider)

Where providers did have to make a report on a family, they observed that families resisted the support on offer for their child due to the erosion of trust. Danielle (social service provider) described a case where she had to file a report on a family with FACS that led to the relationship she had carefully built over six months with the family to unravel.

“So that was - there was nothing you could do about it. But, um, yeah, that kind of, you know, just undid everything that we did in the six months and the relationship that we built. Um, yeah, destroyed it and, you know - a couple of days, and then it took us a long time again to get back and, you know, start off from where we left.” (Danielle - social service provider)

A number of provider characteristics were perceived to enable effective interactions. The ability to be flexible was an important enabling characteristic for providers. Flexibility was identified as specifically required around appointment times and a willingness to change one's working style according to the preferences of families.

"Being flexible with time as well you know, so, we've got to bear in mind that, you know, if we say 9 o'clock, some Aboriginal families are not going to get here in - at 9 o'clock, so being flexible." (Ella - social service provider)

"I think I had to just, um, change how I operated, because I was always the type of person to be punctual - everything has to be done by the book, you know, and then I understand that they're more laid back, and they don't like me walking in with so many books and papers; so I had to leave everything in the car and just go and have conversations." (Danielle - social service provider)

Empathy and insight was also identified as enabling effective interactions. Providers' background experiences of interacting with Aboriginal families and their own experiences as carers of a child with a disability helped to develop these characteristics. Empathy and insight also informed some providers taking a *"soft entry"* approach to service provision.

"Soft entry is the key really." (Mary - education provider)

For Colleen (education provider) *"soft entry"* involved maintaining a presence in early childhood settings, which enabled her to identify children with a *"soft disability"* who had not been diagnosed. Instead of bombarding families with talk of diagnoses and treatments, she identified that it was most effective to take a step back and gently assist families access the assistance they require.

"And especially being in a [Aboriginal child care centre] we've picked up on kids, you know, we're helping kids that are really on the cusp and really with their soft disability just through saying look little [child's] struggling, just bring her over every day and just practice this, that and the other." (Colleen - education provider)

Perseverance in chasing up families who providers had lost contact with was also important to enabling effective interactions.

“I've got this little one who hasn't shown up and I just, you know, he needs the service and I just think, where am I going wrong that I can't seem to link in with mum? Did I lose the trust, did I...You know, so you just question everything you do and you just try different avenues.” (Amanda - education provider)

Providers who were willing to step outside their traditional role description in providing support for families were also identified as enabling. Ella (social service provider) whose role as part of a multidisciplinary assessment team was to focus on assisting with a diagnosis, described a willingness to provide further support for some families who she could see were *“hitting a brick wall”* in trying to access services after the diagnosis.

“I mean, if I feel that a family is really struggling, for example, look, you know, ah, you know, the other day, well, two weeks ago, I had a mum with six children, single mum, and she just was - struggling, so I've made two follow up phone calls, and I actually referred her to, you know, for her child to get some behaviour support intervention. So families like that, obviously, I am going to work closely with, and it's not just the one follow up phone call, it's more.” (Ella - social service provider)

6.6 Provider adjudications – “I don't have any preconceived issues with Aboriginal families”

Adjudications in terms of perceived provider judgments about the social and moral candidacy of families accessing services could either enable or impede families' access to services. Past negative adjudications, such as racism and stigma, experienced by families in relation to interacting with mainstream health, education, and social service providers were identified as key to influencing families' interactions with providers in accessing care for their children. Providers also identified two elements that they perceived enabled positive adjudications. These are explored in further detail below.

6.6.1 Impact of past adjudications

Providers identified that negative experiences from families interacting with mainstream health, education, and social services in the past were a key impediment to effective interactions with providers in relation to service provision for children. It was observed that families might have avoided accessing mainstream services due to a fear of initiating the involvement of FACS and concern over negative adjudications on their ability to care for their children.

“Then there is that stream [of Aboriginal families] which is extremely wary of all authority, and very sceptical and wary of, ah, mainstream services...because there’s a fear that involvement in mainstream services may ultimately lead to FACS involvement...those who run away from the services because they fear, basically, they get brought to the notice FACS.” (Frank - health provider)

Negative experiences of interacting with mainstream education services in particular were identified by providers as having impeded effective interactions. Past negative experiences with the Department of Education was perceived to lead to a lack of confidence for families accessing mainstream education services. These experiences were observed to make families reluctant to raise concerns with a school for fear of causing trouble for their child.

“That’s a bit of a tightrope as well, because sometimes, often, the families have not had good, ah, relationships or good experiences in the schools that they went to. And that, sort of pervades their thinking around transition for their children going to school...often in a meeting in a school, often you can see that they’re quite agitated or, um – agitated is a good word, or even nervous.” (Brenda - education provider)

Due to past negative experiences of interacting with the mainstream education system, holding meetings in the office of a school principal was perceived by some providers as confronting for families. Education providers who considered the physical setting of meetings at schools, and implemented strategies to address this, were identified as potentially making families feel more comfortable.

6.6.2 Elements enabling positive adjudications

Two elements were identified as having enabled providers to carry positive adjudications into service provision to families. Having personal and/or professional background experience interacting with the Aboriginal population, and appreciating that the Aboriginal population is not homogenous, allowed providers to make less stigmatised adjudications. Some non-Aboriginal providers who had personal and/or professional background experience interacting with the Aboriginal population identified that this helped enable the influence of positive adjudications in their interactions with families. This background experience was perceived to assist with providers not having preconceived stereotypes about Aboriginal families and an awareness of the impact of racism. For example, Brenda (education provider) identified that having grown up in the Northern part of Australia meant that she was very familiar interacting with Aboriginal people.

"I think I was fortunate. I grew up in [urban area in the Northern part of Australia], so a lot of my background is from living in [area]. And, you know, there were always Aboriginal children, obviously, in our classrooms, in our lives, as friends. So I don't have any preconceived issues with Aboriginal families."

(Brenda - education provider)

Providers also identified that accepting people the way they are, developing trust, and perseverance were elements enabling effective interactions in relation to families' potential perceptions of provider adjudications.

"Obviously Aboriginal families may have their own prejudices about receiving services from whites and government services that some of our other families may not but generally it's all about developing that trust and keeping your word and not bullshitting... You know, that's basically what it's about just being honest and transparent and truthful. If you can't do something, say you can't do something and why...If you can do something, persevere until, don't give up halfway through because that just breeds, you know, the person at the other end having distrust for services." (Tracy - social service provider)

Appreciating that the Aboriginal population is not homogenous also enabled providers to ensure positive adjudications were carried into service provision to families in relation to addressing stereotypes. Providers felt it key to understand that even within communities, different families would have different preferences for service delivery. It was observed that some families may prefer not to be singled out as Aboriginal. Understanding this was perceived as important in shaping service provision techniques for the needs and preferences of individual families.

“And sometimes you will see Aboriginal people and you don’t have an issue, you don’t need to seek what’s the difference in this consultation from the other consultation.” (Brian - health provider)

One provider perceived that there were at least two “streams” of Aboriginal families in Western Sydney whose experiences were different in terms of their level of comfort in accessing mainstream services. The first “stream” was comfortable accessing mainstream services and did not identify themselves as Aboriginal to providers as they were perceived to prefer the anonymity. Frank (health provider) perceived that for these families, finances and knowledge were the variables effecting service access rather than Aboriginality. The second “stream” of families was those for which mainstream services were never acceptable.

“There is a significant stream in that population which finds, ah, mainstream services perfectly acceptable. And there is a stream that runs away from them at every opportunity. So they’re never acceptable.” (Frank - health provider)

Understanding the different levels of what role families want a child’s cultural background to play in service provision was identified as important for providers in being able to adjust service provision techniques accordingly to meet the preferences and needs of individual families.

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

The perception that many Aboriginal families do not want the help offered by non-Aboriginal providers was prominent in providers’ experiences of interacting with families. Understanding and addressing this perception was identified as important as

it could lead to provider withdrawal. Underlying this perception for some providers was the influence of the Stolen Generation, introduced in Chapter Two Section 2.1.2. Charmaine (education provider) identified that the few carers who accepted help from her service usually had *“high expectations”* for their child and were motivated to actively pursue all available supports. However, she perceived that the majority of families encountered were not interested in the help of non-Aboriginal providers.

“They don’t want it. They don’t want us.” (Charmaine - education provider)

This perception manifested in the context of Charmaine’s service being handed a funding directive to target Aboriginal children. Charmaine needed to therefore actively engage with Aboriginal families, which she found challenging in relation to offering help that she felt was not wanted. For Charmaine, the legacy of the Stolen Generation influenced this perception, as she perceived that there was a negative association between non-Aboriginal providers intervening in telling carers what is needed for their child and the destructive child removal policies of the Stolen Generation.

“The Aboriginal population don’t want you to tell them how to work with their children and how to manage their children from my impression.” (Charmaine - education provider)

A lack of interest in obtaining a diagnosis and engaging in early prevention was also perceived to be underlying the perception that families do not want the help of non-Aboriginal providers. Another provider, Colleen (education provider), described feeling that the Aboriginal community in general were not interested in her help as the aim of her program was to get children a diagnosis if required. In this case, the perception that *“they don’t want us”* was about a rejection of the Western bio-medical approach to service provision with the narrow focus on the need to obtain a diagnosis to gain access to services and support, rather than a rejection of individual providers because they were not Aboriginal.

“A big focus on a community that weren’t interested and don’t want it...But they were described as, ah, people at risk or with a disability. People weren’t interested in getting diagnosis, prevention.” (Colleen - education provider)

Improving non-Aboriginal providers' understanding of ways to work effectively with Aboriginal families was identified as key to overcoming withdrawal of services due to the perception that families do not want help. Improved understanding was identified as involving having a holistic and contextual understanding of what families were going through external to providing a service for the medical needs of the child. Danielle (social service provider) described witnessing providers withdrawing from supporting families due to a lack of understanding about why they perceived families did not want their help. Increased information and training in this area was perceived to be important in addressing this outcome.

"I think it's so important for staff to have that understanding. Because, um, I have seen in - in the last five years, I've seen, um, many case managers, um, withdraw from um, supporting families, particularly from Aboriginal backgrounds, because they feel that 'we're here to offer, they don't want any help, we can't do anything'." (Danielle - social service provider)

Providers also identified that non-Aboriginal providers needed to be flexible in reconfiguring service provision techniques to find alternate ways of providing services when facing perceived resistance to services. The need to reconfigure service provision techniques for Aboriginal children was perceived by some providers as challenging for providers working in early intervention for children with a disability as they were already dealing with what they perceive as a vulnerable population. Mary (education provider) described concern over the need to *"tick the Aboriginal box"* to meet directives to target Aboriginal children in light of her perception that *"they don't want us"*. She felt that reconfiguring service provision techniques to meet these types of directives came at the expense of other children with disabilities on the waiting list for her service who were put on hold so that they could *"tick the Aboriginal box"*.

"The waiting list of 40 kids, but because they were – were not, you know, didn't tick the Aboriginal box, we were saying, 'well you're on hold while we go and try and really impose ourselves on these people that don't want us'. I mean it doesn't make sense, does it?" (Mary - education provider)

A number of providers identified the need to avoid tokenistic engagement in reconfiguring service provision techniques to provide culturally safe services for

families to address perceived resistance. Avoiding tokenism was described in terms of the need for genuine reciprocity in exchanging support and information with Aboriginal people, integrating culture throughout programs, and a focus on employing Aboriginal providers in non-Aboriginal Community Controlled Organisations who have the necessary skills.

"I think [integrating culture throughout program] just makes it less tokenistic. So, you know, because a lot of people think, well, you know, I use Aboriginal fabrics and I, you know, and I have a couple of Aboriginal puzzles and stuff like that." (Amanda - education provider)

"I know Department of Education's got a policy that if someone applies for a teacher position and they're Aboriginal, they automatically get it, you know, that just makes me angry because they're not necessarily good at the job and going to be great working in that special school, okay. It's stupid and tokenistic and stupid." (Mary - education provider)

Mark (health provider), an Aboriginal provider, described witnessing tokenistic engagement by some non-Aboriginal providers, and their services, with the Aboriginal community in Western Sydney influenced by what he believed was funding and policy directives. He identified that pursuing meaningful engagement with the community was key to avoiding the perception of tokenistic engagement.

"I suppose, what doesn't work is this, um, other people have other agendas besides trying to do best by our community. That's more them just trying to tick the box to say that they're working with Aboriginal services or programs...you can pick up quite quickly, especially if you know they haven't done a bit of background work, and they just want you to be involved to tick that box." (Mark - health provider)

6.8 Operating conditions and local production of candidacy

The dynamic process of the joint negotiation of candidacy between families and providers through the stages of candidacy was perceived by providers as managed within the context of operating conditions. Providers identified two key operating

conditions that influenced the local production of candidacy for Aboriginal children with a disability in their experiences of service provision to families. The underlying issues of trust and power relations between families and providers throughout the stages of candidacy were perceived to be influenced by the socio-political context of colonisation and the impact of the Stolen Generation. Providers also defined the impact of policy and funding directives by the uncertainty they introduced to their service provision to families. These two operating conditions are explored in further detail below.

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

Providers identified the ongoing impact of Australia’s history of colonisation on the Aboriginal population, in particular around the Stolen Generation, as a key factor that impeded effective interactions with families. This awareness manifested in the importance many providers placed on providers being sensitive to people’s life experiences, that families could *“feel policed”*, and a lack of trust of mainstream services.

Within the context of the impact of the Stolen Generation, providers perceived that providers who come in to tell carers what they were doing wrong in parenting their child could be a significant impediment to effective interactions. Providers, therefore, observed the importance of being sensitive to people’s life experiences when interacting with families.

“Oh you’re coming in to tell them where they’ve gone wrong and how they’ve parented wrong and how they’re not doing it right...and you know, that’s really confronting, you know, isn’t it?” (Colleen - education provider)

Some providers identified that part of being sensitive to people’s life experiences was to be aware of the challenges some carers may face in relation to their own experiences of disrupted parenting.

“And looking at the statistics and looking at scenarios, we did go through scenarios, no, and people that did not have – children that were not raised with the love of their parents and then being parents themselves parenting was a big

challenge to be parents if they were not – they didn't have that experience themselves giving something that they didn't receive. So having an understanding of all that in this area of education and care is it's very important, so you can appreciate a bit knowing the challenges that people go through."
(Dana - education provider)

For Danielle (social service provider), the need to be sensitive to people's life experiences was especially pertinent in her role as a government employed social service provider. Danielle observed that for some families on her caseload, the ongoing impact of past government policies behind the Stolen Generation linked with current perceptions of feeling targeted by government agencies, in particular criminal justice agencies, influenced families' perceptions of interactions with her as *"feeling policed"*. These wider contextual factors inhibited Danielle's attempts at building trusting relationships with some families. However trusting relationships were essential to being able to provide support.

"Well, ah, it takes a lot of effort, because you - it's not so easy to put your point across, because it's so easy for them to then consider you as a supporter of the police. So you then automatically become, you know, the opposition party, kind of...So it was, um, there's a lot of animosity and, you know, um, and that's what the children are taught as well, you know." (Danielle - social service provider)

Providers also identified the erosion of trust in mainstream services due to the ongoing impact of the Stolen Generation to be a key impediment to effective interactions with families. Some providers linked this erosion of trust to a reluctance to confide in mainstream health providers and disclose information.

"It's easy to think of it as a historical event that happened and – you know – we've moved on but it really wasn't that long ago, and it is something that's still alive in the minds of people who are alive today...I can understand where they're, reluctant, maybe reluctant to trust in a system that's been imposed on them...because essentially we've introduced western medical systems and a western social system on a culture that is not western." (Sally - health provider)

Belinda (health provider) described instances where she observed families not feeling comfortable in a hospital environment. This discomfort could manifest in two juxtaposing ways. For some families, mistrust of hospitals meant that they would not leave their child alone in that environment, where for other families it meant they rarely visited their child in hospitals, preferring to spend their time outside.

“What we then see though is, almost two opposite, responses from one family to the next, families that are very present and won’t leave their child alone for a moment. Conversely, other families that are very, very absent. And they’ll come and visit the child briefly or fairly rarely, and spend most of their time outside of the hospital. When they’re here in the hospital, they’re clearly not comfortable in the hospital. So it’s almost the two opposite responses, if you like. Of, I can’t possibly leave, through to, you know, I actually can’t be here, I don’t feel comfortable to be here.” (Belinda - health provider)

This mistrust of hospitals in particular was identified by one provider as linked to the historical role they played in the Stolen Generation as institutions involved in the removal of children from their families. Some providers identified increasing the number of Aboriginal providers in the mainstream system as a potential strategy to address this erosion of trust.

“I guess, I don’t think that there are, sort of, enough Aboriginal workers and if [carers] already have this perception that, you know, it’s like, you know, I’m not going to see a white person because of the whole Stolen Generation, the trust issue is not there you know, so, yeah.” (Ella - social service provider)

6.8.1.1 The role of cultural competence in guiding interactions

Cultural competence was identified as an important factor by providers to effectively guide their interactions with families. Cultural competence training was the main professional avenue of addressing cultural competence identified by providers. Providers described receiving training through different delivery methods and highlighted a number of elements, which they perceived as important to effective training. They shared various opinions of the training they had received. For example, providers explained that while a lack of training could lead to feeling uncertain and

uncomfortable in their interactions with families, training could also instil fear in non-Aboriginal providers worried about the things they should and should not do. Key to overcoming such issues were alternate ways for providers and their organisations to enhance culturally competent practice through practical experience and increasing Aboriginal providers in the workforce.

Cultural competence training

Providers identified a number of different delivery methods for the training they had received. These included cultural awareness workshops run by Aboriginal Community Controlled Organisations and government departments. Content of these workshops was around information on Australia's history, focused clinical cases, advice on how to best interact with Aboriginal patients and their families, some of the main issues providers might encounter, as well as where they could access help, if required. For some providers, the workshop format best suited their style of learning compared to more formal presentations.

"I think it was also the way that it was run, because it was run more like a workshop, and maybe that was just more from my style of learning, I just don't love lectures. Rather than being told, it was nice to kind of have to come up with that yourself." (Sally - health provider)

Outside of workshops, Beverley (health provider), an Aboriginal provider, identified that the delivery method of training in her workplace was centred on encouraging staff to implement practical steps in conjunction with training sessions. This was explained as important to translating policy into practice. Providers were required to identify ways that they planned to translate what they had learnt into practice. For Beverley (health provider), enabling providers to understand how cultural competence requirements related to their specific roles and breaking down how they can be applied in a practical way was important.

"Do I need to go have a cuppa and meet the liaison officer? Do I need to think about the data that my unit engages in? Have I ever asked anybody a question, have I looked at the projects that my team could engage in? Is there some training that I now need to think about? What sort of conversation can I have

with my line manager? Stuff like that. What do I do to encourage my organisation to build this into ongoing practice?” (Beverly - health provider)

Some providers also identified that there had been a shift in the training received compared to what was offered in the past. Brian (health provider), who had worked with Aboriginal families for over two decades, described that when he was in training for his discipline, there was no formal training around working with Aboriginal families. The little training he did receive was not enforced like it is now for current students. Some providers hoped the increase in education leads to increased cultural competence.

“But I do think that maybe there might be a bit of a shift in the younger generations now because just in the way education is and how kids are taught in school these days, so we might see a shift.” (Christine - health provider)

Providers highlighted two elements they perceived as important to effective training. These were addressing the difference between equality and equity, and creating a safe space. Some health providers described their approach to service provision as treating everyone the same. One provider perceived that the education received over the years in high school and university inevitably overcomes any racism, and that therefore not many health providers would hold racist views or make assumptions of differences between patients.

“I think racism is bred out of ignorance more than anything else and I like to think that there aren’t any medical professionals out there that are that ignorant...I think by the time you get through, you know, 13 years of high school and five years of medical training and, you know, three years of specialising and whatever else that, you know, you’re pretty much educated out of that stupidity. I think it would be very strange to find a practitioner who would hold racist views.” (Martin - health provider)

Cultural blindness by some providers was identified by others as culturally incompetent practice. Countering the perception that everyone should be treated the same was Beverly (health provider), an Aboriginal provider, who identified that an important element of training was that it should address the difference between

equality and equity. In response to individuals who might perceive that Aboriginal people were “*getting a free ride*” and that everyone should be treated the same, Beverley identified that highlighting the difference between equality and equity helped to explain the need for specific programs and consideration for the Aboriginal population.

“Equity is the overall principal under which that functions. And, again, people get very confused with equality and equity and I simply have to continually say to people, you know, what we want to shift is the thinking that I treat everybody the same, to I treat everybody so they have the same chance at the same health outcome. And you would be surprised at the amount of face shifts, you can see this whole thought process going, crap [laughs]”. (Beverley - health provider)

Creating a safe space for providers to engage in training was another element identified by some providers. Beverley (health provider) perceived that her attendance at training sessions helped to create a safe space for other providers as they could observe her interacting with the Aboriginal consultant running the training in a relaxed way. She felt that this helped to create a non-judgemental atmosphere for providers to engage with training.

“I stay on heckling, but mostly it’s there because people can see that two Aboriginal people, two very different looking Aboriginal people, having a bit of a giggle about a few different things in a safe space with however many people are there, without judging people for what they’re saying, because they’re breaking through their own personal barriers, and trying to shift it.” (Beverley - health provider)

A couple of providers described two inverse perceptions they had about the training they had received. These were that a lack of training could create uncertainty in their interactions with families, and conversely, that training could instil fear in providers. Effective training was perceived by these providers to be important in achieving better outcomes for families. Training was identified as assisting the development of a better understanding among providers of how to interact with families which in turn was perceived to provide the opportunity to provide better

support, leading to better outcomes. It was observed that without this understanding, providers could inadvertently create a negative perception of themselves with families that, could impact willingness to access services and support.

“if you - you’re not going to, um, have an understanding, you have your own opinion and you’re going to behave accordingly, you’re again going to leave a really bad taste in their mouth and they’re not going to want to access your service. So you’re not doing them any favours. So I think it’s important that there should be more training.” (Danielle - social service provider)

Some providers identified that a lack of training led to feeling uncertain and uncomfortable interacting with families. This was perceived to impede their ability to support families.

“And on my first experience, you know, I did feel that there was not enough, um, comfort level. Um, and it had nothing to do with the family, it - it was more to do with me, because I didn’t have sufficient information about their background, about, well, you know, what their history was, what they’d been through what’s an appropriate style of working, you know.” (Danielle - social service provider)

Madeline (health provider) described an instance where an early educator in the program she was involved with struggled with some of the stories families were telling her, particularly around trauma that they had experienced, in knowing how to respond due to a lack of training.

“The early educator realised that she – as a teacher, because they probably don’t get a lot of training in counselling, so she did struggle and in supervision she mentioned, you know, ‘I feel like I go just to talk to families and they’re telling me stuff and I really don’t know what to do with it’.” (Madeline - health provider)

A lack of training was perceived by some providers as leading some providers to feel uncertain and uncomfortable in their interactions with families, and could instil fear in non-Aboriginal providers worried about the things they should and should not do. Sally (health provider), when she first started practicing, described feeling scared interacting

with Aboriginal patients and their families due to trying to remember what to do and what not to do from her training. The more experience she gained in interacting with families through her practice and becoming more comfortable with her medical knowledge, were identified as key to overcoming this fear.

“I guess initially when you see a patient in the hospital, you go oh my gosh it’s an Aboriginal person, okay, what do I need to do? And you sort of go – oh – and you hear all the stuff about, you know, the eye contact and things like that and, to be honest I found that just, as I’ve gotten more comfortable being a doctor and just more comfortable with my medical knowledge and knowing that I know what I’m doing, um, the interaction just becomes a lot more natural.” (Sally - health provider)

Enhancing cultural competence through training and cultural immersion

Providers identified practical experience as essential to overcoming some of the issues raised around training, and to enhance culturally competent practice. For some providers, undertaking university placements was the best way to understand the importance of culturally competent practice. Practical experiences of interacting with families were perceived to not only assist providers with overcoming fear associated with doing the wrong thing, but were also identified as essential in providing valuable insight into the particular challenges faced by Aboriginal children with a disability and their families.

“What worked really well was the fact that we went into new territory that we hadn’t been in before and even though we had reservations, I think we did it reasonably well and it gave us an insight into the difficulties that are out there for Aboriginal families, it gave us an insight into the difficulties that, anyone working with Aboriginal families has.” (Charmaine - education provider)

Some providers observed that while providers could learn issues around cultural competence in a theoretical way through training, nothing could replace the understanding providers received from practical experience.

“I think just be more aware of why, and even though people have informed me to be more aware of the reason why people might be hesitant to use services is

because of that. I think realistically, as a non-Aboriginal person, people can tell you and you can look up information, but I think you've got to work with people to really see that, because having a theoretical understanding of something is not in comparison to the practical stuff." (Madeline - health provider)

In the context of concerns identified by some providers over policy directives to target Aboriginal families and the perception that *"they don't want us"*, Mary (education provider) identified that practical experience had played an essential role in overcoming some of her concerns. For Mary (education provider), although the difficulties encountered in trying to access families caused some frustration, the practical experience of having to interact with families helped challenged some of her beliefs and *"pushed her outside her comfort zone"*. This was described by Mary (education provider) as a really positive experience.

"...because we actually enjoy, you know, [colleague] and I had to sit down sometimes and admit and say god this is actually pushing us out of our comfort zone and challenging our beliefs, challenging our historic views of these situations and social problems and making us think differently and that's fabulous, you know...Yeah, it is exposure and it's great. So in that sense it's really, really positive." (Mary - education provider)

Increasing the number of Aboriginal providers is essential to enhancing culturally competent practice

Providers identified that increasing the number of Aboriginal providers in mainstream services was also essential to enhancing culturally competent practice. Increasing the number of Aboriginal providers in mainstream services was perceived as important to increasing families' trust of providers. This was identified by one provider as achieved through Aboriginal providers increasing the perception of confidentiality and not feeling judged.

"Let's see if little [child] can stack blocks and you know, so they can gently do that through play and it's more connected because she's the neighbour of his sister's so and so and I can trust her, confidentiality... 'I know she's not going to go back to her little white office and go oh, I met this Aboriginal family that, you

know, they had snotty noses' and you know, they have that distrust around us and I completely get that." (Colleen - education provider)

Tracy (social service provider) identified that having Aboriginal providers employed in mainstream services was an important part of enhancing culturally competent practice. Being able to access the expertise and knowledge of these providers was perceived to assist with providing culturally competent care to families.

"When we had an Aboriginal staff member on the team, that was fabulous because you'd go to him or her and say, 'I've got this family', and tell the story and say, 'What do you think?', and then the Aboriginal workers would say, 'What about this, what about that, have you thought about this, have you thought about that?'" (Tracy - social service provider)

Ella (social service provider) identified that a key consideration for employment of Aboriginal providers in mainstream services would be to employ both men and women so that families had the option to choose one or the other.

"The other thing is, like, if there is, you know, one - you know, male and one female in terms of, you know, being more culturally aware, you know sometimes the females might not be, you know, comfortable with a male or a male might not be comfortable with a female." (Ella - social service provider)

Cultural competence was identified as needing to be embedded throughout organisations from the top down. Mark (health provider), an Aboriginal provider, identified that he would like to see more mainstream organisations implementing organisation wide policies around cultural competence and safety to ensure that they engaged with the Aboriginal population and that their providers respected the diversity within the community. Mark described the current approach in mainstream organisations as *"hit and miss"*. Dedicated Aboriginal programs and workers were identified as a potential way to help ensure cultural competence was embedded within organisations.

"It's a hit and miss, because, like...we're an NGO, so we have got my role, and we've invested in it, and it's up from the top level right down to the bottom. Then it's integrated into the programs, and the organisation. Yeah, but it's hit

and miss, I think, where some organisations more, if they haven't got an Aboriginal program, or particular worker leading that, it, sort of, um, gets left to the side." (Mark - health provider)

Providers identified that an increase in Aboriginal providers in mainstream services across the health, education and social service sectors needed to be met with a commitment by the different levels of government and mainstream organisations to provide long-term support through school and tertiary training. This support was identified as required for Aboriginal providers to be equipped with the necessary skills and knowledge to be suitable for their chosen positions and then be able to go back and work effectively in their community.

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

Providers' experiences of funding and policy directives were defined by the uncertainty they introduced into their service provision to families. Long-term investment was identified as required for effective service delivery with short funding cycles negatively impacting the sustainability of programs. Short funding cycles were perceived as creating uncertainty for both families and providers. Providers also identified the rollout of the National Disability Insurance Scheme as a policy directive that had raised a number of concerns characterised by uncertainty over the impact it will have on both service provision, as well as the experience of families in getting used to a new set of providers and having to tell their story all over again. These two operating conditions influencing interactions between families and providers are explored in further detail below.

6.8.2.1 Funding

Providers identified that funding directives played a key role in service provision to families. It was perceived that funding cycles particularly influenced the experiences of both the families receiving services and the providers providing the service. Short funding cycles were identified as having increased uncertainty for both

families and providers. Funding directives were also perceived to have influenced service provision in relation to the impact of funding constraints on families at the lower end of the social gradient.

Providers identified that long-term investment was key to effective service provision to families, and required to build sustainable and effective programs to empower families. Long-term investment was perceived as important to enhancing the pre-existing strength and resilience of carers to recognise and manage the needs of their children across the life span.

“It’s about building the relationships, hanging in there for the long term and then empowering these people and building the resilience of these people to recognise their child’s need to learn how to work with their child and that is lifelong.” (Mary - education provider)

Some providers identified short funding cycles as having had a negative impact on the sustainability of programs and increased uncertainty for both families and providers. The discontinuation of funding in short funding cycles was perceived by some providers as inevitably leading to the withdrawal of providers and their services. Madeline (health provider) described the inability of her service to secure continuing funding as key to the discontinuation of the program for school readiness she was involved in. The withdrawal of her service especially impacted families whose children did not have a diagnosis. For Madeline (health provider), one of the most difficult aspects of withdrawal due to lack of funding was knowing that the program was generating positive outcomes that could be lost due to the inability of some children without a diagnosis to access ongoing support.

“I really do believe when you can see families who, the parents are more confident, the children are able to sit in the classroom and participate and then you don’t know what’s going to happen afterwards, because if you’re someone who’s got support from someone else it’s good to be able to keep it going, but when that support goes, can you sustain it yourself if you’ve got so many other issues going on in your life? If you’ve got support it’s sometimes a lot easier than if you don’t have the support then or the reminder, is that strategy going to keep happening?” (Madeline - health provider)

Madeline (health provider) also identified that the withdrawal had a significant impact on the providers involved with the program. She observed that it was frustrating for providers who could see that they were achieving positive outcomes. This was further exacerbated by the uncertainty of knowing that they would also be without employment.

“It doesn’t feel good...and it’s hard for the staff as well; they put all that effort in and then don’t even have a job at the end of it either. So it feels uncomfortable, it’s frustrating...As an organisation we find it frustrating ‘cause we could see the benefit but we don’t have the funds ourselves to keep something going.” (Madeline - health provider)

Funding constraints on service provision to families were identified as disproportionately impacting families at the lower end of the social gradient. Providers identified that service provision for many families at the lower end of the social gradient was funded through bulk billing. Simon (health provider) identified that this model of funding increased high turnover of patients, which could negatively impact the quality of care.

“We’ve got fund constraints and what tends to happen is that, you know, there’s a social gradient in Australia whereby unfortunately people of certain backgrounds tend to need our support in the lower [socio-economic status] group, and naturally being in the lower [socio-economic group] group means also less access to care, that could be higher bulk-billing rates in certain communities and where there are high bulk-billing rates there tends to be more patient churn or turnover so those people being seen for a couple of minutes at a time, rather than having an adequate, you know, 20 or 30 minutes spent with them, and therefore it becomes quite difficult to provide the care that’s needed within a very short period of time but unfortunately there’s no other sustainable way to fund it, so it’s funded by loose change.” (Simon - health provider)

6.8.2.2 National Disability Insurance Scheme

Providers identified that the rollout of the National Disability Insurance Scheme raised a number of concerns characterised by uncertainty over the impact it might

have on families. Providers observed that from their knowledge of the scheme they will need to carefully construct the wording of their recommendations in assessments to ensure families receive all the support they require, case management will no longer exist with the introduction of plan coordinators only focusing on coordinating plans rather than providing traditional case management, and the need for flexibility for families who require extra support. Some providers identified potential benefits associated with the National Disability Insurance Scheme rollout. These included the potential for a rise in standards in service provision due to competition between services, the potential for less red tape in dealing with NGOs compared to government services, and allowing itinerant families to bring their child's care plans with them if they move to enable consistent care.

"With my own experience with an NGO here they may be able to, um, things a lot quicker without the red tape." (Mark - health provider)

However, many providers raised a number of concerns in relation to how the scheme might impact service provision to families. Underlying these concerns related to how the scheme might impact service provision to families was a feeling of uncertainty exacerbated by a general lack of information to providers on how the scheme will be operationalised in practice. A key concern was over the impact that the withdrawal of government services from disability service provision might have on families with the most complex cases. Tracy (social service provider) identified that the disbanding of the government department she worked for was a concern as they often took care of the most complex cases. Tracy perceived that the increased role of NGOs in this space might lead to families with complex cases falling through the gap in service provision, as she believed that NGOs were not as persistent as her department in supporting complex cases.

"When you talk to our non-gov partners, their idea of complex, we laugh because they really have no idea of the type of clients that will be coming to them that in the past, as soon as it got too hard for the non-govs, they'd refer back to [government department] and say, 'Too hard for us, not enough money attached to that person, they're not viable, put them back to [government department]'. 'Cause as I said, [government department] doesn't give up. You

know, so there won't be that service of last resort. And that's an issue and will be an issue I think." (Tracy - social service provider)

Concern related to how to ensure the quality of services from the NGOs that families will be accessing with their funds was also raised by a number of providers. It was identified that assessing the quality of services without the assistance of a case manager might be difficult for some families.

"So with [NSW government department] not there anymore, probably the families now have got money to spend but, it's what are the - who are the service providers who are going to provide that service and what's the quality of that going to be and who's going to monitor that and how are the clinicians going to make sure or help the families, you know, make sure they get good service. So those are the issues we don't quite know yet." (Shelley - health provider)

"We can see a lot of families are going to struggle with the idea of trying to develop goals for their children because you don't know what you don't know. Unless you have somebody who's able to guide you in say developmental stages perhaps if you're looking at therapy. I mean how do you know if a service is giving you a good service or a bad service? What yard stick do you use for that?...And if there's nobody around to provide that or to support you to develop that yourself, that could be difficult. So I can see there's going to be some teething problems and I can see that there's going to be families who fall through the cracks." (Tracy - social service provider)

Other key concerns included the impact on families who have difficulty self-managing money, and confusion over what services will be funded.

"Lots of people are trying to inform people of what, you know, will happen, but I think that is an issue that for lots of Aboriginal families who don't get a diagnosis maybe when they go to school it might get picked up, but they've missed all that early intervention stuff." (Madeline - health provider)

Mark (health provider), an Aboriginal provider, identified particular concern around the change to services for families. He perceived that the large shift in the service

landscape might make it harder for families to navigate the service system in needing to work out which NGO was going to look after them.

“From experience, what I’m seeing now, especially with, disability, and stuff with children I think it’s going to be a little bit worse especially with the change with the [National Disability Insurance Scheme]...I think it may be a little bit worse, because people were just getting used to what was already there with [government department]. And now that it’s going to be dismantled into NGOs, and that” (Mark - health provider)

Associated with this was Mark’s (health provider) concern that families will need to get used to a new set of providers which could be “daunting” in relation to having to tell their story all over again.

“The biggest impact is having to tell their story again. So they have to repeat themselves when they would have got used to one worker that knew them, spoke about how things work, for example, for little Johnny, and what their issues were. And they have to go again and repeat that. I think it’s going to be daunting to the families. I know a lot of families that were just thinking, well, do I have to tell my story again?” (Mark - health provider)

6.9 Summary of key findings

Identification of candidacy - “It’s better to start early intervention quickly”

- Need for providers to support carers in identifying when a child might have a condition requiring assessment.

Navigation of services - “It’s quite a complex trail”

- Costs associated with accessing services (e.g. private providers, food, transport, parking) impeded the ability of some families to navigate services.
- Lack of information about, and education on, how to access services impeded the ability of families to navigate services.
- First-port-of-call providers (e.g. preschool teachers, GPs, Aboriginal Health Workers) have the potential to identify children with issues and link their families into the service system.

Permeability of services - “Why should you have to have a label to get services?”

- Low permeability of services associated with a lack of diagnosis, which was

perceived as incongruous with the preference of some families.

- The case management model was considered key to enhancing permeability of services for families.

Presentation at services - “I had to just change how I operated”

- Provision of supportive resources such as highlighting strengths and support networks and linking carers with other carers, were key to supporting carers.
- Taking a holistic approach, working with a key worker who a family was familiar with, and an awareness of the time required to build relationships with families were important.
- Inappropriate communication strategies (e.g. use of jargon) impeded effective interactions.
- Bureaucratic working styles and provider obligations as mandatory reporters could erode trust.
- The ability to be flexible, empathetic, and willing to step outside traditional role boundaries enabled effective interactions

Provider adjudications - “I don’t have any preconceived issues with Aboriginal families”

- Families’ past experiences of racism and stigma in relation to interacting with mainstream providers were identified as key to influencing families’ interactions with providers.
- Appreciating that the population is not homogenous, allowed providers to make less stigmatised adjudications.

Offers and resistance to services - “They don’t want us”

- Underlying the perception for some providers was a negative association between non-Aboriginal providers intervening in telling carers what is needed for their child, and the destructive child removal policies of the Stolen Generation.
- For other providers, the perception was about a rejection of the Western bio-medical approach to service provision with the narrow focus on the need to obtaining diagnoses.

Operating conditions and local production of candidacy

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

- Enhancing culturally competent practice through practical experience and increasing Aboriginal providers in the workforce were identified as important.

Program changes related to funding and policy - “Having to tell their story again”

- Long-term investment was required for effective service delivery with short

funding cycles negatively impacting the sustainability of programs.

- The rollout of the National Disability Insurance Scheme was a policy directive that had raised a number of concerns characterised by uncertainty over the impact it will have on service provision. The large shift in the service landscape might lead to lack of continuity for families. An associated concern was that families would need to get used to a new set of providers.

6.10 References

1. Dixon-Woods M, Cavers D, Agarwal S, Annandale E, Arthur A, Harvey J, Hsu R, Katbamna S, Olsen R, Smith L & Riley R. 2006, 'Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups', *BMC Medical Research Methodology*, vol. 6, no. 1, p. 35.

Chapter Seven: Provider understanding of factors influencing interprofessional collaborative practice

7.1 Introduction

Providers' perceptions, understandings, and experiences of working together across the health, education, and social service sectors centred on their perception of factors that either impeded or enabled collaboration. These are explored in this chapter through an adaptation of the Collaborative Practice to Enhance Patient Care Outcomes framework [1], introduced in Chapter Four Section 4.2.2. The adapted framework explores the processes and determinants of interprofessionality in the specific context of service provision to Aboriginal children with a disability and their families (Figure 7.1). Interprofessionality is defined as *"the development of a cohesive practice between professionals from different disciplines"* [1](p. 9). The child and family, who are both the intended recipients and active members of care, are at the center of the framework. The needs of children and their families instigated interprofessional collaborative practice between providers across sectors and determined the task complexity to be addressed through collaboration. Interprofessional collaborative practice was influenced by interdependent interactional (meso) and organisational (exo) factors. Interactional (meso) 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 relation to factors that influenced trusting relationships and willingness to work together, particularly with Aboriginal providers and services. Organisational (exo) 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 enable interprofessional communication. The processes of interprofessional collaborative practice at the meso and exo levels were managed within the context of systemic factors of policy and funding at the macro level.

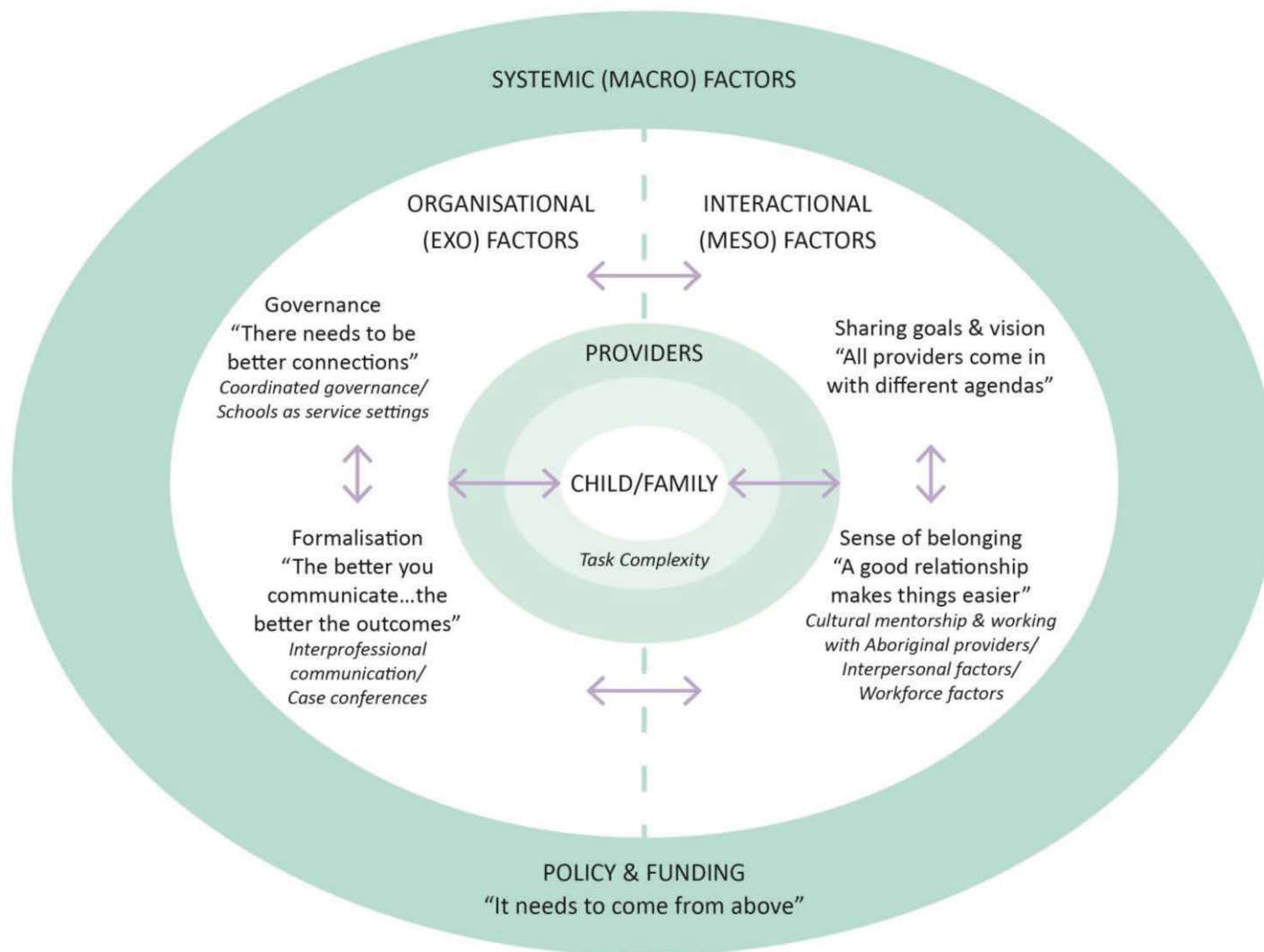


Figure 7.1 Provider understanding of factors influencing interprofessional collaborative practice

7.2 Interactional (meso) Factors

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

The complex, cross-sector service landscape of working in the area of Aboriginal childhood disability influenced the ability of providers to share common goals and vision. Providers characterised the service landscape within which they practiced as complex due to the multiple providers and services involved. It was perceived by some providers that the lower socio-economic demography of Western Sydney, in particular, had led to an increased number of NGOs, which had added more services to an already complex system. This was identified as having led to confusion among providers as to what other providers were involved with a family and the role they played in care.

“And there’s so many additional services out there these days for children...and with the [National Disability Insurance Scheme], it’s going to be even more complex...just trying to work out who’s involved, what they’re doing, that duplication of services.” (Brenda - education provider)

Confusion caused by the involvement of multiple providers and services was perceived as a cause of frustration for providers. Some providers described having invested significant time in establishing the groundwork for working within early childhood settings, only to have new providers come in, creating tension between providers and a loss of trust. Lydia (education provider) identified that the large amount of providers working within early childhood settings caused frustration for staff within these settings. Although most early childhood educators were willing to receive support from external providers, Lydia (education provider) perceived that some educators were overwhelmed in trying to filter information and implement it within their settings. This frustration was identified as having impeded providers working together.

“I actually went to a centre last week and one of the educators that I was speaking to about a student was a bit abrupt with me...she was a bit, you know, ‘well, we’ve already had their speechie come in and told us to do X, Y and Z’, and ‘why do we need to listen to you’ kind of thing, which I understand that, but unfortunately in that circumstance that speechie isn’t talking to me and I don’t

receive any information of what they're doing...you try and play middleman because you want to support the student, but you're not necessarily always on the same page with other agencies that we are working with.” (Lydia - education provider)

Providers across all sectors identified that the impact of this complex service landscape on working together was compounded by a lack of coordination. Differing agendas between providers involved in the care of a child was perceived to lead to conflicting approaches to assessment and management of the child’s needs and as a waste of resources.

“So all providers come in with different agendas...like an [occupational therapist] wants to fix the child in terms of how they function, the speechie [speech and language pathologist] wants to fix the child in terms of their speech, everyone has their own agenda ...So this parent is given 300 conflicting ideas of how this child should be fixed.” (Colleen - education provider)

The complex service landscape was also identified as having led to role duplication and lack of clarity between providers. It was identified that confusion was caused over which provider was responsible for what. Providers described instances where they were unaware that other providers were involved in a child’s care. At times, two providers could have been working on the same issue with a child but coming from different approaches.

“Because you know, quite frequently you can have two different people working on the same thing but teaching in very different ways, and it's not necessarily - you know, you're putting more work on yourselves and kind of backtracking kind of thing.” (Lydia - education provider)

When developing new programs it was identified as important not to replicate the objectives of existing services within the area.

7.2.1.1 Linking role

Providers who worked in formal and informal linking roles helped other providers to navigate the complex service landscape and facilitated the sharing of

goals and vision. Informal linking roles involved providers who took on the task even if it was not part of their role description. Linking roles were identified as key in raising the awareness of providers of other available services. They were also identified as having enabled pathways for providers to link with one another.

“So if they’ve got an issue with a child or with a transition, then they’ll ring me and often ask, you know, ‘where do I go with this’, you know, ‘what’s the next step, what would you do?’ Or if they’re having problems then they can call me in, so I can go and have a look at that child in preschool. So that works really well.” (Brenda - education provider)

A key element to providers being effective in linking roles was identified as individual provider passion. This passion was perceived to have enabled providers in linking roles to persevere in the face of impeding factors related to working across disciplines and sectors. Passion was also identified as encompassing a genuine interest in other people and how to connect them.

“I’m just really interested in people and interested in their story, and I’m thinking, well, this is what I think that person’s about so that would link quite well with that other person...and 99.9% of the time it’s a great outcome. I think basically just being interested in people.” (May - education provider)

Another key requirement was that the provider in the linking role was easily contactable.

“Number one, it’s a one person call, so it’s the same person you call all the time. Number two, she answers her mobile or she calls back if she’s busy. Number three, she gives you feedback. So remember Mr. So and So, they are now with [NGO].” (Brian - health provider)

An interesting issue raised was the “intangibility” of provider characteristics that enabled being effective in a linking role. This was identified as a particular issue in relation to consideration of how to identify the right people to employ in these roles.

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

The cross-sector, and cross-cultural, collaboration required for providing services to Aboriginal children with a disability inspired unique interactional processes for providers in relation to their sense of belonging in this space. Trusting relationships among providers in this area and their willingness to work together were influenced by three key factors: 1) cultural mentorship and non-Aboriginal providers working with Aboriginal providers and services, 2) interpersonal factors, and 3) workforce factors, influenced the ability for providers to build the trusting personal and professional relationships to enable effective interprofessional collaborative practice. These three factors are explored in further detail below.

7.2.2.1 Cultural mentorship and working with Aboriginal providers and services

Working with Aboriginal providers and services was identified as helping to overcome acceptability issues with families and an important part of enabling service provision. Working with Aboriginal providers was perceived to provide non-Aboriginal providers with insight into the specific needs of families, assisting the development of acceptable management plans. Aboriginal providers were identified as also involved with assisting in following-up with families in the community, particularly important in ensuring continuity of care for itinerant families.

“I think it allows us to develop a lot more insight into the patient in the sense of understanding not only what they presented with but also understanding the cultural context in which we are delivering the management as well, these things that they’re able to provide is a way to put forward a management plan that will work with the circumstances of the Aboriginal person.” (Simon - health provider)

Although providers identified a number of positive outcomes from effectively working together with Aboriginal providers and services, they also identified that important outcomes from effective working relationships were difficult to measure. This was perceived by some providers to be unlike the types of outcomes usually measured in policy. Despite being difficult to measure, these outcomes were perceived as

important to being able to work effectively with Aboriginal providers and services. For example, Mary (education provider) described the “*ripple effect*” of effective working relationships as contributing to the success of the program she was involved with.

“Sadly, we can’t measure the ripple effect of these people but interestingly, we’ve picked up a couple of centres from people ringing up saying, ‘Look I used to work at such and such when the program was there, now I’m the director of [childcare centre], and is there any chance staff can come and work here now?’. So I guess that’s the only way we can measure the success of that.” (Mary - education provider)

For Mary (education provider), this was particularly important in reflecting on the difficulty she had engaging with Aboriginal families at the start of the program.

Impeding elements

Providers identified two elements that could impede non-Aboriginal providers working effectively together with Aboriginal providers and services. These were the perception of reverse racism and Aboriginal teams being insular. Some providers perceived that they had encountered reverse racism in their interactions with Aboriginal providers. These providers believed that they had experienced instances where they felt discriminated against as a non-Aboriginal provider particularly at times where they perceived Aboriginal providers as resistant to them entering their settings. For Mary (education provider), the perception of reverse racism was influenced by wider experiences she had in networking at a conference.

“[We] went into a small group to discuss some topic and we were referred to as white gutter trash...and so, to slap that generalist opinion on all of us, I found really insulting. I actually got up and walked out of that session. Um, so I think that we’ve got a long way to go...”

Q: How did that make you feel?

Angry to be honest, I don’t consider myself to be white gutter trash.” (Mary - education provider)

Associated with this was the perception of some Aboriginal teams as “insular” which impeded some non-Aboriginal providers working together with them. Some providers reflected that this perception of insularity was generated by it being difficult to make friendly contact with some Aboriginal teams, and some Aboriginal teams not drawing on the skills and resources of non-Aboriginal providers.

“We have an Aboriginal play group that meets across the classroom to me. And a couple of times I have said ‘hi’ but...even though I’ve been here for years and I do it all the time, they don’t, sort of, lean over the fence and chat. It’s always, sort of, like, you know, you’re over there. So it doesn’t matter how friendly you are.” (Amanda - education provider)

For Brenda (education provider), this insularity was “a real barrier” which she thought was unfortunate in light of the assistance and support Aboriginal teams could provide for the children who were referred to her service.

“It’s always been something that’s in the back of my mind, always, particularly when I do have an Aboriginal child referred. I think to myself, ‘oh, my goodness, it would be great if we had that sort of close working relationship’. But it’s just not.” (Brenda - education provider)

Enabling elements

Providers identified four key elements that enabled working effectively together with Aboriginal providers and services. These included the importance of relationships, enabling approaches to working together, personal characteristics of individual providers, and increasing the number of Aboriginal providers in the workforce. These elements are explored in further detail below.

Importance of relationships

Relationships with Aboriginal providers and services were identified as a vital part of working effectively together. Previous relationships from involvement in past programs, relationships with key Aboriginal contacts as cultural mentors, and working indirectly through existing services were perceived to be particularly enabling. Relationships with Aboriginal providers and services developed through working

together on past programs were perceived to be a key enabler. Providers identified that this was especially pertinent in relation to being invited to work with Aboriginal providers and services in future programs.

“Through our work in the playgroup, we built relationships with the community, the families, the kids, the director of those centres that we entered. So then through [centre director], we entered [Aboriginal childcare centres]...And also we were a part of [Aboriginal childcare centre] opening...because I’d been around for a good year like I was a part of the opening ceremony and...I had that sense of belonging from the roots.” (Colleen - education provider)

May (education provider) described developing a long lasting relationship with an Aboriginal Liaison Officer, who became a cultural mentor, from initially working with her in a previous role for a Western Sydney council.

“I think I was very fortunate in having a fantastic mentor, the Aboriginal liaison person in [council], who had a very natural, very good ability of coaching and mentoring adults, in regards to sharing information very simply but very precisely about the Aboriginal culture and the differences and similarities and things like that and I was very fortunate to have that person be there for me for that.” (May - education provider)

Many providers identified the important enabling role of key Aboriginal contacts acting as cultural mentors. Key Aboriginal contacts were identified as enabling the process for non-Aboriginal providers to work within communities, providing advice on appropriate cultural protocols for working together with Aboriginal providers and implementing programs, and providing an avenue for non-Aboriginal providers to increase engagement with Aboriginal teams.

“I met a lovely elder through the [Aboriginal childcare centre] thing. She came to me...and said, ‘You can call me aunty’ – and I thought she’s a person that you’d go ‘hey Aunty, how do I get the kids to this or how can I get some acceptance around disability or how can I explain to the other kids that this little fellow’s so shy it’s best for him at the moment if we keep out of his way’...and through her I could have an insight.” (Colleen - education provider)

It was also observed that accessing key Aboriginal contacts was sometimes challenging in terms of finding the right person who was also interested in working with non-Aboriginal providers.

“You’ve got these key people on that side but you’ve got to get to them and they’ve got to want to work with you.” (Mary - education provider)

Brenda (education provider) identified that establishing good communication between herself and an Aboriginal Liaison Officer who had been a key Aboriginal contact in the past was important to the success of their relationship. Good communication was defined in terms of the ALO bringing concerns about a child to Brenda who then would work with her to find a way to support the family.

“She would just come in and talk to me about a family. She would talk to me about the development of the child. And if I could see some red flags then I’d say, well, how about we go and have a look at this little one in preschool? And how about we have a look and see whether this child needs some additional assessment, or a formal transition to school? Yeah. That worked really well.”
(Brenda - education provider)

Providers also identified that working indirectly through existing services enabled working effectively together with Aboriginal providers and services. This involved going through formal consultants from Aboriginal organisations with existing connections and trust in the community to connect with Aboriginal services, and informally through teams within the same organisation who had developed existing relationships with Aboriginal services that providers could tap into.

“I came to the decision that it was no use for me to go in and approach an Aboriginal service and say, ‘Look I’m here to help you, you know, aren’t you lucky?’...We ended up having to do it via the back door. So we did it through another service who was working with the Aboriginal community and then they put us in contact with a person who was the director of an Aboriginal childcare centre and so through her, we then started working with her centre...So it wasn’t direct contact that worked for us, it was indirect and I think that was far more successful.” (Charmaine - education provider)

Working indirectly through existing services was perceived as enabling the development of relationships with the services, which in turn enabled working with Aboriginal providers in future programs.

Enabling approaches

Providers identified a number of various approaches to working with Aboriginal providers and services that were enabling. A key approach was long-term investment in taking the time required to develop relationships coupled with perseverance. Taking the time to develop relationships was important in gaining the respect and trust of Aboriginal providers and services.

"I've often found them over the years just really quiet sort of people, and they don't like to be talked at. You know, it's sort of like you have to get to know them on a few different levels. It's almost like you've got to earn some respect before they're going to listen to what you've got to say. And I can't blame them for that." (Amanda - education provider)

Mary (education provider) identified that persisting over a long period of time with building up trusting relationships to lay the groundwork for programs was important. This was contextualised within her experience of frustration caused by other providers coming into an Aboriginal service her organisation was working with and trading off on the trust and groundwork that they had laid over time.

"So [special educator] hung in there and worked damn hard on some very boiling hot and some very stressful days to make this whole thing happen, then you get another service turn up and arrive at the childcare centre, when we've been doing the ground work to get this kid to this childcare centre and they say, 'Hello, I'm a speechie [speech and language pathologist] and I'm here to do half an hour with so and so, can I just remove him from the room and sit down here?'. It is completely undermining." (Mary - education provider)

Associated with taking the time to develop relationships was the importance of perseverance in maintaining a presence in the face of Aboriginal providers and services that were initially unwilling to engage. This was perceived to take the form of providers working outside their traditional role boundaries and attending community events.

“I think what helped is not going away, so even when people were not – not not welcoming, but thinking, ‘well, I don’t know who you are so I’m not really sure whether I should get involved with you’, type of thing, we just kept going, so we’d go to community events on the weekend, and we just kept going.”
(Madeline - health provider)

Involvement in community events external to traditional job requirements was a key approach for a number of providers in enabling the ability to work together with Aboriginal providers and services. Laying the groundwork in the community through attending community events was described as having enabled the effective implementation of programs.

“But we spent a lot of time before the actual school readiness program started, just being at community events and talking to people and being around; I think that made a difference too, we didn’t just rush in and go, ‘we’re starting next week’.” (Madeline - health provider)

May (education provider) described engaging with the wider community through involvement in community events as “vital” to working effectively with Aboriginal providers and services. Central to this belief was an understanding that working with Aboriginal providers and services was not a traditional “nine to five position but 24/7”.

“So it’s not just something that I do in my work, Saturdays and Sundays I might go to different events or do certain things as part of reconciliation as well.”
(May - education provider)

The physical space where providers were situated was perceived as also enabling. Physical proximity of the location of mainstream health and Aboriginal services was identified by some providers as having enabled the development of relationships between providers from each service, in turn increasing the number of Aboriginal patients seen by the mainstream service. Brenda (education provider) identified that in the past she developed an effective relationship with an Aboriginal Liaison Officer enabled by working next to each other within the same room along with other providers. This was perceived to have enabled effective teamwork and the Aboriginal Liaison Officer having an understanding of her role.

"I think we had a personal relationship and that was really great, and we were sitting very close to each other, and she had a really good understanding of what I did, because we were near each other...[Aboriginal Liaison Officer] was the only one who wasn't working in the actual room with the other Aboriginal education officers, so she was actually working in a room with a group of us. So there was out-of-home care, there was myself, you know, the intervention, there was, – oh, they used to call them truancy officers, and [Aboriginal Liaison Officer]...Those sorts of teams work really well." (Brenda - education provider)

Ensuring open communication was perceived as another enabling approach. Open communication was observed to be particularly effective when it was the "right" type of communication, with both sides having an understanding of what their commitments were and a willingness to share information in relation to working together. Rachel (health provider) identified that key to building a relationship with an Aboriginal health service was getting them to understand the role of her program in relation to children in OOHC. She identified that there were misunderstandings around what role her program had in the wider OOHC system and that open communication was important for clarification.

"I guess once we build those relationships they know that we're not, I guess, they know what we do. Because there's quite often a misunderstanding of what we do. And so if they're referred to in health as out of home care then that could be taken so many different ways like do we go to people and care for them in their homes or do we remove the kids or do we provide home care services to the elderly." (Rachel - health provider)

It was also identified as important for providers to acknowledge that their service may not be the best service for the community in their approach to working with Aboriginal services. Madeline (health provider) described an instance in which her program was working with an Aboriginal early childhood education service that eventually withdrew from the program.

"You've just got to acknowledge that sometimes things don't work and it's not the right time for that program to work or – 'cause they were starting their business as well, it was all very new...you've got to be honest and sometimes

you do have to acknowledge that you're not the service for that community, or that community needs to say, 'Well, actually, you're not the type of service we want here; it's not working for us', and I think that's okay." (Madeline - health provider)

Provider characteristics

A number of personal provider characteristics were identified as enabling working effectively together with Aboriginal providers and services. These included being relatable, genuine, honest, flexible, and having the ability to listen to, and respect, the advice of community elders. Providers also identified the importance of being able to self-reflect and learn from mistakes in working with Aboriginal providers and services. Providers who were willing to change their practice according to their reflections on what did and did not work were perceived as most effective.

"She just went great guns because she was so approachable, she was also somebody who if something did go wrong she acknowledged it, learnt from it, and moved on instead of working in that one particular way." (Madeline - health provider)

May (education provider) described an instance where she was working with an Aboriginal early education provider and her initial communication strategy was related to her natural predisposition towards being a *"mother"* in personalising interactions. She identified however that this provider was uncomfortable with her style of communication. May (education provider) then approached key Aboriginal contacts to request advice on what she was doing wrong so that she could fix mistakes that had been made.

"You make mistakes along the way, and you need to learn making the mistakes, but I have built a respectful relationship with Aboriginal elders in the area and they help me." (May - education provider)

Increasing the Aboriginal workforce

Some providers identified increasing the number of Aboriginal providers in the workforce as key to increasing the cultural competence of non-Aboriginal providers and addressing some of the elements impeding working together.

“So for us we had some Aboriginal staff and some non-Aboriginal staff, the Aboriginal staff supported the non-Aboriginal staff within the community to understand the cultural aspects of working in that community.” (Madeline - health provider)

An important element of this approach identified by providers was for the wider service system to properly support Aboriginal providers who entered the mainstream workforce. Beverly (health provider) identified that it was important to support Aboriginal providers, as those who have had negative experiences of working in a mainstream organisation could influence the wider community’s view of that organisation.

“If they’re struggling in the workplace, you know, you’ll go home like everybody does and debrief, but you can’t control who shares your debriefing...There will be occasions when too much of that pain has been shared, and that mars the reputation of the organisation.” (Beverley - health provider)

Support was identified as including access to an inclusion professional support program that worked alongside Aboriginal educators for a few days a week to support them in early childhood education settings, linking Aboriginal providers with other Aboriginal providers working in the same field to act as mentors, and culturally competent non-Aboriginal managers to build cultural safety in workplaces.

“I’ve just, let them know there is a support group, like if there’s a meeting that they can attend to give that support because they may be the only Aboriginal educator in that service, and have a lot of expectations on them to share their culture.” (May - education provider)

An additional identified element to support was that organisations should support pathways through tertiary qualifications into the workforce for Aboriginal providers.

“I think what we need is a willingness for services to support pathways into mainstream qualifications, and that’s improving over time as we’re getting scholarships through universities and so on, but we’re really only just reaching the first generation of Aboriginal kids that are going through to year 12, there’s a raft of families that you know might be the first time that they’ve had somebody go through year 12, let alone go through [Technical and Further Education] or uni. As an organisation, we need to be prepared to look at the long distance pathways.” (Beverley - health provider)

For Beverley (health provider), addressing misperceptions non-Aboriginal providers may have about targeted positions for Aboriginal providers was important in ensuring that Aboriginal providers feel supported.

“There’s a perception as well that Aboriginal people are being given positions without having the capacity, the skill, the competence, whatever, to deliver it in preference of someone who might have that, and so we’re certainly seeing that there’s a lack of awareness within the organisation generally about what it is about identified positions, about targeted positions.” (Beverley - health provider)

7.2.2.2 Interpersonal factors

Interpersonal factors influenced the ability of providers to build effective personal and professional relationships that enabled a sense of belonging for providers working in this context. In exploring their experiences of interprofessional collaborative practice, providers described interpersonal elements as either having impeded or enabled collaboration. These impeding and enabling elements are explored in further detail below.

Impeding elements

Working in silos and coming in as an expert were perceived as having impeded collaboration. Providers who were only interested in working within their professional silos were identified as impeding the ability of providers to work together. Working in silos was perceived as a key impediment to the integration of service provision.

“I think one thing we did find, and I don’t think is unique to Western Sydney, is that service providers work in silos...so we found with some service providers it was great, we could get in and go, okay, let’s see what we can do to help this family, some service providers wouldn’t talk to us at all.” (Madeline - health provider)

Tracy (social service provider) described an experience she had in trying to work with a mainstream school whose teacher in charge of student support believed that providing support for children with a disability was not the role of the education sector.

“Each time I go in thinking this time will be better and it never is because the head teacher...has such antiquated ideas about people with intellectual disability and about her role in trying to address some of the needs for those children.” (Tracy - social service provider)

Coming in as an expert when entering different settings could also impede the ability of providers to work together. This was perceived to be particularly relevant for providers entering early childhood education settings and schools. Some providers identified that coming in as an expert could cause providers in these settings to become defensive.

“Any centre and any school, is very quickly, in defence mode if you come in as the expert and go right, what we’re going to do is get you visuals and da, da, da and you’re not doing this properly and you really should be doing this but you know, they’re obviously going to be very defensive about look, we don’t want that expert here, we don’t want that consultant here because it’s too aggressive.” (Colleen - education provider)

Enabling elements

Providers identified four elements that enabled collaboration. These were perseverance, flexibility, being proactive, and building relationships.

A key enabler of working together with other providers was identified as perseverance in investing the required time to establish trust and rapport. Committing

to maintaining a presence in a service setting or with other providers was perceived as important to achieving positive outcomes from working together.

“So we were able to build what ended up being a good program but my goodness it was really difficult work and really hard to crack and I think what we’ve learnt is that these relationships that you build are long term...You have to be in there for the long haul to make it work.” (Mary - education provider)

Brenda (education provider) identified that being in a long-term position enabled sustainability in a fluid service landscape. Having been in the same role for over a decade was perceived as an advantage to other providers accessing her service. Brenda (education provider) described this as particularly important in light of the high staff turnover in early childhood education settings.

“I think stability is the key, as far as this job goes, having the same person here, and having that negotiation with [non-government early intervention and early education services] with all of those services....there’s such a change over in staff, particularly now it’s really difficult to keep up with...I know [non-government early intervention service] has just had a whole lot of new people, so when I’m negotiating with those people on the phone they’re not quite sure of what they should be asking or how they need to negotiate for that particular family. So it’s filling those gaps sometimes as well, without making them feel uncomfortable.” (Brenda - education provider)

Providers who were flexible and approachable were also perceived to enable the ability to work together. Flexibility was identified as especially required around organising meetings with other providers. Recognition that outcomes and how the meeting plays out may change from initial expectations was perceived as important.

“You really can’t assume that a meeting is going to work the way you think it’s going to work, you just go in with certain goals for the meeting, but they may look so different at the end [laugh].” (May - education provider)

Being approachable and acknowledging that all providers brought something to the table in terms of expertise was also identified as enabling. This was perceived as

important to providers learning from one another rather than individual providers thinking that they had all the answers.

“You need to be approachable and you need to acknowledge that everyone’s got something to bring to the situation, that no one knows everything...to respect that other people have got knowledge in a different way to you.”
(Madeline - health provider)

Being approachable was also perceived to involve reaching out to other providers. Some providers identified the value of receiving a report back from providers that they had referred a child to *“keep them in the loop”*. Taking the time to confirm the involvement of other services in families’ care rather than just assuming involvement was also perceived as important.

“I think it’s just courtesy. So if someone’s referred somebody to you, you know, it’s courtesy to write back to them and say, you know, this is what we’ve found and this is what’s happening.” (Martin - health provider)

Providers who were proactive in collaborating with other providers were identified as enabling working together. Early childhood education providers in particular, who were educated about disabilities and proactive in seeking collaboration with providers from different sectors, were perceived to enable other providers to work effectively with them. These providers were identified as extremely helpful by other providers as they understood the importance of supporting children and were proactive in providing information and asking for assistance where needed.

“They will quite often come up and ask me questions as well and say, we’ve got this going on can you help us with this, or can I have a copy of that game, and I’m always happy to share, and that’s good to see, the centres that are proactive.” (Lydia - education provider)

Being able to build relationships was perceived as key to effectively working together with other providers. Dana (education provider) identified that building relationships with early childhood educators had assisted in the development of trust. In one instance, attempting to access support and diagnosis for a child in OOHC was enabled by having developed trust with the childcare centre director which she

believed made the director more comfortable in disclosing relevant information about the child. Elements that were perceived to enable the building of relationships included being helpful, providing positive encouragement, taking the time to be available, and networking gently.

“Sometimes just sitting down one-to-one, and I always make sure that I give them some positives when I start. I say, ‘Look, I really like how you did this and this, but I noticed that he was struggling with this or this. How about next time we try blah, blah, blah, blah, blah?’, and I’ll try and finish off with a positive, because I just feel that often centre staff are quite either undertrained or, quite overwhelmed.” (Amanda - education provider)

Colleen (education provider) identified that the willingness of providers to step outside their traditional role boundaries to build relationships was important. Colleen described this as being willing to help set up equipment and cleaning up at the early childhood education settings she attended. It also involved demonstrating to providers in these settings that she was not only interested in helping her “target child” but was also willing to work with other children who she identified as potentially having issues.

“I think just, getting in and showing that you’re an astute sort of worker and you’re on site and you’re there for the kids and you know, if my target child is working on activities without any problem, I’ll move over and work with another child that I can identify has a weakness of some sort...So I’m not just going to hover over my target child and go, [child] needs special equipment or [child] needs this, you need to do this for [child].” (Colleen - education provider)

Building relationships between providers was identified as a process that took time and long-term investment. Organisations that allowed their providers to invest the required time were perceived as important to building good relationships.

7.2.2.3 Workforce factors

Workforce factors related to high workload and staff turnover across the early intervention service system were identified as impeding the ability of providers to collaborate. Providers across the health, education and social sectors described high

workloads as having impeded the amount of time they could dedicate to working with other providers.

“I think the first barrier is just time. Because obviously the teachers are busy, 9.00 to 3.00 every day, and probably before and after that time as well, by the time the child comes in to see me at 4.00...the teacher is no longer there or contactable.” (Sally - health provider)

Workload burden was identified by a number of providers as impeding the time they were able to spend communicating with other providers. They also perceived workload burden to be a key factor in why other providers may not have shared information with them.

“It might be a time factor as well, you know, the amount of students that they have on their caseload, and you know, the amount of work and hours that they're doing, also I think there can be too many people who are working with the child, and when you've got five or six different people asking you for this, this and this, and that's just for one child alone, sometimes it can be the first thing that gets left off, because it's quite daunting and overwhelming [for the provider].” (Lydia - education provider)

High staff turnover was identified as impeding communication and was perceived as particularly prevalent in the early childhood education sector. High staff turnover was identified as having led to inconsistencies in what information was passed on from providers exiting a role to new providers.

“I think staff turnover, because when you go for meetings and there's constantly new people, there is those gaps, because information has not been passed on and you feel you're just repeating yourself and really there are no outcomes.” (Danielle - social service provider)

7.3 Organisational (exo) Factors

7.3.1 Governance – “There needs to be better connections”

Governance at the organisational level played a key role in the form of leadership related to interprofessional collaborative practice. Governance was

perceived to have influenced two key areas, that 1) lack of coordinated governance across the service landscape was a key influence on interactions at the meso level, and the 2) importance of governance to unlocking the strength of schools as settings for early intervention. These two factors are explored in further detail below.

7.3.1.1 Lack of coordinated governance across the service landscape

Lack of coordinated governance across the service landscape was identified as having a key influence on interactions between providers at the meso level. Improved coordination between providers and services was described as “critical” but difficult to achieve. The lack of a common link between services and someone who was responsible for bringing providers together to work in a more streamlined way was perceived as a key impediment to improved coordination. Belinda (health provider) identified that lack of coordination led to an individual case-by-case approach to care that could make it difficult for providers to keep re-establishing links with other providers.

“My experience to date, would be that it becomes about an individual case, and then each time, you’re looking at who do we get from education for example, to discuss this particular patient. Who do we get from whatever other sector? Rather than, we know we’ve got this situation, we need to call in this person from this sector, this person, this sector. There’s no automated process, if you like. It becomes very individualised. And then each time you have another patient, you’re starting from scratch again.” (Belinda - health provider)

Some providers also perceived that disconnect between the health and education sectors in particular contributed to the complex service landscape. This disconnect was identified as having impeded providers from both these sectors to work effectively together.

“Overall, I think there needs to be better connections between health and education...I think that there’s a big disconnect there between health and education and always has been.” (Brenda - education provider)

For example, Sally (health provider) identified that the lack of connection between herself and schools impeded effective communication. The disconnect with education

providers meant that she often relied on second hand accounts from carers about what their opinions were on a child's progress.

"We also don't coordinate well with, say, the schools, it would be really nice when I do see a patient and I'm diagnosing them with say a learning delay or something like that to know what the school thinks, and it's always just hearsay from the parents – 'oh, the teacher said this two years ago, and then I thought I'd leave it and take them to a speech pathologist', and you just don't know what's happened in that time." (Sally - health provider)

Role of governance in training providers to collaborate

In the context of what was perceived as the impact of lack of coordinated governance, a number of providers identified a need for governance to play an increased role in training providers on how to collaborate. Some providers perceived that lack of training impeded the ability of providers to work effectively together. Belinda (health provider) identified that due to her professional focus on in-patient clinical care; her understanding of what other services offer was "very poor".

"And I know certainly for myself...because I'm in inpatient clinical care area, my understanding then of what can be offered from other sectors and how they can get it is very poor. So it can be hard to even find who knows what they have to even think about offering. I'm sure very often, there's fabulous resources or services available that we don't even know to look for or to recommend." (Belinda - health provider)

Training was identified as important for organisations to implement. Some providers perceived that cross-sector training had enabled providers to work together effectively.

"So I guess a lot of our time is training my staff on how to be collaborative with the school because you don't want to go in and tell the school how to do their job because they're the educators and they're spending most of the time with the kids." (Shelley - health provider)

Madeline (health provider) identified that her organisation had provided training to schoolteachers on how to best support children as part of its school readiness program.

Feedback from the teachers was that they passed the information onto other teachers within the school.

“If the teachers have the time to come to the training it was great, we didn’t just say Kindergarten, [year] one and [year] two could come - it was anyone in the school, and when we interviewed the teachers at the end they were saying they were passing on information to other teachers as well.” (Madeline - health provider)

Lack of an organisation wide culture informed on how to work effectively with other providers was perceived to be influenced by high staff turnover and inadequate systems for sharing information.

In the face of fluid funding and service landscapes, ensuring the sustainability of programs producing positive outcomes once a service withdrew from a setting was important for providers. A perceived solution to ensuring sustainability was for organisations to build the capacity of providers in those settings (e.g. playgroups, childcare centres, schools ect.) through training, so those providers were able to continue to carryon programs.

“The teachers don’t get that training, so we gave the teachers the training, we gave them the handouts for the handwriting group, we wrote the manual, we left it, you know, we bought everything they needed for that. I mean, they would have to replenish it, but we bought it all so this is a whole package, this is what you need to do, and we trained the staff on how to do that.” (Madeline - health provider)

Upskilling Aboriginal providers through training was identified as particularly important. For Mary (education provider), working with Aboriginal early childhood education providers to be able to identify issues and accessing support options without having to worry about eligibility criteria was an important step towards reaching more Aboriginal children and their families.

“It’s about having expertise present. It’s about having good expertise in those early childhood services and then it just kind of can happen very gently and it doesn’t have to be compartmentalised into a problem diagnosed ticker box here,

like if we could really just get our act together and get early educators and early intervention people a bit more skilled, that's really what it's about." (Mary - education provider)

7.3.1.2 Unlocking the strength of schools as settings for early intervention

Providers identified that in comparison to other areas, schools in Western Sydney were particularly open to working with other providers and services, highlighting the potential strength of schools as settings for early intervention. Governance was perceived to play a central role in unlocking the strength of schools as service settings in the form of the importance of buy-in from schools.

Working with schools as service settings for early intervention was a key area of interest for providers. Particular strengths of this approach included the richer information generated through conducting assessments within schools, and that for many children schools are a stable part of life. Some providers identified that providing services and support through schools as service settings enabled service provision in the context of the involvement of multiple services as schools were a stable venue. Some counter-strengths of schools as service settings for early intervention were also identified. These included variable experiences of collaborating with schools, some were described as *"fantastic"* others as *"abominable"*, and in cases of children who changed schools. Madeline (health provider) identified that in the school readiness program she was involved with, one of the difficulties was ensuring continuity of care for children who moved from school to school.

"That's one thing we found, that just because a child started in a school didn't mean that they stayed there; they might move from school to school, and we tried as best we could to follow them so there were some children who, when they moved from one school to another, the early educator for the first week was in the classroom every day to help support them because they knew her and they felt comfortable with her, so if we could, when the child transitioned to another school we went with them as well too." (Madeline - health provider)

In comparison to other areas of Sydney, providers identified that a key strength of Western Sydney was that the majority of schools were welcoming and accommodating

of children with disabilities and collaborating with external providers. Other areas of Sydney were perceived as not as accommodating of children with different needs. Colleen (education provider) perceived that schools in Western Sydney were different as they were more used to seeing children with a range of different issues. As such, she found that their level of acceptance was greater than other areas.

"I find in the West, the schools very welcoming actually because, they're very used to having children from all sorts of type of backgrounds and all sorts of issues...if you say, 'Look I'm a special educator that's worked with [child] in this setting, can I help to orientate him to this setting?', they're usually like, 'Yeah, come on in'...you know, they would not blink. They're very good at inclusion."
(Colleen - education provider)

Governance was perceived to play a central role to working with schools as service settings in the form of the importance of buy-in from schools. A key element, which impeded collaboration with some schools, was identified as school principals that were unwilling to collaborate. Some providers identified that the decentralised structure of the Department of Education meant that principals were able to make decisions in the day to day running of schools. Due to this, it was observed that if a principal was unwilling to allow external providers to collaborate with their school those providers were unable to work in that setting. Some schools were identified as more receptive to collaborating with external providers than others. Some providers identified that implementing collaborative programs within school settings was impeded if the principal was not willing to collaborate.

"...how well informed [principals] are and how they can see a program being of benefit to the students and if they're prepared to put themselves out or the staff to put themselves out." (Tracy - social service provider)

Conversely, buy-in from education providers, including principals, was identified as a key enabler to collaborating with schools as service settings for early intervention. Buy-in of education providers in relation to support for collaborative programs run within schools was identified as important for the effectiveness of programs.

“What works well with the schools...if they've got an issue with children and they want us, we'll ask them to do an assessment within the school but actually get buy-in from the school counsellor to go in and do the assessment...and we then talk to the teacher or the school with the parents' permission just to find out what's happening in the school and what they find has been helpful or hasn't been helpful.” (Shelley - health provider)

Supporting buy-in were principals who were willing for their staff to work outside their traditional roles, and schools with good communication systems from the macro to meso levels. It was identified that good communication systems ensured that the whole school was aware of programs taking place and that there was support from the principal.

“If the communication within the school wasn't strong then it was difficult. If there was good communication through the principal down to everybody else, they knew when we were coming and what was going on.” (Madeline - health provider)

It was also identified as important for providers to go into schools as equal partners with education providers within those settings. This was in contrast to telling education providers what to do.

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

Interprofessional communication was considered by the majority of providers to play a key role in interprofessional collaborative practice. The formalisation of processes at the organisational level was identified as essential to effective interprofessional communication. Case conferences, in particular, were perceived as an effective model of formalised communication through which providers and carers managed the task complexity of collaboration across sectors in providing care for Aboriginal children with a disability.

7.3.2.1 Interprofessional communication

In general, providers perceived a lack of effective communication and information sharing between providers, and across sectors. Only one provider

specifically identified that they had no issues in relation to sharing information. This might have been influenced by the provider being part of a multidisciplinary assessment team in comparison to other providers working in more isolated contexts. Lack of formalised communication and information sharing processes made it difficult for many providers to effectively support children and their families, and was identified as a potential cause behind why some children fall through the assessment and treatment gap. It was identified as having impeded the ability of providers making referrals to relevant services and their ability to follow-up. Danielle (social service provider) perceived that this was particularly relevant for children with mild disabilities who may not have received a diagnosis due to their condition being not as easy to diagnose unlike more severe conditions. Lack of early intervention in these cases was perceived as potentially leading to adverse outcomes later in childhood and across the lifespan.

“Because sometimes we felt that a lot of kids, particularly like I said with mild intellectual disability, would fall through the cracks, because their GP would fail to make the referral or advise to make a referral to [government department], and they would end up going to normal schools, and then you’d see the child struggling and it would be too late. So it would’ve helped if that referral would come earlier...and then there’s no follow-up, and then after years there’s so much damage that it’s hard to repair.” (Danielle - social service provider)

A lack of sharing information on available services and how to connect with other providers and best utilise each other’s support was identified as leading to the unnecessary duplication of services. It was also perceived by some providers as having made it difficult for providers whose professional networks were outside of the Western Sydney area to support families.

“What wasn’t done well there was, there wasn’t somebody overseeing the whole thing...when I’d chat with a family that I felt like they’ve come to the point where they’re really seeing that there’s certain things happening, there wasn’t anyone to come in and go...this is what’s available in your area. I didn’t know so I couldn’t go I know a great [paediatrician] let’s just go and just rule some things out...I didn’t have resources.” (Colleen - education provider)

Providers identified that, when done effectively, communication between providers could improve outcomes for children and their families. Sharing information across sectors was perceived to have facilitated disparate pieces of information to mutually inform each other, leading to the ability to effectively shape service provision to meet the individual needs of families.

"The better you communicate at all levels and all providers whether it be education or health, you know, I think again, the better the outcomes." (Martin - health provider)

Many providers identified implementing streamlined processes to share information as important in laying the foundation for interprofessional communication. Potential streamlined processes that were identified included putting a standard process in place across all sectors to identify conditions and needs and how to connect with relevant services, as well as a common system for sharing general information from areas such as housing, child services, health and education.

"I think firstly...there has to be some process for identification, particularly when they're accessing, maybe health or whatever, education, just so that, the person supporting them has got a better understanding of how they need to be supported. So there has to be some system." (Danielle - social service provider)

Establishing formal pathways for collaboration was also identified as key to ensuring that policy is carried out in practice. It was identified that although providers and their services may have good intentions to collaborate, formal pathways needed to be developed to carry them out.

"I think we have to be actively looking for areas to collaborate. And know what to do when we find them. I think sometimes there's all of these helpful desires but we haven't figured out the practice element. And so we have to figure out the path that enhances that practice." (Beverley - health provider)

A key element of this was perceived to be establishing processes for building partnerships. These processes would ask questions around expectations for a partnership, conflicts of interest, and legal requirements.

Impeding elements

Providers identified three elements related to formalisation at the organisational level that impeded effective interprofessional communication. These were a disconnect between processes and perspectives related to disability across disciplines and sectors, disjointed methods for communication, and the lack of effective systems for sharing reports and information.

A disconnect between processes and perspectives related to disability across disciplines and sectors was perceived as an impediment to effective communication. Providers identified instances where there was disconnect between what the Department of Education perceived were the educational needs of children, and the assessment by health providers. Some providers observed that reports from health providers containing recommendations for a child's education needs could lead to disappointment for families when they provided it to a school and found out that their child was in fact not eligible for specific funding and support.

"I think often that puts the family on a path of, you know, they're quite disappointed when they do head on down to the local school and start talking about the level of need their child has, and then find out that there's not going to be much in the way of additional support, because that child is not eligible for funding support. Whereas on the recommendations from the paediatrician or the psychologist, it will often say that this child needs substantial assistance in a classroom...And the lack of understanding, I think, as well, between health and education, about what sort of funding is available and what sort of diagnosis we need to be able to apply for additional funding for particular children...there's always been that disconnect." (Brenda - education provider)

Disconnect between processes and perspectives was also evident in the way different providers wrote up profiles on the same individual. Danielle (social service provider) identified that often when she gathered reports from different providers on a client they read as though they were reporting on different individuals which made it difficult to interpret information.

“There should be one system that can be used, and which we can share the same information or access the same information. Because we all do client profiles, but we all do it differently. So somehow, I don’t know, when we put those profiles together, they look like different people it’s not even the same person. So there needs to be something more standard.” (Danielle - social service provider)

Providers identified that the system for methods of communication between providers was sometimes disjointed. There was a perceived lack of formally established communication channels between the health and education sectors. This led to health providers sometimes hearing unclear second hand accounts from carers as to what teachers had noticed about their child.

“A lot of the time it was just the teacher at the end of the day saying to the parent I just noticed that, your son is doing this, maybe see the doctor. And then it gets to me and I don’t actually understand what they’re concerned about.” (Sally - health provider)

Comparisons were made by some providers between efficient internal hospital referrals, and “messier” referrals to external services. It was perceived to suggest that the more internally streamlined a referral system was, the easier it was for providers to communicate. Referral systems that relied on cross-sector referrals could make it more difficult for providers to communicate. As a provider in the community, Martin (health provider) described frustration with the established method of communication to refer patients to a tertiary hospital. Referrals were done through fax without any direct voice contact with hospital providers. As the referring provider, Martin (health provider) did not receive any direct communication.

“So to get them into the [clinic], the way that works is that we fax off a referral letter. So we don’t have any voice contact with them at all. You fax off a letter. It goes into the ether and you hope for the best and sometime in the next 12 months that patient is then contacted directly by [hospital].” (Martin - health provider)

Other disjointed methods of communication included primarily corresponding through letters which providers may not receive in a timely manner, and playing “phone tag”.

“The only way we communicate is with letters between each other that may or may not get where they need to be getting in a timely manner, and it’s really hard to sort of pick up a phone and talk to someone when the patient’s in front of you. It’s a bit more – sort of so I’ll call you back and you play phone tags for a couple of days until you eventually actually talk to them and can’t remember why you wanted to talk to them in the first place, and it’s very disjointed.”
(Sally - health provider)

Shelley (health provider) identified that the disjointed referral system between assessment and intervention services could lead to relevant information getting lost in translation.

“The other issue is, of course, that because we don't give the interventions from here you spend a lot of time developing a fantastic rapport with the family, it's a lot of trust and rapport with the family. But then you have to hand them over to someone else to do the intervention. And I find that's really not a good system actually because, I think a lot of it is lost in translation.” (Shelley - health provider)

Providers identified three issues related to systems of sharing reports and information that impeded effective communication. Confidentiality was an issue for many providers. It was perceived by some providers that only necessary information should be shared and that processes around confidentiality should be respected. Brenda (education provider) described receiving confidential reports about families from health providers because they knew she would pick the case up and contact the family. She felt that she was the inappropriate contact in these cases and that they should have been sent to the local school counsellor first.

“[Confidentiality] doesn’t seem to be a huge issue with some agencies, I suppose...often, you know, a psychologist or a paediatrician will send me through a report and I know nothing about the family, and that’s not appropriate. But they know that if they’re sending it to me then I’ll pick it up

and contact the family...those sorts of things should really go to the school counsellor at the local school, rather than me. I'm not a psychologist." (Brenda - education provider)

Issues around confidentiality were also identified as playing a role in providers, either not being willing or constrained by rules, sharing information. Some providers described the willingness of other providers to share reports and information as variable. While they experienced that some providers were happy to share information related to their involvement with a child, others were not willing.

"It's one of those things, speechies [speech and language pathologists] and other [occupational therapists] can say, 'send me an email', and they quite quickly do saying this is what we're working on and these are the goals that we have in the sessions that we're doing, but I think sometimes there also is a little bit of holding back on the strategies or the resources that they use...Sometimes I'll have to speak to the parents and they're like, 'Oh, we're doing this strategy', or, 'Our speechies have given us this resource to use', and unfortunately I have to rely on the parents to hand that to me so I can use it with their child as well across the settings." (Lydia - education provider)

The lack of a system for providers to easily access information across different sectors also impeded communication. It was perceived to impede the ability of providers to improve their knowledge of, and ability to access, relevant information outside of their own sector.

"I think some part of the information should be easily accessible, and something like, a person is on the housing register we don't know that you know, so how am I supposed to follow-up with Housing, when I don't have that information? So certain, basic information like schooling, housing, health, whatever medical appointments et cetera should be shared; that information should be transparent." (Danielle - social service provider)

Providers identified that in the past the requirement for providers to obtain the permission of the family to share reports with other providers also impeded communication. Miscommunication was caused in one instance by health providers

thinking that their reports were being shared with education providers, whereas the reports were being held by the Department of Education due to a lack of permission to share.

“I know in the past that places like [Department of Health assessment team] would speak to families about getting permission to hand reports over to a particular person with Department of Education, and that was one of our senior District Guidance Officers. But they were being held [at the Department of Education] and they weren’t filtering through...so the understanding from the health professional is, all of those assessments are coming through, but they weren’t actually filtering through.” (Brenda - education provider)

The need for consent was perceived to have made some communication between providers dependent on the willingness of carers to provide consent, which could be difficult. Dana (education provider) described an instance where she was attempting to arrange support services for a child in foster care and faced a complex system for sharing information between herself and other providers exacerbated by difficulties obtaining consent from the foster carer. It took months to obtain consent to share information which delayed early intervention for the child who ended up diagnosed with autism.

“They had some Aboriginal children at the centre and they had concerns with these children with their differing abilities and the high level of support that these children required with behaviour, but their behaviour was a consequence of other conditions as well. And one of these children was living in a foster care arrangement, and the foster carer was from a linguistically diverse background, not Aboriginal. And the service found it extremely difficult to work collaboratively with this foster parent. They didn’t find her very cooperative, even to sign a permission for me to go and support them with this child and access support and all that, it took a long time to try to access this person’s cooperation to start doing something about it.” (Dana - education provider)

Other providers identified difficulty obtaining consent to share information from carers due to their lack of understanding as to the importance of consent.

Enabling elements

Providers identified two factors related to formalisation that enabled effective communication. These were the implementation of legislation to navigate issues around consent to share information, and formal and informal networking groups. The introduction of the Chapter 16A legislation, a law that allows government and non-government organisations to share information if it relates to a child's health, welfare or wellbeing without contacting Community Services or gaining consent from a legal guardian, was identified as enabling some providers to share certain information more easily within and across sectors.

"As soon as they brought in the 16A legislation where we could exchange information if it's for a child's health and safety. That was the first step to freeing up that information exchange...There would be certain things [child services] can't tell us of course if it's going to court for instance, and they can't share that specifics of the court matter before it's actually been to court. So they'll have some legal constraints about what they can share but the other like general information they'll share with us." (Tracy - social service provider)

Formal and informal networking groups were also identified as a key factor enabling effective communication. Networking groups took the form of both internal groups within organisations, such as internal hospital networking meetings, as well as external cross sector groups with representatives from government social service and disability agencies, multi-cultural community groups, and health services. These groups were identified as important in creating a space within which providers were able to discuss issues they were facing and how they could more effectively use each other's supports.

"There's a lot of networking groups you know, and I think those - that's a good way to really share information, and discuss what barriers each provider is facing or each sector is facing." (Danielle - social service provider)

Colleen (education provider) described the benefits of a regional early childhood intervention networking group she had been involved with in another area of Sydney. She identified that having a similar group for the Western Sydney area would be a

good way to raise awareness of the different services involved in early intervention, map out any overlaps, and plan who is responsible for what.

“We regionally have these [early childhood intervention meetings], that’s sort of what’s needed there, like we have a sort of regional gathering of all agencies concerned with early intervention, and if we had one in that area, if they sat us down in one of these halls to look at, like these are our local speechies, you know, who are the wandering salesmen that are servicing this area...’Right, have you got transition to school covered?’, ‘Great, well I won’t do it, you do it’.”
(Colleen - education provider)

7.3.2.2 Case conferences as an effective model of formalised communication

Many providers perceived case conferences as an effective model of formalised communication. Through case conferences providers and carers were perceived to manage the task complexity of collaboration between providers across sectors in providing care for Aboriginal children with a disability. One of the key reported benefits of the model was that it addressed miscommunication between providers and the lack of coordination that could result from miscommunication. The model was identified as allowing providers time to meet face-to-face and trouble shoot issues immediately.

“Well, it allows for all providers to sit down on the table together, and discuss the issues that they see arising in the immediate situation. It often means that, you know, we hear each other’s thoughts out loud rather than just, hearing them on paper or seeing them on paper.” (Simon - health provider)

As the family was also involved in case conferences, the model was perceived to enable them to help correct or clarify issues so that all the providers were on the same page in terms of supporting the child and family. This was identified in comparison with other methods of communication, such as letters or individual telephone conversations, which could produce miscommunication.

“The idea of that is to bring all of the different parties that might be involved in that child’s care, into the room at one time. Just so that everyone’s hearing the same message and you know, linking up so that what one specialist is saying

doesn't conflict with what someone else is saying and so forth...It also heavily stops parents from getting mixed or conflicting messages from different parties, because you've got them all sitting in the one room at the one time." (Belinda - health provider)

Some providers perceived that having the family involved also enabled them to see collaboration between providers and that things were happening even if it took a while. The model was also perceived to empower families to ask questions of providers and receive answers in a timely manner.

"Even if there wasn't a huge amount of progress, at least the family could see that people were actually trying to work towards that." (Madeline - health provider)

The model was also identified as helping to avoid role duplication as all providers involved were made aware of who is responsible for what.

"I think the key strength is that each discipline is able to hear what the other is thinking and being able to say, 'Mmm, that's then going to conflict with what I was planning for the child', or, 'Yes, let's both do that together', or whatever it might be. So there's a lot of collaboration, so that you're not doubling up or wasting time and you know, redoing things in different ways." (Belinda - health provider)

An important element to successful case conferences were all relevant providers involved having the same objectives and putting in place a single action plan for how to achieve them.

"One family we had [social services department] there, we had our service there...the child and family centre were there, the [Aboriginal health service] were there, and there was a couple of other people – there were, like, seven different services...even if they couldn't come, people would ring up and say, 'This is my report', which was great because then everyone knew what people were doing and we had an action plan and said, 'Okay, you're going to', and 'you had to report on your action when you got back'. Even the families would too." (Madeline - health provider)

Some providers reported that although the model was useful in enabling effective communication, a key difficulty was scheduling a suitable time for all providers to attend.

7.4 Systemic (macro) Factors

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

The processes of interprofessional collaborative practice at the meso and exo levels were managed within the systemic factors of policy and funding at the macro level. Policy and funding factors at the macro level were identified as key influences of collaboration. The influence of these two factors is explored in further detail below.

7.4.1.1 Policy directives

Providers across all sectors identified two specific policy directives that influenced working together with other providers. These were directives to target Aboriginal children with a disability, and the National Disability Insurance Scheme. Policy directives to target Aboriginal children with a disability were perceived to have led to increased competition between services for Aboriginal clients. Some providers perceived the increased competition as driven by self-interest instead of a desire to help the community. For Colleen (education provider), this was evident in the case of a child who had what she termed a “soft” disability. She perceived that other services were not interested in supporting the child as they were focused on severe and easily diagnosed disabilities for which it was easier to access funding.

“Because [child] is, you know, really falls in, you know, in attention and behaviour, ah, and a little bit of the learning delay, he hasn’t attracted, you know, 300, sort of, support services.” (Colleen - education provider)

A positive outcome of these types of funding directives was that it was identified as enabling some providers and their services to actively engage with families, which they would not have normally attempted due to lack of funding and difficulties attempting to access the community. This was perceived to have subsequently increased their level of working with other providers in the area.

“It also enabled us to work in an area that we probably would not have gone into if we hadn’t have been forced to do it because as I said, the funding wasn’t there for us to do it and it was just very difficult.” (Chamaine - education provider)

Lack of additional funding and support attached to these policy directives was a key issue for some providers. This was perceived as particularly significant for NGOs who had to find other avenues of funding, such as benefactors, to carry out the directive. Some providers also expressed frustration at the lack of support around how to best access the community.

“Also given how angered I was by the policy that was simply slapped onto us in a very tokenistic way by government with no support, not just monetary support, no guidance in terms of accessing what are very difficult communities of people to crack.” (Mary - education provider)

Providers also perceived that the rollout of the National Disability Insurance Scheme might impact their ability to work together with other providers. The loss of contacts within the system due to service changes was identified as a key issue.

“You know, with the [National Disability Insurance Scheme] coming in, instead of handing over to one organisation or whatever, you don’t know who you’re going be handing over to or the NGOs that are out there. We’ll have to wait and see but I think the [National Disability Insurance Scheme] will bring its own challenges.” (Shelley - health provider)

Providers also identified that the competitive funding structure of the National Disability Insurance Scheme could potentially negatively impact services working together. Increased competition was perceived by some providers as potentially leading some services to become less open to working with one another. It was suggested that some larger services may also “muscle out” smaller services in order to increase their funds despite the fact that they may not have the same level of expertise in particular areas.

“That could be a bigger concern with [National Disability Insurance Scheme] coming in – now we get block funding and it’s three months before and so you

know you've got the money to provide the service, but if in the future the user pays, it is going to swap it around a bit. I don't know...whether organisations are going to be as open with each other." (Madeline - education provider)

Tracy (social service provider) identified that for providers employed by the government, there was a wariness of moving into the NGO sector in light of the government withdrawing from service provision. She observed that some government providers preferred working within the public sector. This was perceived as potentially leading to the loss of these providers and their valuable experience from service provision altogether.

"Most of us have had sort of enough experience with some of the non-govs to not want to work for them. There's so much political stuff that goes on in non-government agencies, that our staff who value having that reassurance that they're working for a public institution they don't want to go out into that sector and try and work as well as try and manage the political side of things." (Tracy - social service provider)

7.4.1.2 Funding

Providers identified that variable and inconsistent funding impeded the ability of providers to work together. Government funding perceived as not well planned was perceived as having impeded the ability of services to plan for the future. Funding structures aimed at increasing competition for the same pool of funding was also identified as impeding providers working together due to competition motivated by self-interest. It was perceived to impact working together at the meso level by providing an incentive for services not to refer to other services to protect caseload targets.

"Collaboration's dead in the water...Collaboration doesn't exist now because of that absolute viscous seeking of dollars and so many services irresponsibly applying for a grant, getting the bucks because they're a big organisation with a big capital base and then trying to work out how to do it." (Mary - education provider)

Charmaine (education provider) identified that rather than the government solely providing a pool of funding and expecting services to work together at the meso level, a policy directive to force services to work together should be built into funding requirements so that the impetus for working together comes from the macro level.

“Services are not going to collaborate where there is money involved, where there is funding for providing a service... It needs to come from above.”

(Charmaine - education provider)

Providers also identified that funding requirements needed to be flexible in recognising that working with Aboriginal providers and services within the community takes time. This was perceived as particularly relevant for services that were new to an area.

“We’ve had programs over here where you get funding and by the way, you’ve got to start next week, and that does not work in those communities, especially if you’re new. Like, if you’re known in that community and you get extra funding people are really like, ‘Yay, great, come on, let’s see what we can do’, but if you’re new you can’t just run in and go, ‘By the way, we’re starting next week’.” (Madeline - health provider)

Some providers felt that government at the macro level needed to play a more central role in enabling providers to work effectively together. It was suggested that for working relationships between non-Aboriginal and Aboriginal providers it would be helpful for the government to provide non-Aboriginal providers with information on lessons learned in how to work most effectively. This was perceived to help non-Aboriginal providers save time by being able to avoid going down the wrong track.

“The government has so much data and they’ve learnt so many hard lessons...why can they not draw on the lessons learned, and then impart that information to us, you know, what we know doesn’t work is A, B and C, so don’t waste your time and our money doing that.” (Mary - education provider)

Providers also identified that the government should be actively assisting providers at the level of service provision to work together. It was not enough for some providers for the need for providers and services to work together in service provision to

Aboriginal children with a disability to only be in policy. One suggestion to implement this was for a requirement for services to demonstrate how they had worked with other services as a pre-requisite for funding. It was also identified that government should also integrate strategies to promote providers working together into funding requirements.

“It should be almost before we give you this bucket of money, you have to connect with every agency...like so that’s every early intervention service in your area, we don’t hand over any money to anyone until you’ve all gotten to the room, we want three meetings, not just one token go and have a sandwich and a cup of tea where you’re all talking and you work out who overlaps.” (Colleen - education provider)

This was perceived as potentially helping to address the issues of role duplication and lack of coordination identified at the meso and exo levels of interprofessional collaborative practice.

7.5 Summary of key findings

Interactional factors

Sharing goals and visions - “All providers come in with different agendas”

- Differing agendas between providers was perceived to lead to conflicting approaches to assessment and management and a waste of resources.
- Providers working in formal and informal linking roles helped other providers navigate the complex service landscape and facilitated the sharing of goals and visions.

Sense of belonging - “A good relationship makes things easier”

- Previous relationships from involvement in past programs, relationships with key Aboriginal contacts as cultural mentors, and working indirectly through existing services enabled providers to work effectively with Aboriginal providers and services.
- Working in silos and coming in as an expert impeded collaboration. Perseverance, flexibility, being proactive, and building relationships were enabling elements.

- High workload and staff turnover across the early intervention service system impeded the ability of providers to collaborate.

Organisational factors

Governance - “There needs to be better connections”

- The lack of a common link between services and someone who was responsible for bringing providers together impeded coordination.
- Governance needs to play an increased role in training providers on how to collaborate.
- Schools were identified as particularly open to collaborating, highlighting the potential strength of schools as settings for early intervention.
- Buy-in from principals was important for effectiveness. Supporting buy-in were principals willing for their staff to work outside their traditional roles, and schools with good communication systems at all levels.

Formalisation - “The better you communicate...the better the outcomes”

- Lack of effective formalised communication and information sharing processes led to unnecessary duplication of services.
- Implementation of legislation to navigate issues around consent to share information (e.g. Chapter 16A), and informal and formal networking groups enabled effective communication.
- Case conferences were a key effective model of formalised communication.

Systemic factors

Policy and funding factors - “It needs to come from above”

- The rollout of the National Disability Insurance Scheme was perceived by some providers as potentially negatively impacting their ability to work together. Loss of contacts due to service changes, and the competitive funding structure, were potential issues.
- Variable and inconsistent funding impeded the ability of providers to work together.
- Funding requirements needed to be flexible in recognising that working with Aboriginal providers and services within the community takes times.

7.6 References

1. D'amour D & Oandasan I. 2005, 'Interprofessionality as the field of interprofessional practice and interprofessional education: An emerging concept', *Journal of Interprofessional Care*, vol. 19, no. Suppl. 1, pp. 8-20.

Chapter Eight: Discussion

8.1 Introduction

The findings of this project reveal the importance of taking an ecological approach in addressing factors that enable and inhibit service delivery to Aboriginal children with a disability. Factors at the macro, exo, and meso levels interact to influence provider perceptions, understandings, and experiences in relation to direct service provision to families, and working together across the health, education, and social service sectors. The Candidacy theoretical framework addressed a variety of access and utilisation factors and identified targets for intervention within healthcare services. The Collaborative Practice to Enhance Patient Care Outcomes theoretical framework explored the determinants and processes of interprofessional collaborative practice and identified areas for intervention across the health sector as explored in Chapter Four. This chapter discusses how the qualitative study has contributed to the theoretical application of both 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 in service provision to Aboriginal children with a disability and their families. The project findings will then be discussed in relation to the relevant literature structured by considerations at macro, exo and meso levels.

8.2 Theoretical application of the Candidacy framework

In the qualitative study, exploring providers' perceptions, understandings, and experiences of providing direct services to families assisted in ascertaining the stages and ways that providers perceive Aboriginal families are most vulnerable in accessing services for their children [1]. Findings have highlighted potential areas where future interventions and research might be targeted to improve both families' access and providers' service provision. Dixon-Woods et al. [1] assert that the stage of Offers and resistance is a particularly important stage in their framework for which there has been a lack of research, and recommend further research to explore how offers and

resistance to services are experienced for different vulnerable populations [1]. The perception that many Aboriginal families did not want the help offered by non-Aboriginal providers was reported as being prominent for providers when interacting with families, supporting the importance of the stage of Offers and resistance in the Candidacy framework. Providers linked this perception to a lack of interest in obtaining a diagnosis and engaging in early prevention as part of rejecting the Western biomedical approach to service provision with a narrow focus on the need to obtain a diagnosis to gain access to services and support. It was also linked to the ongoing legacy of the Stolen Generation influencing a negative association between non-Aboriginal providers intervening in telling carers what is needed for their child and the destructive child removal policies. The influence of past negative experiences interacting with mainstream systems on the rejection of offers of services by vulnerable populations has been reported elsewhere. Past negative experiences with the enforcement of involuntary mental health care for people with intellectual disabilities has been found to impede uptake of mainstream psychological treatment [2]. Homeless people with mental health issues have also identified experiences of discrimination in past interactions with health systems influencing an unwillingness to access GPs for primary mental health care [3]. The findings from this study contribute to this under-researched but important area. Consideration of the influence of past negative experiences with mainstream systems and policies on resistance to offers of services is particularly important in improving non-Aboriginal providers' understanding of ways to work effectively with Aboriginal families.

Mackenzie et al. [4] argue that operating conditions at the macro level represent the *"least clearly articulated component"*(p. 819) in the original framework and that, for expanding the framework's application to services in sectors other than health, the influence of this aspect of the framework on candidacy at the micro level is particularly important to recognise [4]. In the context of Aboriginal childhood disability and the involvement of providers from the health, education, and social service sectors, the findings of this study demonstrate that operating conditions at the macro level may relate to the impact of the socio-political context of colonisation and the Stolen Generation, and that funding and policy directives are important to consider. Although

the findings cannot be assumed to be generalisable to other Aboriginal and Torres Strait Islander peoples, future research in this area, or other areas of service access for Aboriginal and Torres Strait Islander peoples, should recognise the important role of operating conditions.

In their refinement of the model, Mackenzie et al. [4] also present the concept of multiple candidacies whereby different identities of an individual may intersect to create multiple vulnerabilities in negotiating the stages of candidacy [4]. The influence of financial factors at the stage of Navigation of services in the findings may indicate this concept of multiple candidacies in relation to the intersection of being Aboriginal carers of a child with a disability and socio-economic disadvantage. Intersectionality refers to categories of identity which mutually construct each other to inform experiences of discrimination and oppression [5-7]. Carers have identified the concept of intersectionality in relation to their experiences of interactions with providers in seeking care for their children. Carers' interactions with some non-ACCHO providers were characterised by disempowerment caused by perceiving they were looked down on and judged, both because they were Aboriginal, and a carer of a child with a disability [Green et al. manuscript under review]. Although application of the theory of intersectionality in health is relatively new and continually emerging [8, 9], it has been employed in areas such as HIV/AIDS [10-12], disability [11, 13], reproductive health and infant mortality [14]. The increasing relevance of intersectionality in addressing health disparities is reflected in the emergence of the concept of syndemics. Singer et al. [15] define the criteria of a syndemic as when:

1) two (or more) diseases or health conditions cluster within a specific population; 2) contextual and social factors create the conditions in which two (or more) diseases or health conditions cluster; and 3) the clustering of diseases results in adverse disease interaction, either biological or social or behavioural, increasing the burden of affected populations [15](p. 942).

Both intersectionality theory and the concept of syndemics advance the argument of the need to broaden the focus in health to looking at how different identities or diseases/health conditions intersect within the wider socio-political-economic context to create health disparities. Often public health research focuses on one identity at a time when exploring health disparities [8]. Acknowledging multiple intersecting identities enables appreciation of the multidimensional complexity of health disparities

[5, 8, 9]. Hankivsky and Christoffersen [5] argue that intersectionality *“has the potential to create more accurate and inclusive knowledge of human lives and health needs which can inform the development of systematically responsive and socially just health systems and policy”* [5](pp. 279-280). The potential for application of intersectionality in addressing health disparities, particularly in relation to service access for vulnerable populations, is an important area for future research.

8.3 Theoretical application of the Collaborative Practice to Enhance Patient Care Outcomes framework

Exploring providers’ perceptions, understandings, and experiences of working together across the health, education, and social service sectors expands the original focus of the Collaborative Practice to Enhance Patient Care Outcomes framework beyond the health sector [16]. The cross-sector collaboration required to address the disparity in experiences of disability for Aboriginal children necessitates expansion of the model. Davison, Ndumbe-Eyoh and Clement [17] argue that addressing health inequities, in general, often requires multi-sectoral approaches. In their review of knowledge to action models for promoting health equity, the authors conclude that despite the recognised importance of multi-sectoral approaches, only one model was found to have fully integrated the component [17]. In the context of cross-sector interprofessional collaborative practice in Aboriginal childhood disability, the qualitative study findings highlight the particular importance of considering cultural mentorship and working with Aboriginal providers and services in the interactional dimension of Sense of belonging. At the organisational level, the qualitative study findings highlight the important role of the dimension of Governance in facilitating cross-sector interprofessional collaborative practice, particularly in delivering services within settings external to health, such as schools.

In their presentation of the original framework, D’amour and Oandasan [16] assert that there has been a lack of research on the role of the client or family in interprofessional collaboration, despite their centrality and importance to the process. The authors call for research in the area of interprofessionality to pay specific attention to this important but under researched area [16]. The qualitative study

findings progress understanding of this area in demonstrating the active role carers play in managing the task complexity of collaboration through their involvement in case conferences, an effective model of formalised communication. The findings suggest that supporting this model of care is important in further supporting the role of carers in the model of interprofessional collaborative practice.

The qualitative study findings are explored through an adaptation of the Collaborative Practice to Enhance Patient Care Outcomes framework as they were related to interprofessional collaborative practice. In D'amour and Oandasan's [16] original model, the framework is part of the larger Interprofessional Education for Collaborative Patient-centred Practice framework. The larger framework links the fields of interprofessional education and interprofessional practice. The authors conceptualise interprofessionality in this overarching framework as *"an education and practice orientation, an approach to care and education where educators and practitioners collaborate synergistically"* [16](p. 10). The WHO has also recognised this important link in the Framework for Action on Interprofessional Education and Collaborative Practice [18]. They assert that interprofessional education and interprofessional practice is an important and innovative global health workforce strategy, and that *"interprofessional education is a necessary step in preparing a 'collaborative practice-ready' health workforce that is better prepared to respond to local health needs"* [18](p. 7). Although the findings are focused on the Collaborative Practice to Enhance Patient Care Outcomes side of the Interprofessional Education for Collaborative Patient-centred Practice framework, future research directed at exploring the Interprofessional Education to Enhance Learner Outcomes side, and the links between the two in the area of Aboriginal and Torres Strait Islander childhood disability, would provide a deeper understanding.

The qualitative study findings demonstrate that while collaboration across the health, education, and social service sectors is required for Aboriginal childhood disability, it is a complex concept. The complexity of collaboration as a concept has been identified elsewhere suggesting universal experience [19, 20]. The interdependent factors influencing interprofessional collaborative practice at the macro, exo, and meso levels of the adapted Collaborative Practice to Enhance Patient

Care Outcomes framework highlight the complexity of the concept of collaboration and the necessity of taking an ecological approach. The need to approach collaboration from an ecological perspective to ensure effective outcomes, rather than focus on discrete areas, is widely recognised [21-23]. In their review of interprofessional collaborative practice in primary care teams, Morgan, Pullon and McKinlay [24] found that a multi-level approach considering both macro (top down) and micro (bottom up) factors is important in ensuring successful interprofessional collaborative practice [24]. The 2015 WHO report on the global strategy on people-centred and integrated health services reports that the three challenges to successful integration are system, organisational, and person related, further supporting the need to take an ecological approach [25]. The findings from this qualitative study and the wider literature suggest that collaboration cannot just be considered as a component of policy alone in achieving change in health inequities; rather, there needs to be macro level changes with thorough consideration of interprofessional collaborative processes at the exo and meso levels to ensure that interventions to enhance collaboration are successful and sustainable [20, 26].

8.4 Discussion of findings at the macro, exo and meso levels

Consideration of the interdependence of factors related to service delivery at the macro, exo, and meso levels is essential to implications for policy, practice, education, and research. The project findings highlight the influence of a multitude of factors at these levels on non-ACCHO provider perceptions, understandings, and experiences of service provision to Aboriginal children with a disability and their families. This section discusses the project findings in relation to the relevant literature at the macro (system), exo (organisational), and meso (provider) levels.

8.4.1 Macro (system) level

8.4.1.1 Socio-political context and the role of cultural competence

The providers in the qualitative study emphasised the significant influence that the socio-political context of colonisation has on service access and provision in Western Sydney. This has been similarly identified for other Aboriginal and Torres

Strait Islander peoples, and indigenous populations globally [27, 28]. The findings demonstrate the importance of culturally safe services, with culturally competent providers, to addressing issues of trust and power between families and providers. Herring et al. [29] argue that methods to enhance cultural competence need to take place within a framework that exposes the ongoing impact of colonisation for Aboriginal and Torres Strait Islander peoples through using trauma and racism as lenses [29]. While applying trauma and racism as lenses is essential, the concern that cultural competence training instilled in some non-Aboriginal providers about the things they should and should not do, suggests this is an important area of focus. 'White guilt' experienced by non-Aboriginal providers is argued to lead to inaction and perpetuation of Aboriginal and Torres Strait Islander peoples as 'the other' [29, 30]. Training programs to enhance cultural competence should include specific tools to manage providers' guilt and related concerns [30].

In the current study, providers valued the practical experience of working with Aboriginal families and providers as a method of enhancing cultural competence. This was reflected in the importance placed on relationships with cultural mentors. This study therefore demonstrates the need for ongoing cultural mentorship, particularly around understanding the impact of colonisation and the Stolen Generation on service access for families. Creating a dedicated space for mentorship within the day-to-day realities of service provision is important. Power et al. [31] argue that regular yarning circles within organisations are an effective way to establish ongoing cultural mentorship for staff [31]. Aboriginal and Torres Strait Islander guest speakers facilitate the yarning circles with the aim of promoting discussion and reflection on specific issues, and to *"afford non-Indigenous staff members the opportunity to ask what might sometimes be difficult questions"* [31](p. 441).

8.4.1.2 Increasing the number of Aboriginal and Torres Strait Islander providers in mainstream services

The findings of the qualitative study highlight the need for renewed focus on increasing the number of Aboriginal and Torres Strait Islander providers in mainstream services. The First Peoples Disability Network (Australia) [32] has also called for the

recruitment of more Aboriginal and Torres Strait Islander peoples [32]. Davidson et al. [33] argue that the lack of Aboriginal and Torres Strait Islander providers is due to an *“imbalance of resources and opportunities and a lack of recognition of Indigenous culture, history and values in universities and health services”* [33](p. 73). Specific strategies to increase and retain Aboriginal and Torres Strait Islander providers are required. Providers in this study identified the importance of culturally competent non-Aboriginal managers in building culturally safe work environments. An example strategy for targeted recruitment interventions is presented by Gilroy et al. [27] in recruiting Aboriginal and Torres Strait Islander peoples to the disability service sector [27]. Gilroy et al. [27] suggest three key components: *“(1) promotion strategy to help establish the disability services sector as an employer of choice; (2) localised recruitment strategy; and (3) retention strategy for Indigenous workers”* [27](p. 7). The study findings support the importance of this strategy, but highlight the need for services to address potential negative perceptions from other providers around recruitment targets for Aboriginal and Torres Strait Islander peoples. This is particularly important to ensuring that Aboriginal and Torres Strait Islander providers feel supported in mainstream services.

8.4.1.3 Funding cycles

Providers’ emphasised the uncertainty which short and inflexible funding cycles bring to service provision. Short and inflexible funding cycles have also been reported elsewhere as serving as barriers to the inclusion of children with a disability in mainstream early childhood settings [34]. Carers of Aboriginal children with a disability in Western Sydney have identified that the model of care provided by local ACCHOs enables access to support and services [35]. The findings of the current qualitative study also demonstrate the important role ACCHOs play in the wider service system. Despite this, Baeza and Lewis [36] argue that funding of ACCHOs is so often fragmented and unpredictable that *“many of them are, in effect, funded to fail”* [36](p. 723). This study supports the need for careful consideration of how funding directives are shaped and implemented across the service system in the area of Aboriginal childhood disability.

8.4.1.4 National Disability Insurance Scheme

Although not a direct focus of the qualitative study, providers identified the rollout of the National Disability Insurance Scheme as an important factor influencing service access and provision. Concerns were raised around the uncertainty of the impact the initiative will have on families' access to services and collaboration between providers. The introduction of the National Disability Insurance Scheme in Australia has presented a unique opportunity to address issues related to accessing services and support for Aboriginal and Torres Strait Islander children with a disability and their families. The National Disability Insurance Scheme is currently being trialled in a number of locations, with full rollout expected in 2019 [37]. It is recognised that specific strategies for Aboriginal and Torres Strait Islander peoples with a disability are required in implementing the National Disability Insurance Scheme [32, 38]. The current study highlights some key considerations for the specific implementation of the initiative for Aboriginal children with a disability and their families, as follows.

Providers expressed concern related to children without a diagnosis, or with less severe disabilities, and their eligibility for services and support. Concern that a National Disability Insurance Scheme funding model focused on eligibility through diagnosis could potentially lead to further inequity in service access, particularly for children without a diagnosis, has been raised elsewhere [39]. The National Disability Insurance Scheme focus on targeted disability service delivery is also argued to be potentially at odds with the early childhood intervention movement in Australia towards supporting children with disabilities in everyday settings [39]. Forster [40] argues that there is concern around the National Disability Insurance Scheme funding model potentially separating children with a disability from universal early childhood services, where early childhood development, rather than disability, is the focus [40]. Findings related to the permeability of services and children without a diagnosis, demonstrate that policy in this area should not just focus on disability specific services and obtaining a diagnosis. The current study supports the recommendations presented by Johnston, Luscombe and Fordham [37] in regards to facilitators to the effective implementation of the National Disability Insurance Scheme for families with a child with a disability, namely:

1) flexibility in the model at a systemic level, 2) parents'/carers' capacity for decision-making, 3) parents'/carers' access to information in forms which are meaningful to them, and 4) the capacity building of professionals [37](p. 132).

8.4.1.5 Collaboration across sectors

Globally, the need for collaboration across sectors and the role that policy has to play is recognised by the WHO in asserting that policy to support collaboration should include *“a commitment to communication, streamlined regulation and processes, and flexibility to adapt to different settings”* [25](p. 30). The findings of the qualitative study highlight the need for policy to support cross-sector collaboration between mainstream services from the health, education, and social service sectors, as well as with ACCHOs, in service delivery for Aboriginal children with a disability. The National Disability Insurance Agency, responsible for implementation of the National Disability Insurance Scheme, recognises the importance of creating and maintaining links with mainstream services external to disability specific services, and state that they have implemented protocols for working with mainstream services in each trial site, one of which is Western Sydney [38].

8.4.1.6 Role of government

Providers expressed the need for government to play a central role in facilitating provider collaborative working in the area of Aboriginal childhood disability. It was suggested that for relationships between non-Aboriginal providers and Aboriginal services and providers, the government should provide information on how to work most effectively. This is despite existing literature on this topic [41-43]. It may be that accessing literature on the importance of implementation strategies is not enough, and that a government representative is required at a practical level to guide providers on how best to engage and collaborate. Providers also suggested that requirements to demonstrate collaboration should be a pre-requisite to obtaining funding. Limited and fragmented funding has been identified as a barrier to effective partnerships between Aboriginal and mainstream services in other areas of Aboriginal and Torres Strait Islander health [21, 33]. Long-term and consistent funding is particularly important to the development of trusting collaborative relationships [44].

Globally, the important role of government in regards to reconfiguring funding structures to facilitate collaboration across sectors is recognised. The WHO strategy to achieve health in all policies through collaboration is impeded by vertical funding silos [23]. McQueen et al. [23] propose that joint funding across sectors is a key way to address gaps in collaboration and prevent the duplication of services - for example, through creating specific budgets for providing school based health promotion [23].

8.4.2 Exo (organisational) level

8.4.2.1 The role of organisations in enhancing cultural competence

The findings of the qualitative study show that organisations have a key role to play in ensuring the translation of cultural competence from policy to practice. For many providers, cultural competence training arranged by their organisations was the main professional avenue guiding their interactions with families. Previous research highlights the importance of embedding cultural competence principles throughout all levels of an organisation to ensure translation of policy to practice [45, 46]. The cultural security model developed by Coffin [47] provides a useful framework for how organisations can ensure cultural competence is actively embedded at all levels [47]. Cultural security *“directly links understandings and actions...policy and procedures create standard processes that are automatically applied from the time when Aboriginal people first seek healthcare”* [47](p. 23). Brokerage (equal bi-directional communication between Indigenous and non-Indigenous perspectives), and protocols (creation of processes in consultation with key stakeholders), are the mechanisms used to achieve cultural security [47]. Cultural security emphasises the need to create a system which is consistently culturally appropriate and does not rely on individual provider attitudes [48, 49]. The current study suggests that effective interactions between families and providers may often rely on the individual characteristics of providers. Ensuring culturally competent care necessitates going beyond the individual level between providers and families, to organisations putting in place processes and procedures to embed cultural competence at all levels. The cultural security model demonstrates a practical framework for organisations to conceptualise and implement the translation of cultural competence from policy to practice.

8.4.2.2 Cultural competence interventions

Organisations may face difficulty in determining the most effective cultural competence interventions to implement. This is due to a lack of research evaluating cultural competence interventions and predominance of self-assessment [46, 50]. Creating a stronger evidence base requires the development of measurements that do not only rely on self-assessment [45]. This may assist in the development of stronger assessment tools for organisations to actively implement cultural competence principles at all levels, not relying on the individual characteristics of their providers. Despite insufficient evidence to determine the most effective interventions, a literature review found that there was some evidence for the effectiveness of continuous quality improvement models with indicators developed together with Aboriginal and Torres Strait Islander peoples, and culturally tailored evidence-based interventions incorporating mechanisms for sustainability and evaluation [46]. Bainbridge et al. [46] argue that:

strategies should be developed in consultation with Indigenous Australian health services and communities, tailored to the needs and preferences of specific communities, and embedded within organisational culture, governance, policies and programs of health services [46](p. 19).

The current study findings highlight the need to extend this to include mainstream organisations across the education and social service sectors to ensure culturally competent service delivery for Aboriginal children with a disability and their families.

8.4.2.3 Need for coordinated governance

Providers valued the role of coordinated governance, in the form of leadership, in supporting effective interprofessional collaborative practice. This was considered particularly important for addressing issues related to the complex and fragmented cross-sector service landscape on working with providers from different sectors. Governance is key to ensuring that the success of interprofessional collaborative practice does not solely rely on relationships between individual providers, which is not sustainable [51]. Globally, the WHO recognises governance as essential to addressing service fragmentation and achieving people-centred and integrated health services [52]. The qualitative study findings demonstrate the essential role that

governance plays in facilitating sustainable and effective interprofessional collaborative practice across the health, education, and social service sectors. Requirements for effective collaborative governance include the need to address power imbalances, incentives to participate, establish trust, protocols and MoUs [23].

The study findings highlight the need for governance to play a role in training providers to collaborate across sectors. Cross-sector training implemented by organisations enabled providers to work together effectively. The important role of governance in implementing cross-sector training is recognised both nationally and internationally [51, 53]. A study on inclusion of children with a disability into mainstream early childhood services in NSW, Australia, found that joint training of providers was required to address the divide between mainstream and specialist services [34]. Studies report a number of positive outcomes from cross-sector training. One study evaluating an early childhood development training intervention for Aboriginal Health Workers working in remote communities, found that Aboriginal Health Workers valued joint training with staff from other primary healthcare disciplines in early childhood development, and that it helped to overcome professional boundaries [54]. Another study of interprofessional collaboration in child mental healthcare conducted in Norway with teachers, special educators, psychologists, social workers, primary nurses, child welfare workers, and medical doctors, also found that interprofessional training enhanced teamwork through shared learning [55].

8.4.2.4 Schools as service settings

Buy-in to collaborative programs from schools is key to unlocking the potential this setting offers for early intervention, particularly as a route for access to services for families who might not otherwise have sought them. An Australian study found that delivering interventions in natural settings that children engage with, such schools, and collaborating with providers in these settings, is an important component of interventions for children with a disability [56]. Governance, in the form of leadership from school principals within this context, plays an important role in mediating the

process of public policy to create creative spaces for shifting policy and practice to address new ways of approaching health issues across sectors [23].

8.4.2.5 Formalising communication processes

The findings from the qualitative study reveal that formalisation of processes at the exo (organisational) level is essential to effective interprofessional communication across sectors. Disjointed systems of communication represent a key barrier for providers working in the area of Aboriginal childhood disability. Globally, the importance of formalising communication processes to effectively coordinate care for children with a disability is also recognised [57]. In the United States, a report by the Robert Wood Johnson Foundation [53] found that that *“enabling team members with shared language and tools to promote effective communication helps overcome the barriers associated with the different communication styles and expectations that can impede collaboration”* [53](p. 5). Nationally, DiGiacomo et al. [58] argue that addressing limitations in IT systems at the organisation and policy levels is essential to improving healthcare for Aboriginal people [58]. The *National Early Childhood Development Researchable Data Set* is a data linkage initiative by the Australian Institute of Health and Welfare in the process of development, which underscores recognition of the importance of integrating systems of information from different sectors to facilitate cross-sector communication processes. The Australian Institute of Health and Welfare assert that:

one of the challenges in developing a national system is to broaden the scope of data that are included to multiple domains, such as health, education and community services...while significant progress is being made in the health domain, relatively less work has been undertaken in education and social policy [59](p. 3).

This study supports the importance of this initiative, and advocates for further work in the areas of education and social services.

8.4.2.6 Networking groups

Providers valued formal and informal networking groups as enablers to effective interprofessional communication. Networking groups helped to create a space within which providers could discuss how best to use each other’s supports. The

value of networking groups to interprofessional collaboration has been recognised elsewhere. An Australian study of primary healthcare for Aboriginal and Torres Strait Islander peoples with a chronic disease similarly found that networking between providers was beneficial in extending access to a broader range of relevant services [21]. An evaluation of Mental Health Professionals Network workshops in Australia, aimed at improving collaboration, found that they had a high success rate [60]. The workshops were attended by GPs, psychiatrists, paediatricians, psychologists, social workers, occupational therapists, and mental health nurses, and were supported “*by education and training materials; fostering ongoing, self-sustained interdisciplinary clinical networks; and hosting a website, web portal...and a toll-free telephone information line*” [60](p. 29). The study found that 81% of the participants went on to join other networks of relevant providers in their local areas [60]. Regular networking between stakeholders and creating cross-sector committees to guide collaboration is reported to be an important part of cross-sector collaboration [23].

8.4.2.7 Case conference model

The findings of this qualitative study suggest that case conferences facilitate communication between providers, and are a way for carers to be active participants in collaboration. An Australian study of links between GPs and other primary healthcare providers found a need for formal structures to encourage collaboration and information sharing [61]. A Cochrane review of the impact of interventions for interprofessional collaboration in healthcare found that “*multidisciplinary meetings with an external facilitator, who used strategies to encourage collaborative working, was associated with increased audit activity and reported improvements to care*” [62](p. 2).

8.4.3 Meso (provider) level

8.4.3.1 Increasing community awareness

The ability of families to identify that a child might have a condition requiring assessment and management was perceived by some providers to be influenced by advice provided by their extended community and elders. Aboriginal carers also

identified the key role that the community plays in recognising the need to access support and services [35]. Community influence has likewise been identified in help-seeking by culturally and linguistically diverse (CALD) carers, where extended family and community members sometimes present a barrier by denying presence of a disability [63]. Another Australian study of CALD carers' perceptions of preventive healthcare for their children found that social influence plays a key role in identification of developmental problems and the need to access services [64]. People from socio-economically disadvantaged backgrounds are reported as less likely to present to services due to the normalisation of poor health within their communities and a fear of being blamed by healthcare professionals [65]. The First Peoples Disability Network (Australia) [32] reports that some Aboriginal and Torres Strait Islander people are reluctant to identify as having a disability and that this reluctance *"presents a fundamental barrier for the successful implementation of the [National Disability Insurance Scheme]"* [32](para. 5). Both carers and providers have identified the need for increased signage within communities via community education, information and awareness to enable identification [35]. For providers, it was deemed important that disseminated information be written in easy to understand language for families to enable them to navigate the system. Further research could be done in the area of health literacy for carers and the wider community to potentially assist them in navigating the system and synthesise information.

8.4.3.2 Financial considerations

The influence of financial factors was a key finding related to the ability of families to mobilise the competencies and resources required to navigate a complex service landscape. Financial concerns were also prominent for Aboriginal carers, particularly associated with the economic costs of caregiving. Financial strain was reportedly exacerbated for lone carers [DiGiacomo et al. manuscript under review]. Costs associated with caregiving, including the cost of private providers, food, transport, childcare, and parking, impede the ability of some carers to navigate services. An Australian study of CALD carers similarly found that carers who were unable to afford private providers faced long waitlists and short GP consultation times in accessing publically funded services [63].

8.4.3.3 Complexity of pathways to services

The complex service landscape was perceived to impede the ability of families to successfully navigate services. In particular, providers identified confusion caused by the multiple early intervention services encountered by families. Fragmented service landscapes, and the confusion caused by lack of coordination between services, has been identified elsewhere as an issue for carers [66]. A study of CALD carers in NSW, Australia, similarly found that a fragmented service system, characterised by complex pathways to services and support, was overwhelming for families trying to navigate the system, suggesting that this is also an issue for other vulnerable populations [63]. There is a need for better coordination of services and referral pathways [63]. An Australian policy brief by the Centre for Community Child Health [51] argues the need for greater service integration for children and their families [51]. Direct outcomes of this are suggested to include improved awareness and accessibility of services for families, earlier identification of developmental issues and referrals to relevant providers, reduced social isolation, and increased integrated service delivery [51].

8.4.3.4 Implementing case management through a key worker model

The findings of the qualitative study reveal that case management is key to enhancing the permeability of services for families. Providers valued case management in assisting families to gather information to successfully navigate services, as well as in coordinating care with other providers. Similarly, an Australian study of parental perceptions of service provision for children with developmental disabilities, found that information burden in the form of difficulties obtaining relevant information on services and support, and changes in information needs over time, were key issues, suggesting the need for better care coordination to reduce the burden on carers [67]. The WHO also recognises case management as a key element to achieving people-centred and integrated health services for complex health problems through service coordination [25]. Drennan, Wagner and Rosenbaum [68] argue that traditional case management matches a patient's needs with available services and support but does not always involve *"individualising approaches for different families based on their specific needs, or taking steps towards empowering parents"* [68](para. 7).

The key worker model supports case management and coordination by allocating a person as a single point of contact for the family, removing barriers to access [68-70]. Sloper [66] asserts that a particularly important part of the role is *“the key worker’s knowledge of and ability to access information and services from a range of agencies”* [66](p. 91). Without a key worker, vulnerable families (e.g. those with the most complex cases and severe lack of resources) have been found to have significantly more unmet needs than families with a key worker [66]. A literature review on interventions provided in mainstream settings, for children with disabilities aged 0 to 8 years and their families, found that the key worker model improved quality of life for families and enabled the coordination and successful navigation of the services maze [56]. Strengthening supports for these children through the key worker model required support from organisations in relation to funding the positions and ensuring continuity [56]. Despite reported benefits of the key worker model, there are a number of reported challenges. Challenges include a lack of high quality evidence of effectiveness [68], the impact of large caseloads, especially in providing care across a client’s life span [71], and no dedicated training curriculum [72].

The key worker model has been employed in a number of programs related to Aboriginal and Torres Strait Islander childhood disability. The *Child Hearing Health Coordinators in the Northern Territory* project is focused on Aboriginal and Torres Strait Islander children at risk of hearing loss and OM [73]. Coordinators manage treatment for individual children by linking primary healthcare and specialist providers, and facilitating communication across health, education, and community-based services [73]. Johnston and Pilkington [71] describe the development of a remote paediatric disability program in the Northern Territory for Aboriginal and Torres Strait Islander children based on a key worker model [71]. Key workers in the program are physiotherapists or occupational therapists and referred to as Key Contacts, acting as the point of contact for their community [71]. Reported benefits of the model is the development of trusting relationships with families and local communities, and the help provided to families to navigate care across sectors [71]. Evaluation of the program found that contact with specialists helped build the knowledge capacity of the Key Contacts, and that therefore specialists need to have good interpersonal and

communication skills. Keys to success included building relationships with families over time and conducive personal characteristics of people in the role; the authors concluded that *“the ability of a Key Contact to develop successful partnerships depends largely on their attitudes and values, rather than specific technical skills”* [71](p. 4). This is similar to the findings of this study related to providers’ identification of the important personal characteristics of case managers. Key workers span various disciplines and systems, and the role can also be undertaken in some instances by lay people with relevant life experience [72, 74]. This also suggests that personal characteristics, rather than specific disciplines, are a more important consideration in the recruitment of key workers.

8.4.3.5 Supporting carers

Highlighting strengths and support networks, linking carers with other carers, and providing information and education, were considered by providers as key to supporting carers. The important role providers play in making information about supportive resources available to carers has been identified elsewhere [57]. The need to build the capacity of providers to support carers (especially linking carers) in this way, is an important area for further research [57]. The first strategic direction outlined in the WHO global strategy on people-centred and integrated health services is the need to empower and engage people [52]. According to the report *“empowering and engaging people is about providing the opportunity, skills and resources that people need to be articulate and empowered users of health services”* [52](p. 21). In Australia, the First Peoples Disability Network (Australia) [32] advocate the need for increased education and awareness about rights and entitlements under the National Disability Insurance Scheme and how to navigate the new system through face-to-face consultation [32]. Sukkar, Dunst and Kirkby [75] highlight that while carers of a child with a disability are encouraged to take a more active role in their child’s care, this needs to be supported by providers collaborating with families so that carers *“feel respected, listened to and treated as equal partners”* [75](p. 4). Consideration of this issue is particularly important for Aboriginal childhood disability due to additional challenges faced by families related to acceptability issues when presenting at services. Provider obligations in relation to mandatory reporting, and the effect this had on

building trust with some families, was a key issue for some providers. Mandatory reporting plays a necessary role in child protection. However, consideration of how to support providers and families in rebuilding trust, in the case of a report being made, may be important in offering support to carers.

8.4.3.6 Clarifying roles and responsibilities

Providers, as well as families, may find it difficult to navigate systems and services. In the current qualitative study, the complex cross-sector service landscape of working in the area of Aboriginal childhood disability was found to influence the ability of providers to share common goals and vision. The involvement of multiple providers working in the area was associated with a lack of coordination and differing agendas, causing confusion and frustration. It also led to role duplication and lack of clarity over provider responsibilities. Lack of common goals and vision between different providers, and the frustration this can cause, as barriers to integrated service provision in early childhood have been reported elsewhere [51, 55]. A Norwegian study of provider perceptions of interprofessional collaboration in the area of child mental health, found that clarification of aims and objectives between providers is an important element of collaboration [55]. Clarification of roles and responsibilities in partnerships between providers from Aboriginal and mainstream services is reported as particularly important [30]. Being clear about roles and responsibilities, in relation to providing services to a patient as well as in the collaborative partnership, enables effective collaboration between Aboriginal and mainstream services [42]. A qualitative study of partnerships between Aboriginal Health Workers and occupational therapists in rural/remote communities in Queensland, Australia, also found that a lack of knowledge about role boundaries impeded interprofessional interactions, with the role of Aboriginal Health Workers particularly unclear for some occupational therapists [76]. The Phase one integrative literature review of cross-sector collaborations in Aboriginal and Torres Strait Islander childhood disability detailed in Chapter Three similarly found that the role of Aboriginal Health Workers is unclear to some mainstream providers leading to their underutilisation, despite the important role they play [77]. It is possible that boundary demarcations are needed for providers involved in the area of Aboriginal childhood disability. As introduced in Section 8.4.2.7, case conferences

show promise and should be funded and supported in this area as a potential way to bring awareness to the roles of different providers and ensuring providers share common goals in consultation with families.

8.4.3.7 Working together with Aboriginal services and providers

Cultural mentorship, and non-Aboriginal and Aboriginal providers working together, were key factors influencing trusting relationships among providers. Effective collaboration has also been found to increase provider knowledge of current initiatives and collective approaches to care for Aboriginal and Torres Strait Islander peoples with a chronic disease [78]. Positive health outcomes for Aboriginal and Torres Strait Islander peoples, from non-Aboriginal providers and Aboriginal providers and services working together, have been reported elsewhere [79]. A review of Aboriginal and mainstream health service partnerships found that effective partnerships help to break down barriers associated with past negative experiences interacting with the mainstream health system for Aboriginal and Torres Strait Islander peoples [42].

Although providers identified a number of positive outcomes from effectively working together, they also identified that important outcomes from effective working relationships were difficult to measure. Similar to these findings, Tsou et al. [44] highlight the challenges around measuring outcomes of effective collaboration. The challenge with standardised assessment tools for partnerships between Aboriginal and mainstream services and providers is the important role that specific contexts play in effective partnerships [44]. According to Tsou et al. [44], *“it is imperative that the entire evaluation process, starting from data collection, is not separated from the historical, social and political context in which the partnership operates”* [44](p. 20). Partnership evaluation tools therefore *“need to include culturally appropriate and community relevant outcomes”* [44](p. 20). This may be a challenging concept to the types of outcomes usually measured and identified as important in policy and funding at the macro level, but the findings demonstrate that it is an important consideration. In light of the importance of context, Haynes et al. [30] argue that it is important to explore and understand the factors that influence the effectiveness of Aboriginal and mainstream service and provider partnerships within specific contexts [30]. Fuller et al.

[80] also assert that specific strategies to enhance partnerships between Aboriginal and mainstream health services and providers in local contexts may not be applicable to other contexts as *“partnerships differ according to their location because of the unique and complex interactions between stakeholders and the particularities of local healthcare contexts”* [80](p. 2).

In the project context of Western Sydney, one of the key factors is the importance of relationships between non-Aboriginal and Aboriginal providers and services and the vital role of key Aboriginal contacts acting as cultural mentors. As introduced in Section 8.4.1.1, cultural mentorship was key to enhancing the cultural competence of non-Aboriginal providers. A study of Aboriginal provider perceptions of what would assist GPs to work more effectively with Aboriginal patients, found that cultural mentorship from local Aboriginal people was an important part of creating culturally safe service for patients and educating non-Aboriginal providers [81]. The local expertise of cultural mentors allowed them to provide *“a specialised type of cultural education, increasing GP awareness of local history, patient contexts and community resources and networks”* [81](p. 61). This is similar to the role cultural mentors played for non-Aboriginal providers in the study. Davidson et al. [33] also highlight the important role the cultural mentors play as cultural brokers, but highlight the need to be aware that the *“burden of responsibility of cultural brokerage and advocacy can also take a toll on the individual”* [33](p. 73). In light of the important role of cultural mentors it is essential that support for these people be provided from the macro and exo levels.

8.4.3.8 Time

Providers in the qualitative study identified the importance of long-term investment of the time and resources required to developing trusting relationships between non-Aboriginal and Aboriginal providers and services. The negative impact of short funding timelines on the development of trusting relationships, introduced in Section 8.4.1.3, has also been reported elsewhere [44, 82]. Taylor and Thompson [42] argue that:

mainstream services have been criticised for failing to recognise the time it takes to develop trust with Aboriginal partners...the pressure to develop and deliver within the boundaries of funding cycles can strain a partnership before it is suitably mature...given Australia's history with Aboriginal people, it is imperative that partnerships are not forced in this way [42](p. 304).

The importance of time to building effective relationships is related to the need to address power differentials between non-Aboriginal and Aboriginal providers and services. Whiteside, Tsey and Cadet-James [83] assert that for transdisciplinary teams which include both Aboriginal and non-Aboriginal providers to be effective, issues related to cultural differences and power need to be specifically addressed [83]. Bailey and Hunt [79] also argue that *“partnerships with Aboriginal organisations are far more likely to be successful if the principle of self-determination for Aboriginal people and their community organisations is honoured”* [79](p. 49). A study of the acceptability of participatory social network analysis for problem-solving in Aboriginal and mainstream health service partnerships, found that the tool helped to map out which members of the network held power and provided a platform for Aboriginal providers to raise concerns about roles and responsibilities [80].

8.5 Project strengths and limitations

A key strength of this project was that the aim, objectives, and research process were driven and guided by the community and thus, addressed community needs. This engagement of community ensured that it was conducted in a culturally appropriate manner. Another key strength was the application of an ecological approach to exploring service access for Aboriginal children with a disability and their families. This holistic approach reflects what was identified by Aboriginal carers in the LP120200484 interviews as important. Exploring the understanding of providers from across the health, education, and social service sectors reflected the approach to service provision recommended in international and national policies. Framing the recruitment strategy in this way facilitated the understanding of how the policy recommendations of cross-sector service provision is carried out in practice, or not.

The number of participants from each sector did vary, however the aim was to ascertain their common perceptions, understandings, and experiences of service provision to Aboriginal and Torres Strait Islander children with a disability, rather than

comparing sectors as subgroups like some stratified or quota sampling strategies that require pre-set sample sizes for each stratified group [84, 85]. Even numbers of participants in each sector were not pursued as the research purpose was to canvas perceptions, understandings, and experiences across the service provision landscape within the specific context of the qualitative study ensuring that there were providers represented from each group (e.g. focus on exploring how/if they work together rather than solely comparing sectors, due to the research purpose it was important for the sampling strategy to target participants from the different sectors) [86, 87].

The sample could have been strengthened with a larger representation of participants from the social service sector, however recruitment was difficult due to a macro policy factor. At the time of recruitment, the NSW government Family and Community Services Department of Ageing, Disability and Home Care was in a transitional period of closure due to the role out of the National Disability Insurance Scheme. Caseworkers had either lost their positions or were in the process of finishing up. When arranging an interview, one participant was unsure whether their perspective would be useful given her position would no longer exist next year, and another was concerned with how much time would be involved as she was at the time managing the termination of staff. This context may have influenced the response rate of social service providers. The data from interviews with the social service providers was, however, in-depth and added valuable perspectives.

The small qualitative study sample size and specificity to non-ACCHO providers in Western Sydney, means that the findings are not necessarily generalisable to providers working in the area of Aboriginal and Torres Strait Islander childhood disability nationally, or in the area indigenous childhood disability, internationally. Yet, as introduced in Chapter One Section 1.2, the decision to only interview non-ACCHO providers was guided by cultural mentors and members of the community in relation to what they perceived as important. The perspectives of participants' also added depth and information-rich examples to address the research purpose as it related to the specific community. Clear and detailed description of the recruitment strategy and resultant sample has been provided in Chapter Five Sections 5.2.4 and 5.2.5 to allow

for other researchers to interpret how transferable the findings may be to other populations.

8.6 References

1. Dixon-Woods M, Kirk D, Agarwal S, Annandale E, Arthur T, Harvey J, Hsu R, Katbamna S, Olsen R, Smith L, Riley R & Sutton A 2005, *Vulnerable groups and access to health care: a critical interpretive review*, National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO), United Kingdom.
2. Chinn D & Abraham E. 2016, 'Using 'candidacy' as a framework for understanding access to mainstream psychological treatment for people with intellectual disabilities and common mental health problems within the English Improving Access to Psychological Therapies service', *Journal of Intellectual Disability Research*, vol. 60, no. 6, pp. 571-582.
3. Bristow K, Edwards S, Funnel E, Fisher L, Gask L, Dowrick C & Chew Graham C. 2011, 'Help seeking and access to primary care for people from "hard-to-reach" groups with common mental health problems', *International Journal of Family Medicine*, vol. 2011, pp. 1-10.
4. Mackenzie M, Conway E, Hastings A, Munro M & O'Donnell C. 2013, 'Is 'candidacy' a useful concept for understanding journeys through public services? A critical interpretive literature synthesis', *Social Policy & Administration*, vol. 47, no. 7, pp. 806-825.
5. Hankivsky O & Christoffersen A. 2008, 'Intersectionality and the determinants of health: a Canadian perspective', *Critical Public Health*, vol. 18, no. 3, pp. 271-283.
6. Collins PH. 1998, 'It's all in the family: Intersections of gender, race, and nation', *Hypatia*, vol. 13, no. 3, pp. 62-82.
7. Collins PH. 2015, 'Intersectionality's definitional dilemmas', *Annual Review of Sociology*, vol. 41, pp. 1-20.
8. Bowleg L. 2012, 'The problem with the phrase women and minorities: intersectionality—an important theoretical framework for public health', *American Journal of Public Health*, vol. 102, no. 7, pp. 1267-1273.
9. Powell Sears K. 2012, 'Improving cultural competence education: the utility of an intersectional framework', *Medical Education*, vol. 46, no. 6, pp. 545-551.
10. Weber L & Fore ME. 2007, 'Race, ethnicity, and health: An intersectional approach'. In: Vera H & Feagin JR (ed.) *Handbooks of the sociology of racial and ethnic relations*, Springer, United States, pp. 191-218.
11. Yoshida K, Hanass-Hancock J, Nixon S & Bond V. 2014, 'Using intersectionality to explore experiences of disability and HIV among women and men in Zambia', *Disability and Rehabilitation*, vol. 36, no. 25, pp. 2161-2168.
12. Doyal L. 2009, 'Challenges in researching life with HIV/AIDS: an intersectional analysis of black African migrants in London', *Culture, Health & Sexuality*, vol. 11, no. 2, pp. 173-188.

13. Cramer EP & Plummer SB. 2009, 'People of color with disabilities: Intersectionality as a framework for analyzing intimate partner violence in social, historical, and political contexts', *Journal of Aggression, Maltreatment & Trauma*, vol. 18, no. 2, pp. 62-181.
14. Carbado DW, Crenshaw KW, Mays VM & Tomlinson B. 2013, 'Intersectionality', *Du Bois Review: social science research on race*, vol. 10, no. 2, pp. 303-312.
15. Singer M, Bulled N, Ostrach B & Mendenhall E. 2017, 'Syndemics and the biosocial conception of health', *The Lancet*, vol. 389, no. 10072, pp. 941-950.
16. D'amour D & Oandasan I. 2005, 'Interprofessionalism as the field of interprofessional practice and interprofessional education: An emerging concept', *Journal of Interprofessional Care*, vol. 19, no. Suppl. 1, pp. 8-20.
17. Davison CM, Ndumbe-Eyoh S & Clement C. 2015, 'Critical examination of knowledge to action models and implications for promoting health equity', *International Journal for Equity in Health*, vol. 14, no. 1, p. 49.
18. World Health Organisation 2010, *Framework for Action on Interprofessional Education & Collaborative Practice*, World Health Organisation, Geneva.
19. Huxham C & Vangen S. 2005, *Managing to collaborate: The theory and practice of collaborative advantage*, Routledge, United States.
20. Longoria RA. 2005, 'Is inter-organizational collaboration always a good thing?', *Journal of Sociology and Social Welfare*, vol. 32, no. 3, pp. 123-138.
21. Askew D, B.J., Brown A, Cass A, Davy C, DeVries J, Fewquandie B, Hackett M, Howard M, Ingram S, Lavoie J, Liu H, Mentha R, Peiris D, Simon P, Rickards B, Togni S, 2014, *Complex needs and limited resources: Influences on the provision of primary healthcare to Aboriginal and Torres Strait Islander peoples living with chronic disease*, *Kanyini Qualitative Study Monograph Series: No. 4*, Kanyini Vascular Collaboration, Sydney.
22. Williams P. 2002, 'The competent boundary spanner', *Public Administration*, vol. 80, no. 1, pp. 103-124.
23. McQueen DV, Wismar M, Lin V, Jones CM & Davies M 2012, *Intersectoral governance for health in all policies. Structures, actions and experiences*, World Health Organisation, Geneva.
24. Morgan S, Pullon S & McKinlay E. 2015, 'Observation of interprofessional collaborative practice in primary care teams: An integrative literature review', *International Journal of Nursing Studies*, vol. 52, no. 7, pp. 1217-1230.
25. World Health Organisation 2015, *People-centred and integrated health services: an overview of the evidence, Interim Report*, World Health Organisation, Geneva.
26. Vanderbilt AA, Dail MD & Jaber P. 2015, 'Reducing health disparities in underserved communities via interprofessional collaboration across health care professions', *Journal of Multidisciplinary Healthcare*, vol. 8, pp. 205-208.

27. Gilroy J, Dew A, Lincoln M & Hines M. 2016, 'Need for an Australian Indigenous disability workforce strategy: review of the literature', *Disability and Rehabilitation*, vol. 39, no. 16, pp. 1664-1673.
28. Brave Heart MYH, Chase J, Elkins J & Altschul DB. 2011, 'Historical Trauma Among Indigenous Peoples of the Americas: Concepts, Research, and Clinical Considerations', *Journal of Psychoactive Drugs*, vol. 43, no. 4, pp. 282-290.
29. Herring S, Spangaro J, Lauw M & McNamara L. 2013, 'The Intersection of Trauma, Racism, and Cultural Competence in Effective Work with Aboriginal People: Waiting for Trust', *Australian Social Work*, vol. 66, no. 1, pp. 104-117.
30. Haynes E, Taylor K, Durey A, Bessarab D & Thompson S. 2014, 'Examining the potential contribution of social theory to developing and supporting Australian Indigenous-mainstream health service partnerships', *International Journal for Equity in Health*, vol. 13, no. 1, p. 75.
31. Power T, Virdun C, Sherwood J, Parker N, Van Balen J, Gray J & Jackson D. 2016, 'REM: A Collaborative Framework for Building Indigenous Cultural Competence', *Journal of Transcultural Nursing*, vol. 27, no. 5, pp. 439-446.
32. First Peoples Disability Network (Australia) 2016, *Ten-point plan for the implementation of the NDIS in Aboriginal and Torres Strait Islander Communities*. Sydney, Available: <http://fpdn.org.au/ten-point-plan-for-the-implementation-of-the-ndis-in-aboriginal-communities/> [Accessed 24/04/17].
33. Davidson PM, DiGiacomo M, Thompson SC, Abbott P, Davison J, Moore L, Daly J, McGrath SJ, Taylor KP & Usherwood T. 2011, 'Health workforce issues and how these impact on Indigenous Australians', *Journal of Australian Indigenous Issues*, vol. 14, no. 4, pp. 69-84.
34. Llewellyn G, Thompson K & Fante M. 2002, 'Inclusion in early childhood services: Ongoing challenges', *Australian Journal of Early Childhood*, vol. 27, no. 3, pp. 18-23.
35. Green A, Abbott P, Delaney P, Patradoon-Ho P, Delaney J, Davidson PM & DiGiacomo M. 2016, 'Navigating the journey of Aboriginal childhood disability: a qualitative study of carers' interface with services', *BMC Health Services Research*, vol. 16, no. 1, p. 680.
36. Baeza JI & Lewis JM. 2010, 'Indigenous health organizations in Australia: connections and capacity', *International Journal of Health Services*, vol. 40, no. 4, pp. 719-742.
37. Johnston C, Luscombe D & Fordham L. 2016, 'Working with families as part of early childhood intervention services: Family-centred practice in an individualised funding landscape'. In: Sukkar H, Dunst CJ & Kirkby J (eds.), *Early Childhood Intervention: Working with Families of Young Children with Special Needs*, Taylor and Francis, United Kingdom, pp. 129-142.
38. National Disability Insurance Agency 2015, *Building the National Disability Insurance Scheme Progress Report: year two*, National Disability Insurance Agency, Canberra.

39. Sukkar H. 2013, 'Early childhood intervention: An Australian perspective', *Infants & Young Children*, vol. 26, no. 2, pp. 94-110.
40. Forster J. 2016, 'Development of community-based services for children with disabilities and their families'. In: Sukkar H, Dunst CJ & Kirkby J (eds.), *Early Childhood Intervention: Working with Families of Young Children with Special Needs*, Taylor and Francis, United Kingdom, pp. 143-163.
41. New South Wales Department of Community Services 2009, *Working with Aboriginal people and communities: A practical resource*, New South Wales Department of Community Services, Sydney.
42. Taylor KP & Thompson SC. 2011, 'Closing the (service) gap: exploring partnerships between Aboriginal and mainstream health services', *Australian Health Review*, vol. 35, no. 3, pp. 297-308.
43. Hunt J 2013, *Engaging with Indigenous Australia—exploring the conditions for effective relationships with Aboriginal and Torres Strait Islander communities. Issues paper no. 5.*, Australian Institute of Health and Welfare and Australian Institute of Family Studies, Canberra and Melbourne.
44. Tsou C, Haynes E, Warner WD, Gray G & Thompson SC. 2015, 'An exploration of inter-organisational partnership assessment tools in the context of Australian Aboriginal-mainstream partnerships: a scoping review of the literature', *BMC Public Health*, vol. 15, no. 1, p. 416.
45. Truong M, Paradies Y & Priest N. 2014, 'Interventions to improve cultural competency in healthcare: a systematic review of reviews', *BMC Health Services Research*, vol. 14, no. 1, p. 99.
46. Bainbridge R, McCalman J, Clifford A & Tsey K 2015, *Cultural competency in the delivery of health services for Indigenous people. Issues paper no. 13. Produced for the Closing the Gap Clearinghouse.*, Australian Institute of Health and Welfare & Australian Institute of Family Studies, Canberra & Melbourne.
47. Coffin J. 2007, 'Rising to the challenge in Aboriginal health by creating cultural security', *Aboriginal and Islander Health Worker Journal*, vol. 31, no. 3, pp. 22-24.
48. Farrelly T & Lumby B. 2009, 'A Best Practice Approach to Cultural Competence Training', *Aboriginal and Islander Health Worker Journal*, vol. 33, no. 5, pp. 14-22.
49. National Aboriginal Community Controlled Health Organisation 2011, *Creating the NACCHO Cultural Safety Training Standards and Assessment Process: A background paper*, National Aboriginal Community Controlled Health Organisation, Canberra.
50. Clifford A, McCalman J, Bainbridge R & Tsey K. 2015, 'Interventions to improve cultural competency in health care for Indigenous peoples of Australia, New Zealand, Canada and the USA: a systematic review', *International Journal for Quality in Health Care*, vol. 27, no. 2, pp. 89-98.

51. Centre for Community Child Health 2009, *Integrating Services for Young Children and their Families. Policy Brief No 17*, The Royal Children's Hospital, Melbourne.
52. World Health Organisation 2015, *WHO global strategy on people-centred and integrated health services: Interim Report*, Geneva, World Health Organisation.
53. Robert Wood Johnson Foundation 2015, *LESSONS FROM THE FIELD: Promising Interprofessional Collaboration Practices*, Robert Wood Johnson Foundation, United States.
54. D'Aprano A, Silburn S, Johnston V, Oberklaid F & Tayler C. 2015, 'Culturally Appropriate Training for Remote Australian Aboriginal Health Workers: Evaluation of an Early Child Development Training Intervention', *Journal of Developmental & Behavioral Pediatrics*, vol. 36, no. 7, pp. 503-511.
55. Ødegård A. 2006, 'Exploring perceptions of interprofessional collaboration in child mental health care', *International Journal of Integrated Care*, vol. 6, no. 4, pp. 1-13.
56. Dew A, De Bortoli T, Brentnall J & Bundy A 2014, *Strengthening Supports for Children 0-8 years and their Families: A Literature Review*, University of Sydney, Sydney.
57. National Academies of Sciences Engineering and Medicine. 2016, *Ensuring Quality and Accessible Care for Children with Disabilities and Complex Health and Educational Needs: Proceedings of a Workshop*, The National Academies Press, Washington, DC.
58. DiGiacomo M, Davidson PM, Taylor KP, Smith JS, Dimer L, Ali M, Wood MM, Leahy TG & Thompson SC. 2010, 'Health information system linkage and coordination are critical for increasing access to secondary prevention in Aboriginal health: a qualitative study', *Quality in Primary Care*, vol. 18, no. 1, pp. 17-26.
59. Australian Institute of Health and Welfare 2014, *Developing the National Early Childhood Development Researchable Data Set. Cat. no. PHE 179*, Australian Institute of Health and Welfare, Canberra.
60. Fletcher J, King K, Christo J, Machlin A, Bassilios B, Blashki G, Gibbs C, Nicholas A & Pirkis J. 2014, 'An evaluation of an Australian initiative designed to improve interdisciplinary collaboration in primary mental health care', *Evaluation and Program Planning*, vol. 45, pp. 29-41.
61. Wiese M, Jolley G, Baum F, Freeman T & Kidd M. 2011, 'Australia's systems of primary healthcare: The need for improved coordination and implications for Medicare Locals', *Australian Family Physician*, vol. 40, no. 12, pp. 995-999.
62. Zwarenstein M, Goldman J & Reeves S. 2009, 'Interprofessional collaboration: effects of practice-based interventions on professional practice and healthcare outcomes', *Cochrane Database Systematic Reviews*, vol. 3, no. CD000072, pp. 1-31.

63. Woolfenden S, Posada N, Krchnakova R, Crawford J, Gilbert J, Jursik B, Sarkozy V, Perkins D & Kemp L. 2015, 'Equitable access to developmental surveillance and early intervention – understanding the barriers for children from culturally and linguistically diverse (CALD) backgrounds', *Health Expectations*, vol. 18, no. 6, pp. 3286-3301.
64. Alexander KE, Brijnath B & Mazza D. 2015, 'Parents' decision making and access to preventive healthcare for young children: applying Andersen's Model', *Health Expectations*, vol. 18, no. 5, pp. 1256-1269.
65. Dixon-Woods M, Cavers D, Agarwal S, Annandale E, Arthur A, Harvey J, Hsu R, Katbamna S, Olsen R, Smith L & Riley R. 2006, 'Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups', *BMC Medical Research Methodology*, vol. 6, no. 1, p. 35.
66. Sloper P. 1999, 'Models of service support for parents of disabled children. What do we know? What do we need to know?', *Child: care, health and development*, vol. 25, no. 2, pp. 85-99.
67. Hussain R & Tait K. 2015, 'Parental perceptions of information needs and service provision for children with developmental disabilities in rural Australia', *Disability and Rehabilitation*, vol. 37, no. 18, pp. 1609-1616.
68. Drennan A, Wagner T & Rosenbaum P 2017, *The 'Key Worker' Model of Service Delivery*. Available: www.canchild.ca/en/resources/85-the-key-worker-model-of-service-delivery [Accessed 24/01/2017 2017].
69. Schwaderer KA & Itano JK. 2007, 'Bridging the healthcare divide with patient navigation: development of a research program to address disparities', *Clinical Journal of Oncology Nursing*, vol. 11, no. 5, p. 633.
70. Wells KJ, Battaglia TA, Dudley DJ, Garcia R, Greene A, Calhoun E, Mandelblatt JS, Paskett ED & Raich PC. 2008, 'Patient navigation: state of the art or is it science?', *Cancer*, vol. 113, no. 8, pp. 1999-2010.
71. Johnston H & Pilkington C 2015. 'Evolution of a remote paediatric disability program'. *13th National Rural Health Conference*, Darwin, Australia, pp. 1-6.
72. Naccarella L, Osborne RH & Brooks PM. 2016, 'Training a system-literate care coordination workforce', *Australian Health Review*, vol. 40, no. 2, pp. 210-212.
73. Australian Institute of Health and Welfare 2015, *Hearing health outreach services to Indigenous children and young people in the Northern Territory: 2012-13 and 2013-14. Cat. no. IHW 149*, Australian Institute of Health and Welfare, Canberra.
74. Doolan-Noble F, Smith D, Gauld R, Waters DL, Cooke A & Reriti H. 2013, 'Evolution of a health navigator model of care within a primary care setting: a case study', *Australian Health Review*, vol. 37, no. 4, pp. 523-528.
75. Sukkar H, Dunst CJ & Kirkby J. 2016, 'Family systems and family-centred practices in early childhood intervention'. In: Sukkar H, Dunst CJ & Kirkby J (eds.), *Early Childhood Intervention: Working with Families of Young Children with Special Needs*, Taylor and Francis, United Kingdom, pp. 3-14.

76. Hooper K, Thomas Y & Clarke M. 2007, 'Health professional partnerships and their impact on Aboriginal health: an occupational therapist's and Aboriginal health worker's perspective', *Australian Journal of Rural Health*, vol. 15, no. 1, pp. 46-51.
77. Green A, DiGiacomo M, Lockett T, Abbott P, Davidson PM, Delaney J & Delaney P. 2014, 'Cross-sector collaborations in Aboriginal and Torres Strait Islander childhood disability: a systematic integrative review and theory-based synthesis', *International Journal for Equity in Health*, vol. 13, no. 1, p. 126.
78. Ingram S, Lavoie J, Liu H, Mentha R, Peiris D, Simon P, Rickards B & Togni S 2014, *Complex needs and limited resources: Influences on the provision of primary healthcare to Aboriginal and Torres Strait Islander peoples living with chronic disease. Kanyini Qualitative Study Monograph Series: No. 4*, Kanyini Vascular Collaboration, Sydney.
79. Bailey S & Hunt J. 2012, 'Successful partnerships are the key to improving Aboriginal health', *New South Wales Public Health Bulletin*, vol. 23, no. 4, pp. 48-51.
80. Fuller J, Hermeston W, Passey M, Fallon T & Muyambi K. 2012, 'Acceptability of participatory social network analysis for problem-solving in Australian Aboriginal health service partnerships', *BMC Health Services Research*, vol. 12, no. 1, p. 152.
81. Abbott P, Dave D, Gordon E & Reath J. 2014, 'What do GPs need to work more effectively with Aboriginal patients?: Views of Aboriginal cultural mentors and health workers', *Australian Family Physician*, vol. 43, no. 1/2, pp. 58-63.
82. National Health & Medical Research Council 2003, *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*, Commonwealth of Australia, Canberra.
83. Whiteside M, Tsey K & Cadet-James Y. 2011, 'A theoretical empowerment framework for transdisciplinary team building', *Australian Social Work*, vol. 64, no. 2, pp. 228-232.
84. Onwuegbuzie AJ & Leech NL. 2007, 'Sampling Designs in Qualitative Research: Making the Sampling Process More Public', *The Qualitative Report*, vol. 12, no. 2, pp. 238-254.
85. Robinson OC. 2014, 'Sampling in Interview-Based Qualitative Research: A Theoretical and Practical Guide', *Qualitative Research in Psychology*, vol. 11, no. 1, pp. 25-41.
86. Patton MQ. 2015, *Qualitative Research and Evaluation Methods*, 4th, SAGE Publications, United States of America.
87. Charmaz K. 2014, *Constructing Grounded Theory*, SAGE Publications, United States.

Chapter Nine: Conclusion and recommendations

9.1 Conclusion

Disparities in Aboriginal and Torres Strait Islander childhood disability, as compared with other Australian children, is an important area of focus and a compelling focus of action for the Aboriginal community in Western Sydney. Addressing adverse health, social and learning outcomes is an essential dimension in the national campaign to *Close the Gap* on the disadvantage experienced by Aboriginal and Torres Strait Islander peoples. Addressing this disparity requires recognising the influence of social determinants of health on disability, including the impact of historical trauma, racism and socio-economic disadvantage [1-3]. The cumulative impact of adverse circumstances and trauma across the lifespan cannot be denied. The lack of comprehensive, multifaceted and holistic focus signals the need for a shift in thinking, as the intersection between disability and these social determinants are commonly considered out of the realm of the traditional responsibilities of health, education, and social service sectors. This change in approach is required as the high rates of disability experienced by some Aboriginal and Torres Strait Islander children can have long term negative impacts on their health, social development, as well as broader societal implications on health, education, and employment outcomes [4-7]. To mitigate these potential effects, access to early intervention is crucial, but implementation is challenged by structural barriers as well as knowledge, attitudes and beliefs of providers. Meeting the needs of children and families drove the local Aboriginal community to approach University of Technology Sydney researchers to partner in systematically investigating and addressing the range of barriers to service access for effective early intervention. Carers interviewed in the LP120200484 project described their journeys of navigating pathways to access services and support as encountering significant difficulties navigating the complex service landscape, as well as incompatibility of inflexible bureaucratic rules and lived realities [8]. They also identified that their interactions with providers were characterised by their sense of a lack of empowerment and marginalisation in feeling looked down on and judged, both because they were Aboriginal, and a carer of a child with a disability [Green et al.

manuscript under review]. In this PhD project, improved service access for early intervention was linked to the need for increased cultural competence at all levels of the service system, and collaboration between the health, education, and social service sectors. The aim and objectives for this project developed in consultation with Aboriginal community member and co-leader of LP120200484, Patricia Delaney, who identified a need to focus on non-ACCHO providers and organisations to contribute to the larger picture of service provision. The findings of this thesis contribute to our understanding of the intersection of services across the health, education, and social service sectors. Although there is an increasing amount of data on Aboriginal and Torres Strait Islander childhood disability, solutions are less prevalent.

This thesis has explored the extant literature and undertaken a contextually driven analysis of non-ACCHO providers' perceptions, understandings, and experiences of service provision to Aboriginal children with a disability and their families in Western Sydney. It is important to acknowledge that the local Aboriginal community identified this issue and the project was undertaken with cultural mentorship, with the goal of providing specific recommendations for improving care. During the course of this project, several factors beyond the control of the researchers influenced the conduct of the LP120200484 project and implications for the future. Firstly, government de-funding of the partner ACCHO led to its closure halfway through the project. The closure was identified in media reports as leading to community and provider concern over the safety of transferring patients to non-ACCHO services in light of the lack of trust in mainstream services [9, 10]. Community protest to reinstate funding [11] in light of the essential role of the ACCHO in providing services to members of the local community was unsuccessful. Despite the closure and subsequent change of management of the organisation, LP120200484, and this project, proceeded in consultation with Aboriginal community members in Western Sydney who were part of the research team. Secondly, this project was conducted during the initial trial stages of the National Disability Insurance Scheme. The National Disability Insurance Scheme was rolled-out in Western Sydney in mid-2015 [12], around the same time as government de-funding of the partner ACCHO. Although not a specific focus, the provider interviews documented uncertainty and a number of concerns

around how the National Disability Insurance Scheme would shape service access for Aboriginal children with a disability, as well as service provision to this population. It allowed a preliminary snapshot of provider perspectives of the National Disability Insurance Scheme rollout and identified a number of important areas for consideration in relation to its application for Aboriginal children with a disability and their families.

The qualitative study achieved the research objectives to 1) investigate the important components of collaboration, 2) better understand provider perceptions, understandings, and experiences of providing services, 3) document the barriers and facilitators to service provision, and 4) identify optimal approaches to developing interdisciplinary collaboration. The qualitative approach allowed the perceptions, understandings, and experiences of non-ACCHO providers of providing services to families and working with other providers in the context of Western Sydney. In particular, the qualitative design was aligned with the project aim, aligned with Aboriginal and Torres Strait Islander values, and engaging and respectful of Aboriginal families. The concept of candidacy enabled explanations of the joint negotiation between families and providers of the perceptions of eligibility of Aboriginal children with a disability and their families for services. Providers' perceptions, understandings, and experiences of working together across the health, education, and social service sectors centred on their perceptions of factors that either impeded or enabled collaboration. The concept of interprofessionality described the processes and determinants of interprofessional collaborative practice in this context [13]. Exploring the perceptions, understandings, and experiences of providers delivering care to Aboriginal children with a disability and their families in Western Sydney revealed a wide range of barriers and facilitators to service provision as outlined below.

The findings of this thesis have identified a number of perceived optimal approaches to developing interdisciplinary collaboration to support the multi-dimensional needs of Aboriginal families. Case management was identified to assist families to gather information to successfully access services, as well as providers to coordinate care with other providers. A case manager provides case management through systematically coordinating services for a patient in accordance with their identified needs [14]. Although case management was identified as important, it was

described as not currently implemented well. Reasons for this were a lack of financial and human resources, and uncertainty over how best to implement the model and what it should look like. Informal and formal networking groups were key enablers of interprofessional collaboration as an effective approach to enable communication. Case conferences, multidisciplinary team meetings of at least three providers involved in a patient's care [15], were identified as an effective model of formalised communication between providers from different sectors, especially when they include carers. The model addressed miscommunication between providers and the lack of coordination resulting from ambiguity and uncertainty, and provided a means for carers to be active participants in collaboration.

The negative impact of health and socio-economic inequities over the life-course on Aboriginal people is indisputable [1, 16-18]. Adding the challenges of caring for a child with a disability to this picture has compounding effects leading to increased marginalisation and disadvantage. The findings of this thesis underscore the complexity of the lives of Aboriginal children with a disability and their families and the challenges of interfacing with a diffuse and complex health system. Factors influencing the health of populations are often located outside the health system requiring the health sector to engage with other sectors of government and society to address the determinants of health and well-being. Moreover, failing to acknowledge and deal with systemic and institutional racism is a challenge in improving access and refining health services design.

9.2 Recommendations for policy and practice

Key recommendations for policy and practice to promote service access as part of LP120200484 have been generated from this project. Although not a direct result from the PhD project, issues identified by carers at the micro level as part of LP120200484 included the challenges of navigating access to services and support [8]. Key barriers to successful navigation of services included: delays to assessment and treatment caused by long waitlists; lack of follow-up from providers leading to missed opportunities for timely access to support and services; lack of access to private transportation; and incompatibility between inflexible bureaucratic policy

requirements and the demands and challenges of caring for a child with a disability [8]. Recommendations identified by carers to address these barriers included: increased community education, information and awareness; a model of care that viewed the needs of the child and carer holistically, provided a one-stop-shop and implemented a centralised team-based approach; and, similar to providers, key workers to bridge the gap between carers and the various service systems involved [8].

The key recommendations for policy and practice from the PhD project are presented below according to the macro, exo, and meso levels in recognition of the importance of taking an ecological and cross-sector approach when addressing service access for Aboriginal children with a disability and their families (Figure 9.1).

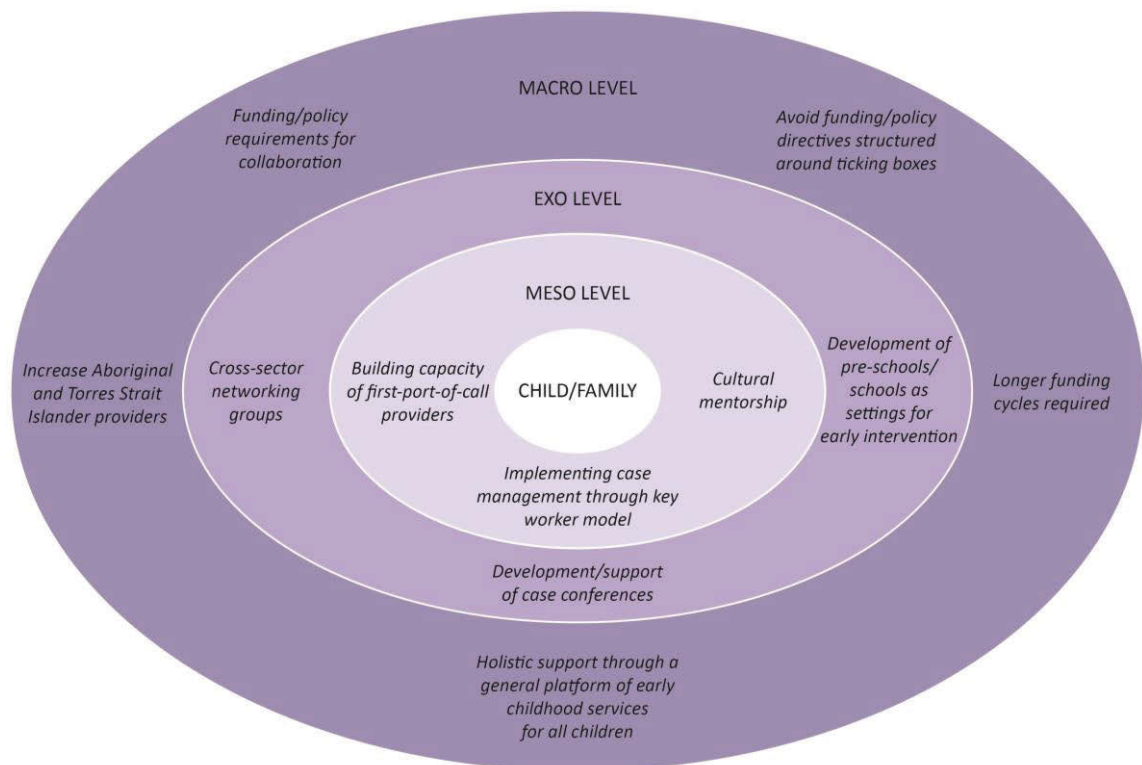


Figure 9.1 Key recommendations

9.2.1 Macro (system) level

Interventions at the macro level are summarised below:

- Development of policy and funding directives should avoid being structured around ticking boxes and encourage meaningful engagement between non-Aboriginal providers and Aboriginal families and services using culturally appropriate models.

- Concrete requirements for collaboration at the exo and meso levels should be built into funding and policy requirements by government at the macro level. For example, a requirement that organisations demonstrate how they have worked together with other relevant organisations and providers, particularly Aboriginal controlled organisations and providers, as a pre-requisite to obtaining funding.
- A need to increase the number of Aboriginal and Torres Strait Islander providers in the mainstream workforce. Increased and secure funding for positions, such as Aboriginal education officers for example, is imperative.
- Early childhood intervention policy for Aboriginal and Torres Strait Islander children with a disability should focus on providing holistic support in the context of a general platform of early childhood services for all children and families.
- Policy and funding directives need to recognise the importance of long-term investment in regards to the time required for non-Aboriginal providers to build trusting relationships with Aboriginal families and services. Longer funding cycles are required.
- A different policy and funding lens is required to measure beneficial outcomes of non-Aboriginal and Aboriginal providers and services working together.

9.2.2 Exo (organisational) level

Interventions at the exo level are summarised below:

- Case conferences should be further developed and implemented to support the role of families in service provision. This can be enabled through funding models.
- Cross-sector networking groups are required to continue to build effective cross-cultural and interprofessional collaborative practice and provide strategic direction.
- Change eligibility criteria for access to support, or match eligibility information to provider recommendations, to implement continuity of care between health care jurisdictions and services.
- Facilitate the development of pre-schools and schools as settings for early intervention. This requires close collaboration with school principals and strategies to achieve buy-in for collaborative programs.

9.2.3 Meso (provider) level

Interventions at the meso level are summarised below:

- Support ongoing cultural mentorship for non-Aboriginal providers.
- Provide funding support to private providers interested in providing free clinics to families to cover additional costs to their private practices.
- Implementing case management through a key worker model, as discussed in Chapter Eight Section 8.4.3.4, was the clear preference of both carers and providers to help both empower families to navigate the system, as well as facilitate cross-sector collaboration between providers. Aboriginal Health Workers employed by Aboriginal Community Controlled Organisations are in a key position to step in to the key worker role for families. Being a key worker in this space requires specific skills, knowledge, and competencies which need to be developed through dedicated training and support by long-term sustainable funding.
- Improved education for providers on how to work effectively with Aboriginal families to address provider withdrawal due to the perception that ‘they don’t want us’.
- Develop the capacity of first-port-of-call providers through information and education to identify families who have fallen through the treatment gap.

9.3 Concluding comments

This thesis has investigated an important area for effectively addressing the health and well-being disparities of Aboriginal Australians. Improving care for children with a disability was identified as an important focus by the Western Sydney community. Guided by the cultural mentorship of the community, this thesis has elucidated the complex and multifaceted process of navigating health and social systems. The findings have provided a unique contribution to the literature in not only describing a phenomena with salience to other vulnerable communities, but has applied novel conceptual frameworks. The Phase two development of a framework for asset-informed service mapping will assist in developing an evidence base for asset-

informed approaches to health inequities, by promoting the systematic and rigorous reporting of methods. This thesis has also extended theoretical application of the Candidacy [19], and Collaborative Practice to Enhance Patient Care Outcomes [13] 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. As the importance of intersectionality is increasingly identified, this methodological approach will be useful [20-22]. Findings from the qualitative study, explored through these frameworks, highlight areas where future interventions and research might be targeted to improve families' access and providers' service provision, such as implementing a key worker model. Several key issues occurred during this study including the rollout of the National Disability Insurance Scheme and closure of the partner ACCHO, underscoring the intensely political issues influencing children and their families' access to services. Improving the health outcomes of Aboriginal Australians is a national priority. Failing to address the needs of Aboriginal children with a disability is a failure of a just and civil society to meet the needs of the most vulnerable. This will require cross-sector, cross-jurisdictional solutions that place the needs of children and families at the centre and assist them in navigating the complex maze of health and social services within a framework of cultural safety and respect.

9.4 References

1. DiGiacomo M, Delaney P, Abbott P, Davidson PM, Delaney J & F, V. 2013, 'Doing the hard yards': carer and provider focus group perspectives of accessing Aboriginal childhood disability services', *BMC Health Services Research*, vol. 13, no. 1, p. 326.
2. Campbell D, Pyett P & L, M. 2007, 'Community development interventions to improve Aboriginal health: Building an evidence base', *Health Sociology Review*, vol. 16, no. 3-4, pp. 304-314.
3. Ou L, Chen J, Hillman K & Eastwood J. 2010, 'The comparison of health status and health services utilisation between Indigenous and non-Indigenous infants in Australia', *Australian and New Zealand Journal of Public Health*, vol. 34, no. 1, pp. 50-56.
4. Morris PS, Leach AJ, Silberberg P, Mellon G, Wilson C, Hamilton E & Beissbarth J 2005, 'Otitis media in young Aboriginal children from remote communities in northern and central Australia: A cross-sectional survey', *BMC Pediatrics*, vol. 5, no. 1, p. 27.
5. Burrow S, Galloway A & Weisssofner N 2009, *Review of educational and other approaches to hearing loss among Indigenous people*, Australian Indigenous HealthInfoNet, Western Australia.
6. Burns J & Thomson N 2013, *Review of ear health and hearing among Indigenous Australians.*, Australian Indigenous HealthInfoNet, Western Australia.
7. Australian Institute of Health and Welfare 2014, *Stronger Futures in the Northern Territory: Hearing Health Services 2012-2013*, Australian Institute of Health and Welfare, Canberra.
8. Green A, Abbott P, Delaney P, Patradoon-Ho P, Delaney J, Davidson PM & DiGiacomo M. 2016, 'Navigating the journey of Aboriginal childhood disability: a qualitative study of carers' interface with services', *BMC Health Services Research*, vol. 16, no. 1, p. 680.
9. Stewart J. 2015, 'Patients fearful ahead of possible closure of western Sydney Aboriginal Medical Service'. *ABC News online*, 22 July, <<http://www.abc.net.au/news/2015-07-21/aboriginal-health-service-closure-to-impact-112c000-patients/6636992>>.
10. Corderoy A. 2015, 'Thousands of Aboriginal patients at risk from health service closure, doctors say'. *The Sydney Morning Herald*, 30 July, <<http://www.smh.com.au/national/health/thousands-of-aboriginal-patients-at-risk-from-health-service-closure-doctors-say-20150729-gims1a.html>>.
11. Gillor G 2015, *Petition to save the Aboriginal Medical Service Western Sydney from forced closure by the Federal Government*. Available: <https://www.change.org/p/the-australian-government-petition-to-save-the-aboriginal-medical-service-western-sydney-from-forced-closure-by-the-federal-government> [Accessed 12/06/2017].

12. National Disability Insurance Scheme 2017, *Early transition in the Nepean Blue Mountains area*. Available: <https://www.ndis.gov.au/about-us/our-sites/nsw/ndis-nepean-blue-mountains-area> [Accessed 12/06/2017].
13. D'amour D & Oandasan I. 2005, 'Interprofessional practice and interprofessional education: An emerging concept', *Journal of Interprofessional Care*, vol. 19, no. Suppl. 1, pp. 8-20.
14. Department of Family and Community Services 2017, *What is case management?* Available: <http://www.community.nsw.gov.au/kts/case-management/case-management> [Accessed 12/06/2017].
15. Department of Health 2017, *Multidisciplinary case conferences*. Available: <http://www.health.gov.au/internet/main/publishing.nsf/content/mbsprimarycare-caseconf-factsheet.htm> [Accessed 12/06/2017].
16. Australian Institute of Health and Welfare 2015, *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples 2015*. Cat. no. IHW 147., Australian Institute of Health and Welfare, Canberra.
17. Australian Health Ministers' Advisory Council 2012, *Aboriginal and Torres Strait Islander Health Performance Framework 2012 Report*, Australian Health Ministers' Advisory Council, Canberra.
18. Loppie Reading C & Wien F 2009, *Health Inequalities and Social Determinants of Aboriginal Peoples' Health*, National Collaborating Centre for Aboriginal Health, British Columbia, Canada.
19. Dixon-Woods M, Cavers D, Agarwal S, Annandale E, Arthur A, Harvey J, Hsu R, Katbamna S, Olsen R, Smith L & Riley R. 2006, 'Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups', *BMC Medical Research Methodology*, vol. 6, no. 1, p. 35.
20. Weber L & Fore ME. 2007, 'Race, ethnicity, and health: An intersectional approach'. In: Vera H & Feagin JR (ed.) *Handbooks of the sociology of racial and ethnic relations*, Springer, United States, pp. 191-218.
21. Bauer GR. 2014, 'Incorporating intersectionality theory into population health research methodology: Challenges and the potential to advance health equity', *Social Science & Medicine*, vol. 110, pp. 10-17.
22. Hankivsky O & Christoffersen A. 2008, 'Intersectionality and the determinants of health: a Canadian perspective', *Critical Public Health*, vol. 18, no. 3, pp. 271-283.

Appendices

Appendix 1: Integrative literature review publication

Green et al. *International Journal for Equity in Health* (2014) 13:126
DOI 10.1186/s12939-014-0126-y



RESEARCH

Open Access

Cross-sector collaborations in Aboriginal and Torres Strait Islander childhood disability: a systematic integrative review and theory-based synthesis

Anna Green^{1*}, Michelle DiGiacomo¹, Tim Lockett¹, Penelope Abbott², Patricia Mary Davidson³, Joanne Delaney⁴ and Patricia Delaney⁴

Abstract

Introduction: Aboriginal and Torres Strait Islander children in Australia experience a higher prevalence of disability and socio-economic disadvantage than other Australian children. Early intervention is vital for improved health outcomes, but complex and fragmented service provision impedes access. There have been international and national policy shifts towards inter-sector collaborative responses to disability, but more needs to be known about how collaboration works in practice.

Methods: A systematic integrative literature review using a narrative synthesis of peer-reviewed and grey literature was undertaken to describe components of inter- and intra-sector collaborations among services to Aboriginal and Torres Strait Islander children with a disability and their families. The findings were synthesized using the conceptual model of the ecological framework.

Results: Thirteen articles published in a peer-reviewed journal and 18 articles from the grey literature met inclusion criteria. Important factors in inter- and intra-sector collaborations identified included: structure of government departments and agencies, and policies at the macro- (government) system level; communication, financial and human resources, and service delivery setting at the exo- (organizational) system level; and relationships and inter- and intra-professional learning at the meso- (provider) system level.

Conclusions: The policy shift towards inter-sector collaborative approaches represents an opportunity for the health, education and social service sectors and their providers to work collaboratively in innovative ways to improve service access for Aboriginal and Torres Strait Islander children with a disability and their families. The findings of this review depict a national snapshot of collaboration, but as each community is unique, further research into collaboration within local contexts is required to ensure collaborative solutions to improve service access are responsive to local needs and sustainable.

Keywords: Aboriginal and Torres Strait Islander, Childhood, Disability, Collaboration, Inter-sector, Intra-sector

* Correspondence: Anna.Green-1@uts.edu.au

¹Center for Cardiovascular and Chronic Care, Faculty of Health, University of Technology, Sydney, PO Box 123, Broadway, NSW 2007, Australia
Full list of author information is available at the end of the article



© 2014 Green et al.; licensee BioMed Central. This is an Open Access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly credited. The Creative Commons Public Domain Dedication waiver (<http://creativecommons.org/publicdomain/zero/1.0/>) applies to the data made available in this article, unless otherwise stated.

Introduction

In contrast to other countries, the Australian population has access to a first-class universal healthcare system and is relatively healthy [1]. Aboriginal and Torres Strait Islander peoples are an exception to this rule. The gap in health outcomes and life expectancy between Aboriginal and Torres Strait Islander peoples and other Australians has been widely reported [1-3]. The rate of death for Aboriginal and Torres Strait Islander children is more than twice that for other children [2]. This disparity in health outcomes extends to disability [4]. Increasingly there is recognition of the importance of the social determinants of health and of health as a human right.

Social determinants of health and human rights

Although there are social gradients in the incidence of disability, it is reported that little attention has been paid to research on the social determinants of health in disability policy [5]. Policy has the potential to act as a structural determinant of health [6]. The Australian Human Rights Commission has drawn attention to a number of human rights violations faced by Aboriginal and Torres Strait Islander persons with a disability. These include individual rights to health and education that are impacted by the high levels of socio-economic disadvantage [7]. The link between disability and poverty is bi-directional [8]. In the United States and Canada, indigenous populations also experience the negative impact of socio-economic disadvantage on service access [9-11]. Racism is another key social determinant of health that negatively impacts service access [12]. Experiences of direct and indirect racism have been linked to distrust of mainstream organizations and providers [2,13].

Health disparities in childhood disability

Aboriginal and Torres Strait Islander children experience a higher prevalence of disability than other children [4]. They encounter higher rates of hearing loss [14,15] which has been linked to the high prevalence of middle ear diseases such as otitis media (OM). Rates of OM experienced by Aboriginal and Torres Strait Islander children are among the highest in the world, similar to those in low income countries and at a level classified by the World Health Organization (WHO) as a massive public health problem [2,16,17]. OM is also experienced for longer and more persistent periods by Aboriginal and Torres Strait Islander children (32 months compared with 3 months for other children) [18,19]. Aboriginal and Torres Strait Islander children have also been found to have a significantly higher prevalence of communication disorders [20] and are 1.3 times as likely to require assistance with self-care, mobility or communication than other children [21]. Such disparity is also evident in developmental delay [22,23]. Early intervention is vital as high rates of

disability can negatively impact education, speech, language and social development, and employment outcomes [13,14,17,19,24-26]. It is also acknowledged that intervening at the early stages of childhood development is more cost-effective than intervening later in life [27].

Social determinants of health and Aboriginal and Torres Strait Islander childhood disability

Aboriginal and Torres Strait Islander children not only experience a higher prevalence of disability but are also disproportionately affected by socio-economic disadvantage [2]. Almost half of Aboriginal and Torres Strait Islander households are in the lowest income group and are 4 times less likely to be in the highest group than other Australians [2]. Socio-economic disadvantage directly impacts disability for Aboriginal and Torres Strait Islander children [25] who are more likely to experience negative developmental outcomes from disabilities like OM-related hearing loss due to social determinants of health [18]. Addressing the influence of social determinants of health on Aboriginal and Torres Strait Islander childhood disability requires a shift in thinking as they are often considered indirect to the traditional responsibilities of health, education, and social service sectors [25,28,29].

Barriers to service access

Aboriginal and Torres Strait Islander children with a disability and their families face many barriers to service access [25]. A key barrier is the confusion caused by complex and fragmented service provision across government departments and agencies working in professional silos [30,31]. This lack of integration is often described by a silo approach. A silo refers to systems and processes that operate in isolation from each other.

Policy response to improve service access

The need for holistic and collaborative responses to disability is recognized internationally [8]. The World Report on Disability identifies that policies within health, education and social service sectors all impact on disability outcomes [8]. Nationally, the Australian Government's "Close the Gap" campaign to reduce Aboriginal and Torres Strait Islander disadvantage advocates the need for collaboration across all sectors and levels of Government for effective service coordination [32]. The national policy direction towards collaboration and whole-of-government approaches is reflected in a number of disability-specific policies and strategic frameworks [3,33-36].

Little is known about Aboriginal and Torres Strait Islander children with a disability [4]. Despite the policy push towards collaboration, there has been no systematic attempt to elucidate how collaboration works in practice across and within sectors involved in service provision. Therefore, the current authors set out to answer the

question: What are the important components involved in inter- and intra-sector collaboration in Aboriginal and Torres Strait Islander childhood disability? Understanding these components will be essential in improving service provision and access for Aboriginal and Torres Strait Islander children with a disability and their families.

Methods

We conducted an integrative literature review using a systematic approach to identify components of collaboration guided by an investigator-developed protocol.

Eligibility criteria

Disability is a complex concept with no universally agreed definition [8]. For the purposes of this review, disability refers to long-term physical, mental, intellectual or sensory impairments that, interacting with environmental and attitudinal barriers, hinder full and effective participation in society on an equal basis with others [37].

Included articles focused on Aboriginal and Torres Strait Islander children with a disability and/or their families/

carers, or providers of services to this population (eg from the health, education and social service sectors), and include reference to collaboration or interaction within or across two or more providers/sectors. We included articles in the English language specifically addressing Australian issues. No publication date limits were imposed and all study designs were included be they quantitative, qualitative or mixed methods. Commentaries were also included. Articles were included regardless of whether they were published in peer-reviewed journals or grey literature. Articles were excluded if their sole focus was on adolescent or adult disability or a population other than Aboriginal and Torres Strait Islander peoples.

Search strategy

A systematic electronic database search strategy using Boolean terms was developed in collaboration with a health librarian. Search terms were Medical Subject Headings (MeSH) terms and keywords including derivatives of the key terms 'collaboration', 'child', 'disability' and 'indigenous' (see Figure 1 for an example). The grey literature

Search strategy for PsycInfo

1. exp. indigenous (DE "Indigenous Populations") OR Australian Indigenous OR Australian Aboriginal OR Aborigine OR Oceanic ancestry group OR ATSI OR Torres Strait Islander.
2. exp. disability (DE "Learning Disorders" OR DE "Developmental Disabilities" OR DE "Disabilities" OR DE "Speech Disorders" OR DE "Hearing Disorders" OR DE "Physical Disorders" OR DE "Learning Disabilities") OR exp. intellectual disability (DE "Vision Disorders") OR learning disorder OR exp. language disorder (DE "Language Disorders") OR exp. communication disorder (DE "Communication Disorders") OR hearing impaired OR hearing loss OR hearing disorder OR visually impaired OR mentally disabled OR developmental disability OR exp. attention deficit (DE "Attention Deficit Disorder with Hyperactivity" OR DE "Attention Deficit Disorder") OR disruptive behavior disorders OR child behavior disorders OR child development disorders OR motor skills disorders OR cognition disorder OR exp. Speech (DE "Speech Disorders") OR language disorders OR exp autism (DE "Autism") OR autistic disorder OR exp. Asperger syndrome (DE "Aspergers Syndrome") OR physical disability.
3. child OR newborn OR baby OR babies OR infant OR infants OR children OR childhood OR neonate*.
4. exp. collaboration (DE "Collaboration") OR exp. collaborative (DE "Integrated Services") OR patient care team OR joint practice OR multidisciplinary care team OR interdisciplinary team OR inter-sector OR intra-sector OR cross-sector OR multidisciplinary OR whole of government OR exp. interdisciplinary (DE "Interdisciplinary Treatment Approach") OR interdisciplinary communication OR intradisciplinary OR inter-professional learning.
5. 1 AND 2 AND 3 AND 4

Figure 1 Electronic database search strategy example*. *Search terms varied slightly for each database.

was searched using variations of the key search terms from each of these groupings.

Information sources

A systematic search of health, education, social science, multidisciplinary and indigenous electronic databases was conducted to identify articles published in peer-reviewed journals. The electronic databases Cumulative Index to Nursing and Allied Health Literature (CINAHL), EMBASE, PsycInfo, Medline, Education Resources Information Center (ERIC), Social Services Abstracts, Sociological Abstracts, Academic Search Complete, Health Collections (Informit), Indigenous Studies Bibliography (AIATSIS), Australian Public Affairs Information Service (APAIS), Australian Public Affairs Information Service - Health (APAIS-health), Aboriginal and Torres Strait Islander Health (A&TSL-health), Health & Society, Multicultural Australia and Immigration Studies - Aboriginal and Torres Strait Islander Subset (MAIS-ATSIS), Rural and Remote Health Database (RURAL), Australian Indigenous HealthInfoNet and Google Scholar search engine were searched from 13th – 14th May 2014. Reference lists were also searched for relevant articles.

Grey literature was identified through a search of websites of Aboriginal and Torres Strait Islander and disability representative organizations, the National Disability Organisations' Clearinghouse, Trove theses database, and Mednar from 23rd May – 4th June 2014. Grey literature identified during the search for articles published in peer-reviewed journals was also reviewed.

Study selection

Returned articles published in peer-reviewed journals were imported into EndNote software. One hundred articles were assessed against eligibility criteria independently by two researchers (AG and MD). Any inconsistencies were discussed until consensus was reached. One researcher (AG) assessed the remaining articles.

Data collection

Data were extracted from the original text of included articles by AG into an a priori designed electronic spreadsheet. Data items included the setting, design, disability/impairment, population, aims, and methods. Data items specific to collaboration were extracted and grouped according to the discipline of providers involved in collaboration, collaborative models, components of collaboration, and key conclusions or recommendations.

Evaluation and analysis

Quality appraisal of the articles published in a peer-reviewed journal was conducted as part of a systematic approach to provide an overview of quality, but was not given weighting in the analysis and synthesis of data due

to the lack of formal methods for this in integrative reviews. Quality appraisal of all included articles published in a peer-reviewed journal was conducted independently by two researchers (AG-MD or AG-TL) who met to establish agreement on the final rating. Any disagreements were resolved through discussion. The following critical appraisal tools were used: criteria for assessing qualitative literature [38], the STrengthening the Reporting of OBservational studies in Epidemiology (STROBE) checklist [39], the Transparent Reporting of Evaluations with Nonrandomized Designs (TREND) checklist [40], the Mixed Methods Appraisal Tool (MMAT) [41], and the Measurement Tool to Assess Systematic Reviews (AMSTAR) checklist [42] to assess qualitative, observational, intervention, mixed methods, and review studies, respectively. All included articles were evaluated using the Level of Evidence ranking system by Melnyk and Fineout-Overholt [43]. Data analysis was guided by the narrative synthesis approach by Popay et al. [44]. After developing the preliminary synthesis of findings we searched for a conceptual model. The model needed to provide a holistic framework centered on the child and their family that encompassed the different system levels of collaboration and how they interact with one another. An adaptation [45] of Bronfenbrenner's ecological model for child development [46] represented a conceptual model in which the relationships in the data could be explored at the macro- (government), exo- (organizational) and meso- (provider) system levels (see Figure 2). The ecological model has previously been referenced in the context of addressing factors influencing equitable service access for underserved populations with a communication disability [47]. To our knowledge, it hasn't before been applied specifically to service access issues in Aboriginal and Torres Strait Islander childhood disability. This organizing framework reflects factors that interact to achieve a desired outcome and also the impact of social interaction. Addressing each element discretely without considering the interdependency of elements is unlikely to achieve desirable outcomes.

Results

The database search and peer-reviewed article selection is depicted in Figure 3. Thirteen peer-reviewed articles met inclusion criteria. The majority of studies were qualitative ($n = 5$) (Table 1) followed by discussion papers ($n = 3$) (Table 2), observational ($n = 2$) (Table 3), intervention ($n = 1$) (Table 4), mixed methods ($n = 1$) (Table 5) and literature review ($n = 1$) (Table 6). The grey literature search retrieved 18 articles that met the inclusion criteria (Table 7). In total, 31 articles were included in the review.

The literature predominantly reported on hearing impairment and related disability, such as learning impairments ($n = 17$). Of the included articles, 14 provided details on 12 different models involving inter- and intra-sector

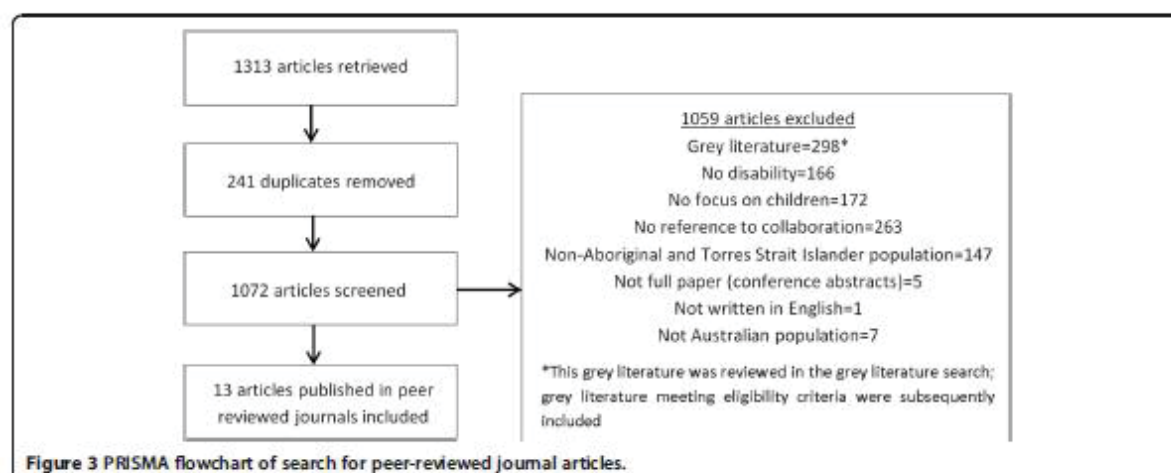
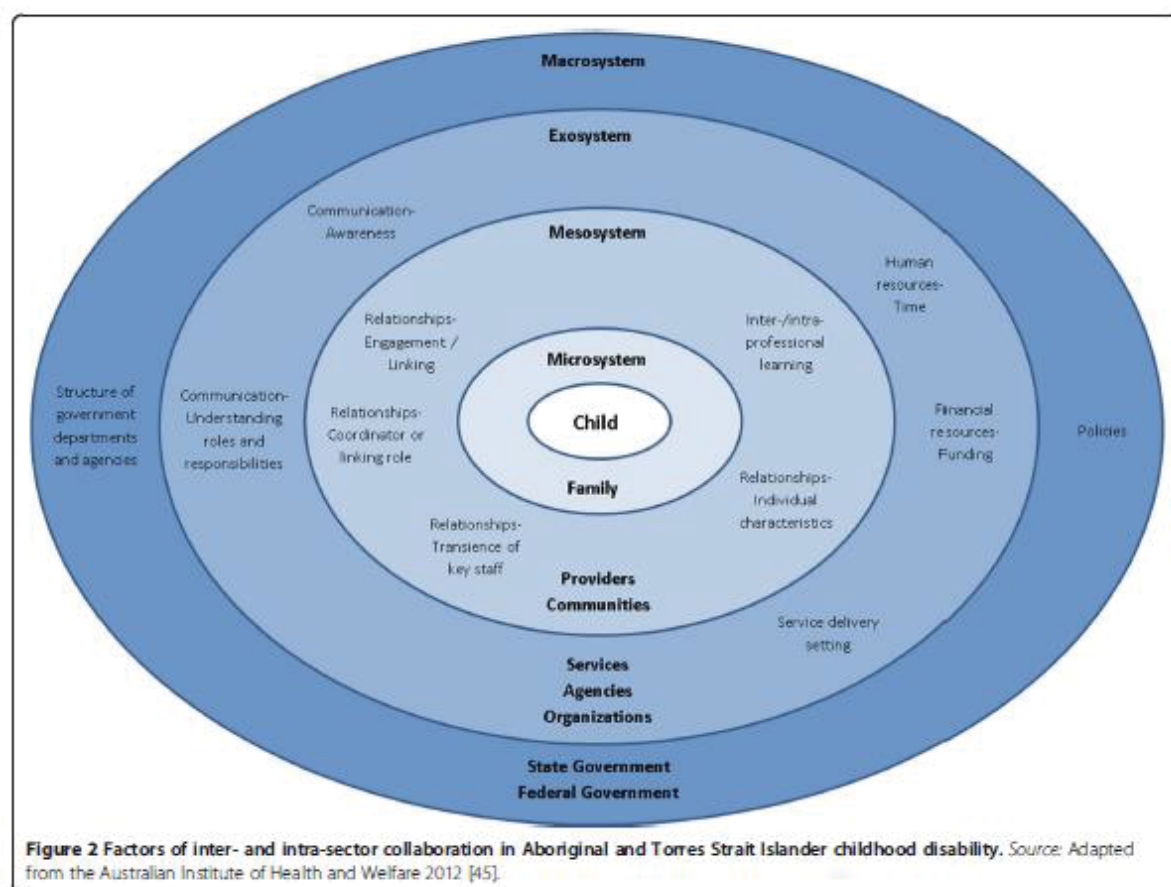


Table 1 Qualitative studies

First Author (year)	Disability/Impairment	Design	Level of evidence	Population	Setting	Aims	Methods	Model involving collaboration
Davidson, B. (2013) [72]	Communication	Qualitative	VI	Aboriginal and Torres Strait Islander children	Aboriginal and Torres Strait Islander Independent Community School; Urban; Queensland	To raise awareness through lessons learned from an inter-professional clinic.	Survey with open ended questions of university students on placement; Informal feedback from teachers	Yes
DiGiacomo, M. (2) (2013) [53]	General disability	Qualitative	VI	17 government and non-government health and social service providers; 5 carers	Aboriginal Community Controlled Health Service; Urban; New South Wales	To determine the elements involved in service access for urban Aboriginal children with a disability.	Community forums using focus group methods	No
McSwan, D. (2001)* [68]	Hearing	Evaluation	VI	Indigenous children from 3 rural/remote schools	Rural/remote communities	Report on a project aiming to develop a whole of community approach to the impact of OM on learning.	Questionnaires and interviews from persons involved in program implementation	Yes
Nelson, A. (2004, 2007) [66,67]	Physical; Developmental; Learning; General disability	Qualitative	VI	43 Indigenous students	Primary schools and preschools; Urban; Queensland	To evaluate a pilot project and explore the elements of a culturally and socially appropriate occupational therapy service.	Focus groups and interviews with teachers and parents; Semi-structured qualitative survey	Yes

*Reports on the same study as the included grey literature report: McSwan, D. et al. (2001) Report: A Whole Community Approach to Otitis Media - reducing its incidence and effects. Townsville: Rural Education, Research & Development Centre, James Cook University.

Table 2 Discussion papers

First Author (year)	Disability/ Impairment	Design	Level of evidence	Population	Setting	Aims	Methods	Model involving collaboration
Aldred, R. (2002) [20]	Development	Discussion paper	VI	Aboriginal children under 5 years old	Urban; Queensland	To explain how the development of a speech pathology position in an Indigenous Hearing Health Service sought to address service access issues.	Author observation and reflections	No
Clarke, K. (2013) [48]	Development; Learning	Discussion paper; Model	VI	Rural and remote Aboriginal children	Rural and remote communities	To present the SpICE Model as part of the solution to the promotion of child wellbeing.	Author observation and reflections	Yes
Kirkham, L.-A. (2010) [59]	Hearing	Discussion paper; Conference report	VI	Indigenous children	Australia	To share findings from the Australian Otitis Media workshop.	Author observations and reflections	No

Table 3 Observational studies

First Author (year)	Disability/ Impairment	Design	Level of evidence	STROBE score	Population	Setting	Aims	Methods	Model involving collaboration
Adams, K. (2004) [65]	Hearing	Observational; quantitative	IV	16	Indigenous children aged 0–11 years old	Gippsland Region; Victoria	To describe the Gippsland Indigenous Hearing Health Program and evaluation results.	Analysis of ear screening outcomes and management	Yes
Smith, A. (2012)* [74]	Hearing	Observational; longitudinal study	IV	16	Indigenous children from 21 schools	Remote Aboriginal community; Central Queensland	To observe the outcomes of the ear screening service in the first 3 years.	Retrospective review of service activity	Yes

*Study is looking at the same service as Elliott, G. (2010) [70].

collaboration. The majority of these models centered on collaboration within different areas of the health sector (intra) ($n = 5$) and between the health and education sectors (inter) ($n = 5$). Half of the models ($n = 6$) were set in schools or early childhood centers and the most common model component ($n = 6$) was a form of capacity building.

Overall, the qualitative studies were generally well-reported according to Kitto et al's criteria for assessing qualitative literature [38] that evaluated clarification of research, data collection techniques, justification of qualitative approach, and interpretation. None of the studies reported on whether the sampling techniques supported generalizability and seldom demonstrated transparency of data analysis or researcher reflexivity. The mean STROBE score for the observational studies was 16 out of 22 (73%). Both studies reported well on rationale, study design, setting, variables, data sources, outcome data, and generalizability. Neither study reported on the eligibility/selection of participants, study size or study limitations. The TREND score was 15 out of 22 (68%) for the intervention study, which reported well on background, methods, and results but not generalizability. The mixed method study received a MMAT score of 50% for the qualitative component, reporting well on data sources and relationship between findings and context but not on analysis or researcher influence, 75% for the quantitative component, reporting well on sampling strategy, measurements, and response rates, and 50% for the mixed method component, reporting well on research design but not limitations. The literature review received an AMSTAR score of 78% for the 9 applicable items and reported well on study selection, data extraction, search strategy, study characteristics and quality assessment of studies. The literature review did not provide a list of excluded studies and there was no assessment of publication bias.

The following section provides a narrative synthesis of the findings using the macro- (government), exo- (organizational), and meso- (provider) system levels of the ecological model to demonstrate the components of

inter- and intra-sector collaboration in Aboriginal and Torres Strait Islander childhood disability.

Macro- (government) system factors

Factor: Structure of government departments and agencies

The siloed structure of health, education and social service departments and agencies was found to impede service integration and the ability of providers to work collaboratively [48]. Siloes of service provision across government departments and agencies and between levels of government [49] negatively impacts service access for families when they have to navigate different waiting lists and assessment processes, and receive disparate pieces of information from professionals working in isolation [48,50,51]. The fragmentation and complexity of government services [52] impede opportunities for collaboration, with some providers reporting difficulties in locating and communicating with relevant services [52,53]. The adoption of a consultative approach across health, education and social service departments has been recommended as a solution for reducing service duplication and fragmentation and is more aligned with the needs of the child- which are beyond the biomedical and include social, cultural, economic and psychological issues [50].

Factor: Policies

Collaboration at the level of policy making can address the barriers generated by existing structures of government departments and agencies. Formalized agreements like memoranda of understanding (MoU) and collaborative frameworks between government sectors can facilitate collaboration at the level of service provision [54]. MoUs between the health and education sectors have promoted collaboration between health professionals and school staff in screening and treatment of middle ear disease to prevent hearing loss [54,55]. Frameworks for whole-of-government approaches have been recognized as important in providing coordinated interagency responses [56–58]. Formalized agreements should focus on detailing a set of long-, medium- and short-term strategies as it

Table 4 Intervention study

First Author (year)	Disability/ Impairment	Design	Level of evidence	TREND score	Population	Setting	Aims	Methods	Intervention type	Model involving collaboration
Elliott, G. (2010)* [70]	Hearing; vision	Intervention	IV	15	442 Aboriginal and Torres Strait Islander children, from 0–6 years old	South Burnett region; Queensland	Feasibility of integrating a mobile telehealth-enabled screening service with existing community health services.	Feasibility determined by the number of consenting children, referral rate, and three-point categorical scale rating the quality of screening images	Mobile telehealth screening service	Yes
First Author (year)	Intervention recruitment	Intervention control Group	Intervention content/ Components			Intervention Duration	Intervention Evaluation			
Elliott, G. (2010) [70]	Schools disseminated consent forms and information sheets; children with parental consent were screened	None	An Aboriginal health worker coordinated a mobile health-screening service which was taken to daycare centers and primary schools. Assessment results were put into a secure database and referrals for review and management were made to local health services and tele-otology clinics.			6 months	Community acceptance, the practical feasibility of presenting diagnostic information for online consultations, and integration with existing community services were evaluated for feasibility.			

*Study is looking at the same service as Smith, A. (2012).

Table 5 Mixed method study

First Author (year)	Disability/ Impairment	Design	Level of evidence	MMAT score	Population	Setting	Aims	Methods	Model involving collaboration
Raman, S. (2011) [63]	Developmental	Mixed methods (quantitative/ qualitative)	VI	*50% **75% ***50%	Aboriginal children in out-of-home care	Urban; New South Wales	Evaluation of the multidisciplinary KARI clinic and its outcomes.	Semi-structured interviews; Review of clinical data collected on the first 100 children seen by the clinic	Yes

*Qualitative component; **Quantitative component; ***Mixed method component

provides clarity around collaborative programs for local providers [55,59].

Exo- (organizational) system factors

Factor: Communication - Awareness

Although multiple agencies and services may be involved with the care of a child with a disability, this does not mean that they are all aware of each other's existence, which can lead to duplication of resources [60]. Both families and providers have identified the lack of communication between, and knowledge of, the different agencies and services as a barrier to accessing available support [53]. Raising awareness of collaborative partnerships through the distribution of educational resources across agencies and services facilitates collaboration and the professional development of providers with little knowledge of disability [52,55,56]. Distribution of these resources helps providers in remote areas of Australia who have reported feeling like they work in isolation [61]. Advertising collaborative projects and the participating personnel also aids collaboration by reducing the risk associated with providers working outside their professional boundaries [50]. Good community awareness of the organization that is providing a program has also been reported to facilitate the establishment of collaborative organizational partnerships with local services [62].

Factor: Communication - Lack of role clarity and responsibility

Ambiguity and lack of role clarity and responsibilities of different providers, agencies and organizations is a key barrier to collaboration at the exo- (organizational) system

level [57]. The role of Aboriginal Health Workers is unclear to some mainstream providers leading to their underutilisation, despite the important role they play [20]. Formally communicating the role and responsibility of each team member is reported as an essential step when putting into practice an inter-agency or multi-disciplinary model [50].

Factor: Financial and human resources

Barriers to the uptake and sustainability of collaborative models include difficulty providing them in sectors that are already facing service provision within a tightening financial environment [48] and a lack of the levels of funding required for providing holistic care approaches [63,64]. Where organizations continue to provide collaborative models of service provision despite lack of appropriate funding they report that this is done so "on sheer good will" [63] with staff often working beyond their normal hours [64].

Building effective and trusting collaborative relationships across different organizations, agencies and services takes time [57,62,65]. Collaboration can be impeded when providers lack the time to develop the skills and build the networks required [53].

Factor: Service delivery setting

The effectiveness of a collaborative program is influenced by the setting in which it is delivered. Collaboration is facilitated by the delivery of mainstream programs in culturally safe environments for Aboriginal and Torres Strait Islander providers, communities and families [51,53,66]. Delivering collaborative health services within schools has

Table 6 Literature Review

First Author (year)	Disability/ Impairment	Design	Level of evidence	AMSTAR score	Population	Setting	Aims	Methods	Model involving collaboration
DiGiacomo, M (1) (2013) [51]	General disability	Integrative literature review	V	7	Aboriginal and Torres Strait Islander children	Australia	To ascertain the elements that impact on access to support and management, diagnosis and prevention.	Integrative review using systematic methods with a narrative synthesis	No

Table 7 Grey literature

Citation	Disability/Impairment	Design	Level of evidence	Focus/Setting	Model involving collaboration
(2006). Australian Indigenous EarInfoNet and InfoNetwork. <i>Aboriginal and Islander Health Worker Journal</i> , July/August 30(3). [61]	Hearing	Content overview	VII	Aboriginal children; To provide information on the Indigenous EarInfoNet web resource to support an Indigenous EarInfoNetwork	No
(2013). Otitis media: helping to close the gap in Indigenous Australia. <i>Medicus (Nedlands, WA)</i> , 53(2). [26]	Hearing	Description of the Earbus program	VII	Description of the Telethon Speech Hearing Centre for Children's Earbus Program in Western Australia which provides ear health checks to Aboriginal and Torres Strait Islander children.	Yes
ARTD Consultants (2008). Evaluation of the Aboriginal otitis media screening program: Final Report. Sydney: NSW Health. [55]	Hearing	Mixed methods; Semi-structured interviews; Case studies; Analysis of screening data	VI	The Aboriginal Otitis Media Screening Program provides free screening to Aboriginal children between 0–6 years old. The aim of the evaluation was to gather information on the program's appropriateness and inform future policy directions.	No
Australian Institute of Health and Welfare (2014). Stronger Futures in the Northern Territory: Hearing Health Services 2012–2013. Canberra: Australian Institute of Health and Welfare. [24]	Hearing	Evaluation of data collected by relevant health professionals on service provided and demographic characteristics of the children	VI	This report provides data on the Northern Territory Child Hearing Health Coordinator (CHHC) initiative.	Yes
Burns, J. & Thomson, N. (2013). Review of ear health and hearing among Indigenous Australians. Western Australia: Australian Indigenous HealthInfoNet. [49]	Hearing	Narrative literature review	VII	This review provides an overview of the ear health and hearing of Aboriginal and Torres Strait Islander peoples to support the development of future policies and programs.	No
Burrow, S., Galloway, A., & Weissfouer, N. (2009). Review of educational and other approaches to hearing loss among Indigenous people. Western Australia: Australian Indigenous HealthInfoNet. [58]	Hearing	Literature review	VII	Summary of the literature on educational and other approaches to hearing loss in Indigenous populations.	No
Burton, J. (2012) Opening Doors Through Partnerships: Practical approaches to developing genuine partnerships that address Aboriginal and Torres Strait Islander community needs April 2012. Victoria: SNAICC. [64]	General disability	Case study analysis approach of interviews; Reports on 9 case studies	VI	Explores the steps mainstream service providers, Aboriginal Community Controlled Organisations and government can take to develop and support partnerships to increase the quality and choice of culturally appropriate services.	No
Gilroy, J. (2012) The participation of Aboriginal people with a disability in disability services in New South Wales, Australia. <i>PhD thesis</i> : University of Sydney. [60]	General disability	Thesis; Focus groups and interviews	VI	This thesis identifies and describes the elements influencing participation of Aboriginal people in disability services from the perspectives of both non-Aboriginal and Aboriginal employees in two NSW funded disability services.	No
Higgins, J. & Beecher, S. (2010) The Secretariat of National Aboriginal and Islander Child Care (SNAICC) Early Days Project on Autism Spectrum Disorders August 2010. Victoria: SNAICC. [71]	Autism Spectrum Disorders	Interviews; Case study	VI	The Parenting Research Centre invited SNAICC to help ensure that the Early Days Project on Autism Spectrum Disorders (ASD), a free national program for parents and carers of a child under 6 with an ASD, is culturally appropriate and inclusive of Aboriginal and Torres Strait Islander families.	Yes
McSwan, D., Ruddell, D., Searston, I. (2001). Report: A Whole Community Approach to Otitis Media - reducing its incidence and effects. Townsville: Rural Education, Research &	Hearing	Evaluation of a feasibility study	VI	Final report of the research project that aimed to reduce the occurrence and impact of OM in 3 Northern Queensland communities; Improve learning outcomes for Aboriginal	Yes

Table 7 Grey literature (Continued)

Development Centre, James Cook University. * [50]					children who have or had OM, and implement culturally appropriate prevention and management practices.	
Ministerial Advisory Committee: Students with Disabilities (2003). Aboriginal Students with Disabilities. South Australia: Government of South Australia. [52]	General disability	Interviews formed into a synopsis of stories; Stakeholder forum	VI		The Ministerial Advisory Committee: Students with Disabilities commenced a project in 2002 to identify issues relating to education for Aboriginal children with a disability to advise the South Australian Minister for Education and Children's Services on policy directions.	No
Ministerial Advisory Committee: Students with Disabilities (2007). Aboriginal Students with Disabilities: Otitis Media and Conductive Hearing Loss. South Australia: Government of South Australia. [56]	Hearing	Comparative case studies; Interviews; Surveys; Literature review	VI		This study examined the programs established to address the high prevalence of OM and hearing loss experienced by Aboriginal children in urban and regional areas of South Australia.	No
New South Wales Ombudsman (2010). Improving service delivery to Aboriginal people with a disability: a review of the implementation of ADHC's <i>Aboriginal Policy Framework and Aboriginal Consultation Strategy</i> . Sydney: New South Wales Ombudsman. [73]	General disability	Literature review; Document review; Stakeholder consultations; Interviews; Review of relevant complaints and inquiries	VI		This review examined the Ageing, Disability and Home Care (ADHC) initiatives to achieve the goals of the Aboriginal Policy Framework and Aboriginal Consultation Strategy, and assessed whether they have resulted in better service access for Aboriginal people with a disability and their families.	No
Purcal, C., Newton, B.J., Fisher, K.R., Eastman, C., & Mears, T. (2013). School readiness program for Aboriginal children with additional needs: working with children, families, communities and service providers. Interim evaluation report. Sydney: Social Policy Research Centre, UNSW. [62]	General disability	Evaluation using participatory research principles; Literature review; Interviews; Review of program data	VI		This project evaluated the Northcott Disability Services school readiness program for Aboriginal children with additional needs to support their transition to school located in an urban and rural area in New South Wales.	Yes
Queensland Health (2009). <i>Deadly Ears, Deadly Kids, Deadly Communities: 2009–2013</i> . Queensland: Queensland Government. [57]	Hearing	Framework description	VII		Description of the <i>Deadly Ears, Deadly Kids, Deadly Communities: 2009–2013</i> strategic framework for Queensland to improve the ear health of Aboriginal and Torres Strait Islander children.	No
Scholes, J. (2010). <i>Deadly Ears Speech Pathology: Working through partnerships to limit the impact of otitis media on the communication development of Aboriginal and Torres Strait Islander children</i> . <i>Talkabout</i> , 23(2). [36]	Hearing	Discussion paper	VII		Describes the partnership population based approach of <i>Deadly Ears Speech Pathology</i> service within the context of the multidisciplinary <i>Deadly Ears Program</i> .	Yes
Simmons, K., Rotumah, V., Cookson, M., & Grigg, D. (2012). <i>Child Hearing Health Coordinators Tackle Ear and Hearing Health in the NT</i> . <i>The Chronicle</i> , 23(1). [69]	Hearing	Program description	VII		Describes the role of the Child Hearing Health Coordinator (CHHC) positions located within the Northern Territory Department of Health, Health Development Unit to coordinate regional programs that are inclusive of hearing health.	No
Western Australia Education and Health Standing Committee (2012). <i>Report on key learnings from the Committee research trip 11–17 March 2012</i> . Perth, WA: Parliament of Western Australia. [54]	Foetal Alcohol Spectrum Disorder; Hearing	Forums; Briefings	VII		Report of a research trip undertaken by the Western Australia Education and Health Standing Committee to explore issues around health and education in North West Western Australia to improve educational outcomes.	No

*Reports on the same study as the included peer-reviewed article by McSwan, D. (2001).

been reported to reduce the stigma and the socio-economic impact of having to attend services in mainstream settings for Aboriginal and Torres Strait Islander families, while increasing program participation [66,67]. Basing health services within schools also allows the services to be responsive to local needs and promotes increased awareness of disability and relevant services among education providers [55,67]. Collaboration between health and education services based in a single setting provides a one-stop-shop, which facilitates the sharing of information between different services and organizations [52].

Meso- (provider) system factors

A number of key factors of collaboration are found at the front line of collaborative service provision within the meso- (provider) system where the interactions occur between providers, communities and Aboriginal and Torres Strait Islander families and their children.

Factor: Relationships

A key facilitator to collaboration at this level is the coordinator or linking role. The appointment of a person external to the services or agencies involved whose role is to link the different players and act as a trainer, motivator and sustainer can be important to a collaborative interdisciplinary approach [50,68,69]. In the context of Aboriginal and Torres Strait Islander childhood disability, this person is usually local to the community (eg a community liaison person, Aboriginal Education Worker, Aboriginal Health Worker) and is a conduit between providers, communities and families, also promoting the cultural competence of services [52,60,64,66,67,70,71].

The effectiveness of the coordinator or linking role in facilitating collaboration is influenced by the individual's characteristics. Being open and inclusive and having personal contacts among decision makers in the organizations, agencies, and services involved promotes collaboration [50]. The effect of individual characteristics on collaborative relationships extends to providers. Collaboration can be impeded by specialist providers choosing to only draw knowledge and skills from their traditional disciplines [48]. Aboriginal and Torres Strait Islander provider experiences of racism and historical trauma can obstruct engagement with mainstream services [53]. Awareness of cultural difference and individual attitudes [72] and getting along well with people [66] are individual provider characteristics that can facilitate collaborative relationships. Transience and turnover of key staff can disrupt collaborative efforts [50,56,68].

Building relationships integral to collaboration at the local level is facilitated by face-to-face provider engagement and 'linking' with communities [48,58,73]. Provider-to-provider engagement is facilitated by demonstrating mutual respect and understanding [50,72], having access

to direct links for communication, and using open and respectful communication strategies [50,51]. The importance of engagement is reflected in the collaborative Specialist Integrated Community Engagement (SpICE) model that is based around the concept of 'linking' different sectors and the community through engagement to build social capital and a 'community of learners' to sustain the collaborative process [48]. Engaging the community can be important to the success of collaborative programs [74] and tapping into existing collaborative relationships in the community can facilitate the engagement process [67]. Where a mainstream organization is unknown to a community, attending interagency meetings in the local area by their providers can facilitate engagement with Aboriginal and Torres Strait Islander organizations [62].

Factor: Inter- and intra-professional learning

The modeling of inter- and intra-professional collaboration by clinical educators from different disciplines for university students on placement has been reported to facilitate a well-coordinated and holistic approach to learning [72]. The sustainability of collaborative practices is increased by empowering students to incorporate the lessons learned into their future practice [72]. Inter- and intra-professional learning also facilitates collaboration by creating supportive relationships between providers from different disciplines [66].

Discussion

The findings of this review depict a national snapshot of collaboration addressing the limited understanding of how collaboration works in practice in the field of Aboriginal and Torres Strait Islander childhood disability. The complex nature of childhood development, particularly for Aboriginal and Torres Strait Islander children, has seen recognition of the need for a shift from a purely medical view of disability to collaborative approaches that also take into account social and environmental factors [47,48,53]. Divisions between mainstream, specialist and non-mainstream services can result from top-down approaches that do not work for addressing complex problems which require 'buy-in' to collaborative approaches at all levels [30,75]. In the move towards collaboration, however, it is important to recognize that collaboration is, in itself, a complex concept which has the potential to inspire innovative solutions or create frustration [76]. Further research is required into collaborations in Aboriginal and Torres Strait Islander childhood disability to maximize the potential, and minimize any negative impacts, of collaborative approaches. The paucity of research on Aboriginal and Torres Strait Islander children with a disability [4] also means exploring the experiences of children and their families in accessing services is

important to completing a holistic picture in order to improve service access.

The importance of respectful communication and culturally appropriate program delivery as found in this review demonstrates the need for cultural competence as a central pillar of collaboration in Aboriginal and Torres Strait Islander childhood disability. Cultural competence requires promotion of attitudes, knowledge and behavior at individual, institutional and systemic levels in order to deliver effective care for Aboriginal and Torres Strait Islander peoples [77]. Culturally competent organizations and systems need to be reflective of the diverse populations they serve, including at leadership and management levels, and through policies which facilitate cross-cultural communication and access [78]. An increased focus on cultural competence may help to address the negative impact of racism on service access and provision.

Although the review focused on Aboriginal and Torres Strait Islander children and is not necessarily generalizable to other indigenous populations, similar health disparities are experienced by indigenous populations worldwide [9,10,47,79]. Investment of time as a facilitator to building sustainable collaborations in the face of government policy and funding cycles is reflected in Canada's collaborative Aboriginal Head Start program to improve indigenous child development outcomes. A key element to the positive impact of the community-based program is the time it took (more than a decade) to establish credibility within communities and build a trained and experienced workforce to work collaboratively [9]. Long-term commitment to sustainable and collaborative relationships with indigenous organizations and communities is also a strategy identified by Aboriginal and Torres Strait Islander organizations to achieve genuine partnerships [80].

Building workforce capacity has been recommended as a key element in improving service access for people with a disability and addressing the social determinants of health [8,47]. Health providers, in particular, have been identified as key players through advocacy, working in partnerships, and working with communities [81]. Collaboration is more likely to be achieved through personal relationships than imposed structures [82], further emphasizing the important role of health, education, and social service providers in improving service access for Aboriginal and Torres Strait Islander childhood disability through collaboration.

Limitations

The conclusions of systematic reviews are inevitably limited by the breadth and quality of the research available for inclusion. Literature relevant to the topic of interest has been mostly discursive, with only eight empirical studies published in a peer-review journal, only one of which has tested an intervention. The focus of the review on

Aboriginal and Torres Strait Islander children with a disability across Australia may mean that it is not generalizable to indigenous populations in other countries or to specific Aboriginal and Torres Strait Islander populations within Australia. This review provides a broad national snapshot of collaboration, but further research within specific local contexts is required to explore ways collaboration can improve access and be responsive to local needs [8,80]. Due to the focus of the review on inter- and intra-sector collaboration, no data for the microsystem of the family and the individual child were collected. The intra- and inter-personal factors and interactions at this level, however, both influence and are influenced by the factors of collaboration at the meso- (provider), exo- (organizational) and macro- (government) system levels.

Conclusions

The policy shift towards inter-sector collaborative approaches represents a strong opportunity for the health, education, and social service sectors and their providers to work collaboratively with each other in innovative ways. As this review has shown however, collaboration is not a simple concept. Many barriers and facilitators exist at the macro- (government), exo- (organizational) and meso- (provider) system levels that influence the effectiveness of collaborative efforts. By identifying the components of inter- and intra-sector collaborations this review provides information to guide future efforts at developing collaborative solutions to improve service access for Aboriginal and Torres Strait Islander children with a disability and their families.

Abbreviations

OM: Orits Media; WHO: World Health Organization; MoU: memorandum of understanding; MeSH: Medical Subject Headings; CINAHL: Cumulative Index to Nursing and Allied Health Literature; ERIC: Education Resources Information Center; APAIS: Australian Public Affairs Information Service; APAIS-health: Australian Public Affairs Information Service - Health; A&TSHealth: Aboriginal and Torres Strait Islander Health; MAIS-ATIS: Multicultural Australia and Immigration Studies - Aboriginal and Torres Strait Islander Subset; STROBE: Strengthening the Reporting of Observational studies in Epidemiology; TREND: Transparent Reporting of Evaluations with Nonrandomized Designs; MMAT: Mixed Methods Appraisal Tool; AMSTAR: Measurement Tool to Assess Systematic Reviews; SpICE: Specialist Integrated Community Engagement.

Competing interests

MD, PD, PA and JD authored two of the articles included in the current review. Quality appraisal of these articles was conducted by AG and TL to reduce bias, and quality appraisal did not influence the findings of the review. The author(s) declare that they have no other competing interests.

Authors' contributions

AG contributed to study conceptualization and design, data acquisition and analysis, and drafted the manuscript. MD contributed to study conceptualization and design, inter-rater checks of data acquisition and appraisal, and manuscript revision. TL contributed to study design, inter-rater checks of data acquisition and appraisal, and manuscript revision. PA, PMD and JD contributed to study conceptualization and manuscript revision. PD contributed to study conceptualization, manuscript revision, and cultural mentorship. All authors read and approved the final manuscript.

Acknowledgements

The project team wishes to recognize Linkage project funding support from the Australian Research Council (LP120200484). AG is a PhD student supported by LP120200484. The project team also greatly appreciates the contribution of health librarian, Ms Jane Van Balen.

Author details

¹Center for Cardiovascular and Chronic Care, Faculty of Health, University of Technology, Sydney, PO Box 123, Broadway, NSW 2007, Australia. ²University of Western Sydney, Locked Bag 1797, Penrith, NSW 1797, Australia. ³School of Nursing, Johns Hopkins University, 525 N. Wolfe Street, Baltimore, MD 21205, USA. ⁴Aboriginal Medical Service Western Sydney, PO Box 3160, Mt Drutt, NSW 2770, Australia.

Received: 22 September 2014 Accepted: 9 December 2014

Published online: 18 December 2014

References

1. Australian Health Ministers' Advisory Council: *Cultural Respect Framework for Aboriginal and Torres Strait Islander Health, 2004–2009*. South Australia: Department of Health South Australia; 2004.
2. Australian Institute of Health and Welfare: *The health and welfare of Australia's Aboriginal and Torres Strait Islander people: an overview*. Canberra: Australian Institute of Health and Welfare; 2011.
3. Commonwealth of Australia: *2010–2020 National Disability Strategy: An initiative of the Council of Australian Governments*. Canberra: Commonwealth of Australia; 2011.
4. Biddle N, Yap M, Gray M: *CABRI Indigenous Population Project 2011 Census Papers. Paper 6 Disability*. Canberra: Australian National University; 2013.
5. Emerson E, Madden R, Graham H, Jewell G, Hutton C, Robertson J: *The health of disabled people and the social determinants of health*. *Public Health* 2011, **125**:145–147.
6. Grant J, Parry Y, Guerin P: An investigation of culturally competent terminology in healthcare policy finds ambiguity and lack of definition. *Aust N Z J Public Health* 2013, **37**(3):250–256.
7. Commission AHR: *Inquiry into hearing health in Australia: Australian Human Rights Commission submission to the Senate Community Affairs Committee*. Australian Human Rights Commission: Sydney; 2009.
8. World Health Organization and World Bank: *World Report On Disability*. Geneva: World Health Organization; 2011.
9. Ball J: Supporting young indigenous children's language development in Canada: A review of research on needs and promising practices. *Can Modern Language Rev* 2009, **66**(1):19–47.
10. Banks S, Miller D: Empowering indigenous families who have children with disabilities: An innovative outreach model. *Disabi Stud Q* 2005, **25**(2).
11. Cappiello M, Gahagan S: Early child development and developmental delay in indigenous communities. *Pediatr Clin N Am* 2009, **56**(6):1501–1517.
12. Castleden H: The Silent North: A case study on deafness in a Dene community. *Can J Nativ Educ* 2002, **26**(2):152–168.
13. Sherwood J: The management of children with otitis media. *Aboriginal Islander Health Wor J* 1993, **17**(4):15–17.
14. Thome J: Middle ear problems in Aboriginal school children cause developmental and educational concerns. *Contemp Nurse* 2003, **16**(1–2):145–150.
15. Australian Bureau of Statistics: *National Aboriginal and Torres Strait Islander Health Survey 2004–05*. Canberra: Australian Bureau of Statistics; 2006.
16. World Health Organization: *Chronic Suppurative Otitis Media: Burden Of Illness And Management Options*. Geneva: World Health Organization; 2004.
17. Morris P, Leach A, Silberberg P, Mellon G, Wilson C, Hamilton E, Beisbarth J: Otitis media in young Aboriginal children from remote communities in northern and central Australia: A cross-sectional survey. *BMC Pediatrics* 2005, **5**(27).
18. Williams C, Jacobs A: The impact of otitis media on cognitive and educational outcomes. *Med J Aust* 2009, **191**(9):S69–S72.
19. Robinson P, Hoskins G, Page S, Peckham C: A national program of Aboriginal and Torres Strait Islander Health Workers to reduce the incidence of otitis media and hearing loss in children. *Aboriginal Is Health Work J* 1997, **21**(5):27–29.
20. Aldred R, Forsingdal S, Baker R: Working together to improve the health status and health outcomes for Indigenous children and their families living in urban settings: the speech pathologist's role. *Acquiring Knowl Speech Lang Hear* 2002, **43**:166–169.
21. Pink B, Allbon P: *The Health And Welfare Of Australia's Aboriginal And Torres Strait Islander Peoples 2008*. Canberra: Australian Bureau of Statistics and the Australian Institute of Health and Welfare; 2008.
22. McDonald J, Comino E, Knight J, Webster V: Developmental progress in urban Aboriginal infants: a cohort study. *J Paediatr Child Health* 2012, **48**(2):114–121.
23. McDonald J, Webster V, Knight J, Comino E: The Gudaga Study: development in 3-year-old urban Aboriginal children. *J Paediatr Child Health* 2014, **50**(2):100–106.
24. Australian Institute of Health and Welfare: *Stronger Futures in the Northern Territory: Hearing Health Services 2012–2013*. Canberra: Australian Institute of Health and Welfare; 2014.
25. Senate Community Affairs References Committee: *Hear Us: Inquiry Into Hearing Health in Australia*. Canberra: Parliament of Australia Senate; 2010.
26. Otitis media: helping to close the gap in Indigenous Australia. *Medicus (Nedlands, WA)* 2013, **53**(2):46–47.
27. Bowes J, Grace R: *Review Of Early Childhood Parenting, Education And Health Intervention Programs For Indigenous Children And Families In Australia. Issues Paper No. 8 Produced For The Closing The Gap Clearinghouse*. Canberra: Australian Institute of Health and Welfare; 2014.
28. Novello A, Degraw C, Kleinman D: Healthy children ready to learn: an essential collaboration between health and education. *Public Health Rep* 1992, **107**(1):3–15.
29. Baum F: Cracking the nut of health equity: top down and bottom up pressure for action on the social determinants of health. *Promot Educ* 2007, **14**(2):90–95.
30. Hunt J: *Engaging with Indigenous Australia—Exploring The Conditions For Effective Relationships With Aboriginal And Torres Strait Islander Communities. Issues paper no. 5*. Canberra and Melbourne: Australian Institute of Health and Welfare and Australian Institute of Family Studies; 2013.
31. O'Neill M, Kirov E, Thomson N: A review of the literature on disability services for Aboriginal and Torres Strait Islander peoples. *Aust Indigenous Health Bull* 2004, **4**(4):1–26.
32. Council of Australian Governments: *National Indigenous Reform Agreement (Closing the Gap)*. Canberra: Commonwealth of Australia; 2008.
33. Commonwealth of Australia: *National Strategic Framework for Aboriginal and Torres Strait Islander Health 2003–2013 Australian Government Implementation Plan 2007–2013*. Canberra: Commonwealth of Australia; 2007.
34. Council of Australian Governments: *Investing in the early years—a National Early Childhood Development Strategy*. Canberra: Council of Australian Governments; 2009.
35. Australian Institute of Health and Welfare: *Disability Support Services 2009–10: Report On Services Provided Under The National Disability Agreement. In Disability series*. Canberra: Australian Institute of Health and Welfare; 2011.
36. Scholtes J: *Deaf Ears Speech Pathology: Working through partnerships to limit the impact of otitis media on the communication development of Aboriginal and Torres Strait Islander children*. *Talkabout* 2010, **23**(2):20–21.
37. Nations U: *The United Nations and Disabled Persons-The First Fifty Years*. New York: United Nations; 2006.
38. Kito S, Chesters J, Grbich C: Quality in qualitative research: criteria for authors and assessors in the submission and assessment of qualitative research articles for the Medical Journal of Australia. *Med J Aust* 2008, **188**:243–246.
39. von Elm E, Altman D, Egger M, Pocock S, Gøtzsche P, Vandenbroucke J: *STROBE Initiative: The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: guidelines for reporting observational studies*. *Bull World Health Organ* 2007, **85**(11):867–872.
40. Des Jarlais D, Lyles C, Crepaz N, TREND Group: Improving the reporting quality of nonrandomized evaluations of behavioral and public health interventions: the TREND statement. *Am J Public Health* 2004, **94**(3):361–366.
41. Pylae P, Robert E, Cargo M, Bartlett G, O'Connell A, Griffiths F, Boardman F, Gagnon MP, Rousseau MC: Proposal: A mixed methods appraisal tool for systematic mixed studies reviews [http://mixedmethodsappraisaltoolpublic.pbworks.com. Archived by WebCite® at http://www.webcitation.org/5tTRTCyJ]
42. Shea B, Grimshaw J, Wells G, Boers M, Andersson N, Hamel C, Porter AC, Tugwell P, Moher D, Bouter LM: Development of AMSTAR: a measurement tool to assess the methodological quality of systematic reviews. *BMC Med Res Method* 2007, **7**(10).

43. Melnyck B, Fineout-Overholt E: *Evidence-Based Practice In Healthcare*. Philadelphia: Lippincott; 2005.
44. Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M, Britten N, Roen K, Duffy S: *Guidance on The Conduct Of Narrative Synthesis In Systematic Reviews. A Product from the ESRC Methods Programme. Version 1*. 2006.
45. Australian Institute of Health and Welfare: *Social and emotional wellbeing: development of a Children's Headline Indicator. Cat. no. PHE 158*. Canberra: Australian Institute of Health and Welfare; 2012.
46. Bronfenbrenner U: *The ecology of human development: experiments by nature and design*. Cambridge, Mass.: Harvard University Press; 1979.
47. Westby C: Implementing recommendations of the World Report on Disability for indigenous populations. *Int J Speech Language Pathol* 2013, 15(1):96-100.
48. Clarke K, Denton M: Red Dirt Thinking on child wellbeing in Indigenous, rural and remote Australian communities: The SPICE Model "I just don't want my kid to struggle like I did at school". *Austr J Indigenous Educ* 2013, 42(2):136-144.
49. Burns J, Thomson N: *Review Of Ear Health And Hearing Among Indigenous Australians*. Western Australia: Australian Indigenous HealthInfoNet; 2013.
50. McSwan D, Ruddell D, Searston J: *Report: A Whole Community Approach to Otitis Media-reducing its incidence and effects*. Townsville: Rural Education, Research and Development Centre, James Cook University; 2001.
51. DiGiacomo M, Davidson PM, Abbott P, Delaney P, Dharmendra T, McGrath SJ, Delaney J, Vincent F: Childhood disability in Aboriginal and Torres Strait Islander peoples: A literature review. *Int J Equity Health* 2013, 12(7).
52. Ministerial Advisory Committee: *Students with Disabilities: Aboriginal Students with Disabilities*. South Australia: Government of South Australia; 2003.
53. DiGiacomo M, Delaney P, Abbott P, Davidson PM, Delaney J, Vincent F: 'Doing the hard yards': carer and provider focus group perspectives of accessing Aboriginal childhood disability services. *BMC Health Serv Res* 2013, 13(326).
54. Western Australian Education and Health Standing Committee: *Report on Key Learnings from the Committee Research Trip 11-17 March 2012*. Perth: Parliament of Western Australia; 2012.
55. Consultants ARITD: *Evaluation of the Aboriginal Otitis Media Screening Program: Final Report*. Sydney: New South Wales Health; 2008.
56. Ministerial Advisory Committee: *Students with Disabilities: Aboriginal Students with Disabilities: Otitis Media and Conductive Hearing Loss*. South Australia: Government of South Australia; 2007.
57. Health Q: *Deadly Ears, Deadly Kids, Deadly Communities: 2009-2013*. Queensland: Queensland Government; 2009.
58. Burrow S, Galloway A, Weissföner N: *Review Of Educational And Other Approaches To Hearing Loss Among Indigenous People*. Western Australia: Australian Indigenous HealthInfoNet; 2009.
59. Kirkham L, Wiersma S, Smith-Vaughan H, Thornton R, Marsh R, Lehmann D, Leach A, Morris P, Richmond P: Are you listening? The inaugural Australian Otitis Media (OMOZ) workshop - towards a better understanding of otitis media. *Med J Aust* 2010, 193(10):569-571.
60. Gilroy J: *The participation of Aboriginal people with a disability in disability services in New South Wales, Australia. PhD thesis*. University of Sydney; 2012.
61. Australian Indigenous HealthInfoNet and InfoNetwork: *Aboriginal and Islander Health Worker Journal* 2006, 30(3):20-21.
62. Purcal C, Newton BJ, Fisher KR, Eastman C, Mears T: *School readiness Program for Aboriginal Children With Additional Needs: Working With Children, Families, Communities And Service Providers. Interim Evaluation Report*. Sydney: Social Policy Research Centre, University of New South Wales; 2013.
63. Raman S, Reynolds S, Khan R: Addressing the well-being of Aboriginal children in out-of-home care: Are we there yet? *J Paediatr Child Health* 2011, 47:806-811.
64. Burton J: *Opening Doors Through Partnerships: Practical Approaches To Developing Genuine Partnerships That Address Aboriginal and Torres Strait Islander Community Needs April 2012*. Victoria: Secretariat of National Aboriginal and Islander Child Care; 2012.
65. Adams K, Dixon T, Guthrie J: *Evaluation of the Gippsland Regional Indigenous Hearing Health Program - January to October 2002*. *Health Promot J Austr* 2004, 15(3):205-210.
66. Nelson A, Allison H: A visiting occupational therapy service to Indigenous children in school: Results of a pilot project. *Austr J Indigenous Educ* 2004, 33:55-60.
67. Nelson A, Allison H: Relationships: the key to effective occupational therapy practice with urban Australian Indigenous children. *Occup Ther Int* 2007, 14(1):57-70.
68. McSwan D, Clinch E, Store R: *Otitis media, learning and community*. *Educ Rural Aust* 2001, 11(2):27-32.
69. Simmons K, Rotumah V, Cookson M, Grigg D: *Child Hearing Health Coordinators tackle ear and hearing health in the NT*. *Chronicle* 2012, 23(1):22-23.
70. Elliott G, Smith AC, Bensink ME, Brown C, Stewart C, Perry C, Scuffham P: The feasibility of a Community-Based Mobile Telehealth Screening Service for Aboriginal and Torres Strait Islander Children in Australia. *Telemed e-Health* 2010, 16(9):950-956.
71. Higgins J, Beecher S: *The Secretariat of National Aboriginal and Islander Child Care (SNAICC) Early Days Project on Autism Spectrum Disorders August 2010*. Victoria: Secretariat of National Aboriginal and Islander Child Care; 2010.
72. Davidson B, Hill AE, Nelson A: Responding to the World Report on Disability in Australia: Lessons from collaboration in an urban Aboriginal and Torres Strait Islander school. *Int J Speech Lang Pathol* 2013, 15(1):69-74.
73. New South Wales Ombudsman: *Improving Service Delivery To Aboriginal People With A Disability: A Review Of The Implementation of ADHC's Aboriginal Policy Framework and Aboriginal Consultation Strategy*. Sydney: New South Wales Ombudsman; 2010.
74. Smith A, Armfield N, Wu W, Brown C, Perry C: A mobile telemedicine-enabled ear screening service for Indigenous children in Queensland: activity and outcomes in the first three years. *J Telemed Telecare* 2012, 18:485-489.
75. Llewellyn G, Thompson K, Fante M: Inclusion in early childhood services: Ongoing challenges. *Austr J Early Child* 2002, 27(3):18-23.
76. Huxham C, Vangen S: *Managing To Collaborate: The Theory And Practice Of Collaborative Advantage*. United States: Routledge; 2005.
77. National Aboriginal Community Controlled Health Organisation (NACCHO): *Creating the NACCHO Cultural Safety Training Standards and Assessment Process: A background paper*. Canberra: NACCHO; 2011.
78. Betancourt J, Green A, Carrillo J, Ananeh-Frempong O 2nd: Defining cultural competence: a practical framework for addressing racial/ethnic disparities in health and health care. *Public Health Rep* 2003, 118(4):293-302.
79. Australian Institute of Health and Welfare: *Aboriginal and Torres Strait Islander people with disability: Wellbeing, participation and support*. Canberra: Australian Institute of Health and Welfare; 2011.
80. Burton J: *Coming Together: The Journey Towards Effective Integrated Services for Aboriginal and Torres Strait Islander Children And Families*. Victoria: Secretariat of National Aboriginal and Islander Child Care; 2012.
81. Allen M, Allen J, Hogarth S, Marmot M: *Working For Health Equity: The Role Of Health Professionals*. London: UCL Institute of Health Equity; 2013.
82. Hunter D, Perkins N, Bamra C, Marks L, Hopkins T, Blackman T: *Partnership Working And The Implications For Governance: Issues Affecting Public Health Partnerships*. United Kingdom: National Institute for Health Research Service Delivery and Organisation programme; 2010.

Submit your next manuscript to BioMed Central and take full advantage of:

- Convenient online submission
- Thorough peer review
- No space constraints or color figure charges
- Immediate publication on acceptance
- Inclusion in PubMed, CAS, Scopus and Google Scholar
- Research which is freely available for redistribution

Submit your manuscript at
www.biomedcentral.com/submit



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

Qualitative studies: * Level of Evidence ranking system, **Criteria for assessing qualitative literature

First Author (year)	Level of Evidence	Criteria for assessing qualitative literature score
Davidson B, Hill AE & Nelson A. 2013, 'Responding to the World Report on Disability in Australia: Lessons from collaboration in an urban Aboriginal and Torres Strait Islander school', <i>International Journal of Speech-Language Pathology</i> , vol. 15, no. 1, pp. 69-74.	VI	8 / 15
DiGiacomo M, Delaney P, Abbott P, Davidson PM, Delaney J & F, V. 2013, 'Doing the hard yards': carer and provider focus group perspectives of accessing Aboriginal childhood disability services', <i>BMC Health Services Research</i> , vol. 13, no. 1, p. 326.	VI	12 / 15
McSwan D, Clinch E & Store R. 2001, 'Otitis Media, Learning and Community', <i>Education in Rural Australia</i> , vol. 11, no. 2, pp. 27-32.	VI	3 / 15
Nelson A & Allison H. 2004, 'A Visiting Occupational Therapy Service to Indigenous Children in School: Results of a Pilot Project', <i>Australian Journal of Indigenous Education</i> , vol. 33, pp. 55-60. / Nelson A & Allison H. 2007, 'Relationships: the key to effective occupational therapy practice with urban Australian Indigenous children', <i>Occupational Therapy International</i> , vol. 14, no. 1, pp. 57-70.	VI	10 / 15

*Melnyck BM & Fineout-Overholt E 2005, *Evidence-based practice in healthcare*, Lippincott, Philadelphia.

**Kitto SC, Chesters J & Grbich C. 2008, 'Quality in qualitative research: criteria for authors and assessors in the submission and assessment of qualitative research articles for the Medical Journal of Australia', *Medical Journal of Australia*, vol. 188, 243.

Discussion papers: *Level of Evidence ranking system

First Author (year)	Level of Evidence
Aldred R, Forsingdal S & Baker R. 2002, 'Working together to improve the health status and health outcomes for Indigenous children and their families living in urban settings: the speech pathologist's role', <i>ACQuiring Knowledge in Speech, Language and Hearing</i> , vol. 4, no. 3, pp. 166-169.	VI
Clarke K & Denton M. 2013, 'Red Dirt Thinking on Child Wellbeing in Indigenous , Rural and Remote Australian Communities: The SpICE Model "I just don't want my kid to struggle like I did at school"', <i>Australian Journal of Indigenous Education</i> , vol. 42, no. 2, pp. 136-144.	VI
Kirkham LA, Wiertsema S, Smith-Vaughan H, Thornton R, Marsh R, Lehmann D, Leach A, Morris P & Richmond P. 2010, 'Are you listening? The inaugural Australian Otitis Media (OMOZ) workshop - towards a better understanding of otitis media', <i>Medical Journal of Australia</i> , vol. 193, no. 10, pp. 569-571.	VII

*Melnick BM & Fineout-Overholt E 2005, *Evidence-based practice in healthcare*, Lippincott, Philadelphia.

Observational studies: *Level of Evidence ranking system, **Strengthening the Reporting of Observational studies in Epidemiology (STROBE) checklist

First Author (year)	Level of Evidence	STROBE score
Adams K, Dixon T & Guthrie J. 2004, 'Evaluation of the Gippsland Regional Indigenous Hearing Health Program - January to October 2002', <i>Health Promotion Journal of Australia</i> , vol. 15, no. 3, pp. 205-210.	IV	16 / 22

Smith AC, Armfield NR, Wu WI, Brown CA & Perry C. 2012, 'A mobile telemedicine-enabled ear screening service for Indigenous children in Queensland: activity and outcomes in the first three years', *Journal of Telemedicine and Telecare*, vol. 18, no. 8, pp. 485-489. IV 16 / 22

*Melnick BM & Fineout-Overholt E 2005, *Evidence-based practice in healthcare*, Lippincott, Philadelphia.

**von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP & STROBE Initiative. 2008, 'The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies', *Journal of Clinical Epidemiology*, vol. 61, no. 2, 1495-1499.

Intervention study: *Level of Evidence ranking system, **Transparent Reporting of Evaluations with Nonrandomized Designs (TREND) checklist

First Author (year)	Level of Evidence	TREND score
Elliott G, Smith AC, Bensink ME, Brown C, Stewart C, Perry C & Scuffham P. 2010, 'The feasibility of a Community-Based Mobile Telehealth Screening Service for Aboriginal and Torres Strait Islander Children in Australia', <i>TELEMEDICINE and e-HEALTH</i> , vol. 16, no. 9, pp. 950-956.	IV	15 / 22

*Melnick BM & Fineout-Overholt E 2005, *Evidence-based practice in healthcare*, Lippincott, Philadelphia.

**Des Jarlais DC, Lyles C, Crepaz N & TREND Group. 2004, 'Improving the reporting quality of nonrandomized evaluations of behavioral and public health interventions: the TREND statement', *American Journal of Public Health*, vol. 94, no. 3, 361-366.

Mixed method study: *Level of Evidence ranking system, **Mixed Methods Appraisal Tool (MMAT)

First Author (year)	Level of Evidence	MMAT score
Raman S, Reynolds S & Khan R. 2011, 'Addressing the well-being of Aboriginal children in out-of-home care:	VI	***50%

Are we there yet?', *Journal of Paediatrics and Child Health*, vol. 47, no. 11, pp. 806-811.

****75%

*****50%

*Melnick BM & Fineout-Overholt E 2005, *Evidence-based practice in healthcare*, Lippincott, Philadelphia.

**Pluye P, Robert E, Cargo M, Bartlett G, O'Cathain A, Griffiths F, Boardman F, Gagnon MP & Rousseau MC 2011, *Proposal: A mixed methods appraisal tool for systematic mixed studies reviews*. Available: <http://mixedmethodsappraisaltoolpublic.pbworks.com>. Archived by WebCite® at <http://www.webcitation.org/5tTRTc9yJ> [Accessed on 14/07/2014].

Qualitative component; *Quantitative component; *****Mixed method component

Literature review: *Level of Evidence ranking system, **Measurement Tool to Assess Systematic Reviews (AMSTAR) checklist

First Author (year)	Level of Evidence	AMSTAR score
DiGiacomo M, Davidson PM, Abbott P, Delaney P, Dharmendra T, McGrath SJ, Delaney J & F, V. 2013, 'Childhood disability in Aboriginal and Torres Strait Islander peoples: a literature review', <i>International Journal for Equity in Health</i> , vol. 12, no. 1, p. 7.	V	7 / 9

*Melnick BM & Fineout-Overholt E 2005, *Evidence-based practice in healthcare*, Lippincott, Philadelphia.

**Shea B, Grimshaw J, Wells G, Boers M, Andersson N, Hamel C, Porter AC, Tugwell P, Moher D & Bouter LM. 2007, 'Development of AMSTAR: a measurement tool to assess the methodological quality of systematic reviews', *BMC Medical Research Methodology*, vol. 7, no. 1, 10.

Grey literature: *Level of Evidence ranking system

First Author (year)	Level of Evidence
EarInfoNet. 2006, 'Australian Indigenous EarInfoNet and InfoNetwork', <i>Aboriginal and Islander Health Worker Journal</i> , vol. VII	VII

30, no. 3, pp. 20-21.

Telethon Speech Hearing Centre. 2013, 'Otitis media: helping to close the gap in Indigenous Australia', *Medicus (Nedlands, WA)*, vol. 53, no. 2, pp. 46-47. VII

ARTD Consultants 2008, *Evaluation of the Aboriginal otitis media screening program: Final Report*, New South Wales Health, Sydney. VI

Australian Institute of Health and Welfare 2014, *Stronger Futures in the Northern Territory: Hearing Health Services 2012-2013*, Australian Institute of Health and Welfare, Canberra. VI

Burns J & Thomson N 2013, *Review of ear health and hearing among Indigenous Australians.*, Australian Indigenous HealthInfoNet, Western Australia. VII

Burrow S, Galloway A & Weisssofner N 2009, *Review of educational and other approaches to hearing loss among Indigenous people*, Australian Indigenous HealthInfoNet, Western Australia. VII

Burton J 2012, *Opening Doors Through Partnerships: Practical approaches to developing genuine partnerships that address Aboriginal and Torres Strait Islander community needs April 2012*, Secretariat of National Aboriginal and Islander Child Care, Victoria. VI

Gilroy J. 2012, 'The participation of Aboriginal people with a disability in disability services in New South Wales, Australia', PhD thesis, University of Sydney. VI

Higgins J & Beecher S 2010, *The Secretariat of National Aboriginal and Islander Child Care (SNAICC) Early Days Project on Autism Spectrum Disorders August 2010*, Secretariat of National Aboriginal and Islander Child Care, Victoria. VI

McSwan D, Ruddell D & Searston I 2001, *Report: A Whole Community Approach to Otitis Media-reducing its incidence and effects*, Rural Education, Research & Development Centre, James Cook University, Townsville. VI

Ministerial Advisory Committee: Students with Disabilities 2003, <i>Aboriginal Students with Disabilities</i> , Government of South Australia, South Australia.	VI
Ministerial Advisory Committee: Students with Disabilities 2007, <i>Aboriginal Students with Disabilities: Otitis Media and Conductive Hearing Loss</i> , Government of South Australia, South Australia.	VI
New South Wales Ombudsman 2010, <i>Improving service delivery to Aboriginal people with a disability : a review of the implementation of ADHC's Aboriginal Policy Framework and Aboriginal Consultation Strategy.</i> , New South Wales Ombudsman, Sydney.	VI
Purcal C, Newton BJ, Fisher KR, Eastman C & Mears T 2013, <i>School readiness program for Aboriginal children with additional needs: working with children, families, communities and service providers. Interim evaluation report.</i> , Social Policy Research Centre, University New South Wales, Sydney.	VI
Queensland Health 2009, <i>Deadly Ears, Deadly Kids, Deadly Communities: 2009-2013</i> , Queensland Government, Queensland.	VII
Scholes J. 2010, 'Deadly Ears Speech Pathology: Working through partnerships to limit the impact of otitis media on the communication development of Aboriginal and Torres Strait Islander children', <i>Talkabout</i> , vol. 23, no. 2, pp. 20-21.	VII
Simmons K, Rotumah V, Cookson M & Grigg D. 2012, 'Child Hearing Health Coordinators Tackle Ear and Hearing Health in the NT', <i>The Chronicle</i> , vol. 23, no. 1, pp. 22-23.	VII
Western Australia Education and Health Standing Committee 2012, <i>Report on key learnings from the Committee research trip 11-17 March 2012.</i> , Parliament of Western Australia, Perth, Western Australia.	VII

*Melnick BM & Fineout-Overholt E 2005, *Evidence-based practice in healthcare*, Lippincott, Philadelphia.

SERVICE MAPPING

A framework for an asset-informed approach to service mapping

Green A, Luckett T, Abbott P et al (2017) A framework for an asset-informed approach to service-mapping. *Nurse Researcher*. Date of submission: 29 March 2016; date of acceptance: 6 October 2016. doi:10.7748/nr.2017.e1479

Anna Green

PhD candidate, Centre for Cardiovascular & Chronic Care, University of Technology Sydney, NSW, Australia

Tim Luckett

Senior lecturer, Centre for Cardiovascular & Chronic Care, University of Technology Sydney, NSW, Australia

Penelope Abbott

Senior lecturer, School of Medicine, Western Sydney University, NSW, Australia

Michelle DiGiacomo

Senior research fellow, Centre for Cardiovascular & Chronic Care, University of Technology Sydney, NSW, Australia

John Delaney

Honorary associate, Centre for Cardiovascular & Chronic Care, University of Technology Sydney, NSW, Australia

Patricia Delaney

Honorary associate, Centre for Cardiovascular & Chronic Care, University of Technology Sydney, NSW, Australia

Patricia Mary Davidson

Dean, School of Nursing, Johns Hopkins University, Baltimore MD, United States

Correspondence

anna.green-1@uts.edu.au

Conflict of interest

None declared

Abstract

Background Asset-informed approaches are increasingly emphasised in public health, but transferring this approach to planning health services requires prospective systematic methods. Asset-informed approaches to service-mapping have started to develop, but there are no standardised guidelines. These methods are becoming of particular interest, as nurses engage in population health activities.

Aim To identify methods of asset-informed mapping for addressing health problems and develop a framework to support the methodological rigour of service-mapping.

Discussion The authors undertook an integrative literature review using a systematic approach and narrative synthesis. Ten articles met the inclusion criteria. Reported methods included the formation of a core team to drive the process, as well as varying detail about methods of collecting data and forming maps. Challenges and solutions included the effectiveness of the core team depending on having a designated leader, frequent meetings and previous partnerships, using community 'cultural brokers', and determining aims and scope.

Conclusion Results of the review can be used to modify existing generic resources for asset-informed mapping to their application in health services. Four main stages seem especially applicable and important: defining the parameters of the service-mapping process; identifying services; mapping services; and consultation and implementation.

Implications for practice The shift towards asset-informed approaches in community and public health is an important step in realising the potential of existing assets in communities to influence health outcomes. The framework offered in this paper is intended to assist in developing an evidence base, by promoting the systematic and rigorous reporting of methods used in asset-informed approaches to service-mapping.

Keywords

asset-based, community health, health, nurse researcher, public health, reporting, service mapping

Introduction

There is increased emphasis internationally on access to and equity in healthcare, as well as a recognition that an aid-based model without community involvement is unlikely to result in structural change (Taylor-Ide and Taylor 2002). Historically, the 'deficit' model of service provision has seen institutionalised help provided by external resources to address an externally identified problem. However, this model promotes passivity, disempowerment, stereotypes and low expectations; it also fails to fuel aspirations, promote engagement or take advantage of existing strengths that can build success. Rather than resolving the problem, the model can sometimes create a crippling dependency and have unintended consequences (Kretzmann and McKnight

1996).

Asset-Based Community Development (ABCD) is a philosophical response to the deficit model that the community-development movement has used to address socio-economic disadvantage (Baker 2014). It advocates the use of assets that already exist in communities to develop solutions (Kretzmann and McKnight 1996, Lightfoot et al 2014). Recognition of the strengths of ABCD has contributed to a shift towards an approach in public health that is informed by assets, focusing on the ability of individuals and communities to develop and sustain positive health outcomes, rather than on deficits and external support (Morgan and Ziglio 2007).

The need to address social determinants of health to address health disparities is

recognised globally and is increasingly a focus for nurses (Commission on Social Determinants of Health 2008, Reading and Wien 2009, Reutter and Kushner 2010). Focusing on communities and developing existing assets is a central component of taking action (Campbell et al 2007, Morgan and Ziglio 2007, Commission on Social Determinants of Health 2008, Marmot et al 2010, Baker 2014). Health professionals are in a particularly strong position to tackle health inequalities through involvement in communities, particularly when they have respected roles, have established relationships and partners with key stakeholders (Allen et al 2013).

Several strengths of using an asset-informed approach in public health are advocated in the literature (Whiting et al 2012). Mapping has been used in different forms as a public health tool for more than a century (Gordon and Womersley 1997). It identifies the relationships between services and potential deficits, and elucidates pathways to care (Luger et al 2001).

Focusing on deficits is a two-edged sword: it can drive initiatives to address health disparities, but can label and stigmatise individuals, communities and populations and fail to build on working systems and processes (Ammerman and Parks 1998). It can also reinforce a traditional, biomedical approach to health inequalities with a focus on the individual, and not appreciating the positive role communities can play.

Community asset-mapping – an important ABCD method – has begun to inform an alternate approach to service-mapping in public health (Morgan and Ziglio 2007). Promoting assets in a community can enable the creation of an inventory or map to connect assets, harnessing their collective potential to address issues in the community (Kretzmann and McKnight 1993, Lightfoot et al 2014).

Assets are generally described as belonging to one of three groups: the skills of individual community members; informal citizen associations such as churches and clubs; and the resources of a community's formal institutions, such as hospitals, businesses, schools and social service agencies (Kretzmann and McKnight 1993). While recognising the importance of the first two groups of assets in developing the resilience and empowerment of individuals and communities, this paper focuses solely on mapping the third group of assets – formal institutions.

Although there is increasing use of asset-informed approaches in public health, there is a lack of published peer-reviewed research

reporting on the methods used (Campbell et al 2007, Friedli 2013). There are no universally accepted guidelines for how an asset-informed approach to service-mapping should work (Whiting et al 2012, 2013), perhaps because it requires tailoring to the needs of communities and identified issues (Crane and Mooney 2005). Evidence of effectiveness is also reported largely through case studies, with a lack of commonality among measured outcomes impeding comparison and the evaluation of effectiveness (Friedli 2013, Baker 2014). This may reflect the nature of asset-informed approaches in general, which pose substantial challenges to conventional research designs such as randomised controlled trials (Campbell et al 2004, Commission on Social Determinants of Health 2008). Yet, failing to report prospective, systematic and reproducible methods limits the development of a critically needed evidence-base in community and global health.

Aims

We set out to identify and describe methods used by previous studies for the asset-informed mapping of formal health institutions, as well as challenges and their solutions with this approach. Our aim was to develop methods that will ensure any reporting of service-mapping in future research is rigorous.

Methods

We undertook a systematic, integrative review of the literature.

Eligibility criteria

To be included, articles had to be written in English, address a health issue, use an asset-informed approach and report on methods used to map formal institutions. No limits were set on their methodological designs but we excluded articles if they provided no details about the methods the authors used.

Information sources and search strategy

We included peer-reviewed and grey literature. We searched CINAHL, Embase, MEDLINE and PsychINFO using combinations of the terms 'asset-based approach', 'asset', 'service map' and 'map'. We were less systematic when searching for grey literature, as there are no agreed methods, but we used the same search terms with Google and the websites of major public health organisations. A single reviewer (AG) assessed the articles against eligibility criteria and searched the reference lists of included articles for further relevant articles.

Peer review

This article has been subject to external double-blind peer review and checked for plagiarism using automated software

Online

For related articles visit the archive and search using the keywords. Guidelines on writing for publication are available at: rcni.com/writerforus

Data collection

AG extracted the data using a standardised extraction tool. Data items included country and health issues, as well as methods of asset-informed approaches to service mapping.

Risk of bias

The variety of designs used in the articles meant we could not apply a standardised assessment of the risk of bias; instead, to

provide an overview of quality, we evaluated the contribution of each article using Melnyk and Fineout-Overholt (2005)'s Level of Evidence ranking system. However, we did not give this weighting in the synthesis of data, because there are no formal methods for this in integrative reviews.

Synthesis

Synthesis used a narrative approach involving textual summary and tabulation (Popay et al 2006). Approaches to asset-informed mapping were grouped according to their descriptions, the main issues discussed, and their arguments for and against an asset-approach to service-mapping.

Results

Seven articles from the database search met the inclusion criteria while the searches for grey literature and of their references identified another three articles (Crane and Skinner 2003, Goldman and Schmalz 2005, Griffin and Farris 2010, Gwede et al 2010, Burns et al 2012, Baker 2014, Caron-Parker and Nichols 2014, Dieleman 2014, Robinson et al 2014, Selamu et al 2015). Results from the search are summarised in Figure 1.

Article characteristics

Most ($n=7$) articles were discussion papers with case studies (Table 1). Publication dates ranged from 2003 to 2015, with more than half ($n=6$) of the articles published in the past five years, possibly reflecting a shift towards asset-informed approaches in health. More than half ($n=6$) the articles were from the United States (Crane and Skinner 2003, Goldman and Schmalz 2005, Griffin and Farris 2010, Gwede et al 2010, Burns et al 2012, Caron-Parker and Nichols 2014), followed equally ($n=1$ each) by Canada (Dieleman 2014), England (Baker 2014), Ireland (Robinson et al 2014) and Ethiopia (Selamu et al 2015). The articles addressed a range of issues including mental health, ageing, community health, cancer and disability. All articles ranked as level six on the Level of Evidence scale – the second lowest level of the seven-level system.

Synthesis

Reported methods for asset-informed approaches to service-mapping

Crane and Skinner (2003), Griffin and Farris (2010), Caron-Parker and Nichols (2014) and Dieleman (2014) reported initially forming a core team to drive asset-informed service-mapping. These teams generally decided what

Figure 1. PRISMA flowchart of database search

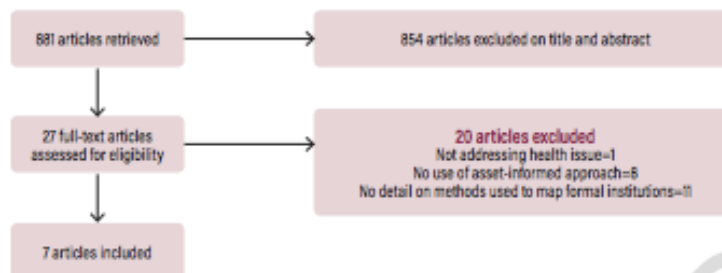


TABLE 1. Summary table of included articles

First author (year)	Country	Design	Health issue	Peer-reviewed	Level of evidence
Baker D (2014)	England	Discussion paper and case study	Not defined	✓	VI
Burns JC (2012)	United States	Discussion paper and case study	Community health	x	VI
Caron-Parker L (2014)	United States	Discussion paper and case study	Ageing	✓	VI
Crane K (2003)	United States	Discussion paper and case study	Disability	✓	VI
Dieleman C (2014)	Canada	Qualitative, focus groups and case study	Mental health	✓	VI
Goldman KD (2005)	United States	Discussion paper and case study	Community health	✓	VI
Griffin D (2010)	United States	Discussion paper and case study	Mental health and disability	✓	VI
Gwede CK (2010)	United States	Discussion paper and case study	Cancer	✓	VI
Robinson D (2014)	Ireland	Published conference abstract	Ageing	✓	VI
Selamu M (2015)	Ethiopia	Cross-sectional survey	Mental health	✓	VI

form the service-mapping tool and were involved throughout.

Details of the methods used to recruit these core teams were scarce, despite their importance. A coordinator initiated recruitment in Griffin and Farris (2010), while Dieleman (2014) reported that key stakeholders initiated recruitment by distributing information packs and through word of mouth.

Only Gwede et al (2010) and Caron-Parker and Nichols (2014) detailed the steps used to decide how to map the services: determining a team leader, the target population and geographical boundaries; developing a plan to collect data, including who would gather the information and what assets would be collected; and discussing issues concerning human and financial resources and how the collected information would be used. Caron-Parker and Nichols (2014) used Google Maps and drove around areas to determine geographic boundaries.

Most articles detailed to some extent how data were collected, with several different methods used. Goldman and Schmalz (2005) and Griffin and Farris (2010) searched for services by examining existing lists of services (for example, local newspapers, service directories and websites) and consulting with key stakeholders. Goldman and Schmalz (2005) and Robinson et al (2014) used 'windshield' or 'on street' surveys, which involve researchers walking or driving around an area noting services they come across; in Selamu et al (2015), community health workers administered a cross-sectional survey key community informants and held community forums with structured mapping exercises to identify services. Gwede et al (2010), Burns et al (2012) and Robinson et al (2014) used geocoding tools to document the data collected.

Services were mapped physically and electronically in various levels of detail. Hard copy service maps involved marking services on street maps (Goldman and Schmalz 2005), service inventory guides (Griffin and Farris 2010, Caron-Parker and Nichols 2014) and a conceptual capacity map (Dieleman 2014). Electronic service maps used software to display categories of services and overlaps (Goldman and Schmalz 2005) and an online mapping tool to generate a list of existing services (Baker 2014).

While involving the community is generally considered central to traditional community asset-mapping, fewer than half the articles (Crane and Skinner 2003, Griffin and Farris

2010, Gwede et al 2010, Robinson et al 2014) reported that the community had identified the issue to be addressed by service mapping. Half the articles (Griffin and Farris 2010, Baker 2014, Caron-Parker and Nichols 2014, Dieleman 2014, Selamu et al 2015) referenced a conceptual framework/method that informed the service-mapping. Only Gwede et al (2010) reported evaluating the service-mapping process and outcomes.

Challenges and solutions identified

Some articles identified that forming a core team to guide service-mapping was an important element of an asset-informed approach. Caron-Parker and Nichols (2014) argued that an unintended outcome of this is the promotion of inter-professional partnerships between team members, which may contribute to a more coordinated, multidisciplinary delivery of services. Aids to creating an effective and sustainable core team include having a designated leader, meeting frequently, and successful partnerships between team members who have previously worked together (Crane and Skinner 2003).

Authors also discussed the importance of certain cultural considerations when forming the core team. Including 'cultural brokers' from the community was vital in identifying important, culturally relevant services that the community used and might otherwise have been overlooked, as was gaining the community's trust and acceptance of the process (Griffin and Farris 2010, Selamu et al 2015). Griffin and Farris (2010) argued that where necessary, inventories of services should be translated into other languages to assist access to the service map. Determining the aims and scope of an asset-informed approach to service-mapping is a particularly important step – Baker (2014) found that focusing on a given outcome, rather than aimlessly mapping services, was essential.

The focus of the process is also important when there is limited funding for new services (Griffin and Farris 2010). Asset-informed approaches to service mapping may not require large financial resources at first, but how to update the map when there are only limited resources is an important consideration. Gwede et al (2010) argued that as updating the map requires human resources, it is important to take a systematic approach to identifying and mapping services, to ensure anyone can update the map when required.

Most articles reported that an asset-informed approach to service-mapping was beneficial; no articles reported negative

outcomes. There were four main benefits reported: it raises communities' awareness of services (Crane and Skinner 2003, Griffin and Farris 2010, Caron-Parker and Nichols 2014); builds partnerships and collaboration in the delivery of services (Crane and Skinner 2003, Griffin and Farris 2010); is an efficient way of using available financial and human resources (Crane and Skinner 2003); and helps with discussion of policy (Gwede et al 2010). However, all evidence for these benefits was anecdotal.

Discussion

This review is the first to identify and summarise methods for asset-informed approaches to service-mapping of formal health institutions. The findings support and extend existing generic tools for community asset-mapping for healthcare, notably the community asset-mapping stages developed by Berkowitz and Wadud (2015). The review and synthesis reported in this paper suggests that four key stages may be especially applicable and important.

The framework

Stage one: Define the parameters of the service-mapping process

This stage involves answering questions about: the size and scope of the service-mapping area; who will be undertaking the work (for example an individual or an organisation, with input from key stakeholders); the length of time that can be dedicated to service mapping; what resources are required (financial and/or human); and what will be done with the results (Berkowitz and Wadud 2015). It should focus on achieving a desired outcome, such as increased access to a particular service, and engage key stakeholders. It should also focus on assets in the communities. Barriers and enablers should be carefully identified.

Stage two: Identify services

This involves conducting an inventory of the relevant formal institutions. Sources of information might include websites and online resources, business directories, informal lists of organisations and community resources, and discussions with key community stakeholders (Berkowitz and Wadud 2015). It is important to keep a detailed record of each source, the date it was searched or accessed, and the services identified through it. This will enable someone else to build on the service map in future, which is particularly important in fluid service landscapes.

Stage three: Map services

The third stage involves mapping the services to desired demands. The aim is to have a visual representation of the list of formal institutions that shows how they may interconnect or that can be used to meet the needs of the community (Berkowitz and Wadud 2015). In some instances, techniques that help to manage and analyse geographical data can augment this process (Gwede et al 2010, Burns et al 2012, Robinson et al 2014).

Stage four: Consultation and implementation

The final stage involves using the formal institutions identified, by making the results available to community members. Implementation strategies could include disseminating the results of the process to community members through a directory of services, for example (Berkowitz and Wadud 2015), or using the map to address an issue through further consultation.

Aims

We aim for this framework to address several important methodological issues raised in the literature. Despite the importance in service-mapping of determining aims and scope, the lack of reporting in the literature on the steps taken to plan service-mapping indicated the need to encourage detailed reporting in the first stage. This will enable comparison and evaluation and increase rigour. The formation of a core team, with cultural brokers if required, should also be considered at this stage, with significant thought put into whom to include to best achieve the project's aims. Members of the core team play a significant role in the process and overcoming barriers.

How to keep the service map up to date was a significant issue raised in the literature. As emphasised in the second stage, a detailed search record is essential to the sustainability of the service map and ensures the effective use of limited financial and human resources.

As nursing embraces the management of populations, as well as individuals, incorporating service-mapping in the planning of health interventions is likely to improve results (Reutter and Kushner 2010, Steenkamer et al 2017). Nurses are increasingly responsible for improving the value and decreasing the cost of health care, so this method of assessment should be considered as a way of improving the coordination of care, as well as its acceptability to and access by individuals, families and populations.

Table 2 presents a summary of the above framework as applied to an example from the authors' own experiences – a project involving mapping services for Aboriginal and Torres Strait Islander families of children with a disability.

Limitations

The results of systematic reviews are limited by the quality and depth of what research is available to be included – discussion papers of case studies and two descriptive research studies, in this case. The focus of this review may also mean that the findings are not necessarily generalisable to areas other than health. In addition, the review method was limited by the fact that only one researcher (AG) selected articles and extracted data, albeit using standardised procedures.

However, by using an integrative review of what was available, this article has started

building a necessary body of knowledge from which evaluation research can be designed to further investigate approaches to and methods for asset-informed service-mapping of formal health institutions.

Conclusion

The shift towards asset-informed approaches in community and public health is an important step in realising the potential of communities' own assets to influence health outcomes. The lack of peer-reviewed research detailing the methods of asset-informed approaches limits the rigour of reporting and attempts to compare studies and evaluate effectiveness.

The framework in this paper aims to assist in developing an evidence base, by promoting the systematic and rigorous reporting of methods used in asset-informed approaches to service-mapping.

TABLE 2. Reporting template for conducting an asset-informed approach to service mapping of formal institutions

Stage 1 – Define the parameters of the service mapping process	Stage 2 – Identify services	Stage 3 – Map services	Stage 4 – Consultation and implementation
Report defined outcome, size and scope of area to be mapped, what assets will be mapped, who will undertake the work, timeframe, required financial/human resources, what will be done with results etc	Report data collection techniques, detailed record of information sources including date searched/accessed etc	Report process used to map collected information to defined outcome	Report how results of the service map were made available to community members/key stakeholders
Example – Parents of Aboriginal and Torres Strait Islander children with a disability needed to understand what services were available and what these could offer. Relevant services were services from the health, education and social service sectors within a metropolitan region of a city. A researcher undertook the service map with the support of a core team of key stakeholders over a three-month period. No financial resources were required. The service map would form a directory of services to be provided to parents.	Example – Sources of information used to identify services included: a list of community resources; a continuous process of service identification by the key stakeholders including local government directories of services and agencies; a desktop review of websites and online resources; and discussions with community members. A detailed record was kept of where each source came from, the date it was searched and the services identified.	Example – Once the services had been identified, they were divided into groups based on their primary relevance for parents. The diagram was designed to present the list of services in the easiest way possible for families to understand. Groups were presented in table format with details under descriptive headings.	Example – The service map formed a directory of services provided to parents and a local community health service to use. Parents and health professionals were encouraged to use the map as a basis for discussion of different service needs and how they might be met.

References

- Allen M, Allen J, Hogarth S et al (2013) Working for Health Equity: The Role of Health Professionals. UCL Institute of Health Equity, London.
- Ammann A, Parks C (1998) Preparing students for more effective community interventions: assets assessment. *Family & Community Health*, 21, 1, 32-40.
- Baker D (2014) Developing and implementing a robust asset-based approach to public health. *Perspectives in Public Health*, 134, 3, 129-130.
- Berkowitz B, Wadud E (2015) Section 8: Identifying Community Assets and Resources. ctbk.ucla.edu/table-of-contents/assessment/assessing-community-needs-and-resources/identify-community-assets/main (Last accessed: 26 May 2016)
- Burns JC, Paul DP, Paz SR (2002) Participatory Asset Mapping: A Community Research Lab Toolkit. Advancement Project, Los Angeles CA.
- Campbell D, Pyett P, McCarthy L et al (2004) Community development and empowerment: a review of interventions to improve Aboriginal health. In Anderson I, Baum F, Bentley M (Eds) *Beyond Band-aids: Exploring the Underlying Social Determinants of Aboriginal Health*. Papers from the Social Determinants of Aboriginal Health Workshop, Adelaide, July 2004. Cooperative Research Centre for Aboriginal Health, Darwin NT, 165-180.
- Campbell D, Pyett P, McCarthy L (2007) Community development interventions to improve Aboriginal health: building an evidence base. *Health Sociology Review*, 16, 3-4, 304-314.
- Caron-Parker L, Nichols S (2014) Asset mapping: a collaborative approach to care transitions with older adults. *Gerontology Special Interest Section Quarterly*, 30, 1, 1-4.
- Commission on Social Determinants of Health (2008) *Closing the Gap in a Generation: Health Equity Through Action on the Social Determinants of Health*. World Health Organization, Geneva, Switzerland.

- Crane K, Mooney M (2006) Essential Tools: Improving Secondary Education and Transition for Youth with Disabilities. National Center on Secondary Education and Transition, University of Minnesota, Minneapolis MN.
- Crane K, Skinner B (2003) Community resource mapping: A strategy for promoting successful transition for youth with disabilities. *Information Brief*, 2, 1, 1-7.
- Deleman C (2010) Mapping community capacity: identifying existing community assets for supporting people with mental health problems who have been involved with the criminal justice system. *Canadian Journal of Community Mental Health*, 33, 3, 29-42.
- Friedl L (2013) 'What we've tried, hasn't worked': the politics of assets based public health. *Critical Public Health*, 23, 2, 131-145.
- Goldman KD, Schmeitz KI (2006) 'Accentuate the positive': Using an asset mapping tool as part of a community-health needs assessment. *Health Promotion Practice*, 6, 2, 125-128.
- Gordon A, Watersley J (1997) The use of mapping in public health and planning health services. *Journal of Public Health Medicine*, 18, 2, 139-147.
- Griffin D, Farris A (2010) School counselors and collaboration: finding resources through community asset mapping. *Professional School Counseling*, 13, 5, 248-256.
- Gwede CK, Wand BG, Luque JS et al (2010) Application of geographic information systems and asset mapping to facilitate identification of colorectal cancer screening resources. *Online Journal of Public Health Informatics*, 2, 1, 2693.
- Kretzmann JP, McKnight JL (1993) Building Communities from the Inside Out: A Path Toward Finding and Mobilizing a Community's Assets. Northwestern University, Evanston, IL.
- Kretzmann JP, McKnight JP (1995) Assets-based community development. *National Civic Review*, 85, 4, 23-29.
- Lightfoot E, Simmelink McCleary J, Lum T (2014) Asset mapping as a research tool for community-based participatory research in social work. *Social Work Research*, 38, 1, 59-64.
- Luger L, Center J, Power R (2010) Mapping as a method for analysing policy response in the management of health services. *Health Services Management Research*, 14, 4, 220-226.
- Marmot M, Allen J, Goldblatt P et al (2010) *Fair Society, Healthy Lives*. The Marmot Review, London.
- Melnik BM, Fineout-Overholt E (2005) *Evidence-Based Practice in Nursing & Healthcare: A Guide to Best Practice*. Lippincott Williams & Wilkins, Philadelphia PA.
- Morgan A, Ziglio E (2007) Revitalising the evidence base for public health: an assets model. *Promotion & Education*, Suppl 2, 17-22.
- Popey J, Roberts H, Sowden A et al (2008) *Guidance on the Conduct of Narrative Synthesis in Systematic Reviews: A Product from the ESRC Methods Programme*. Institute for Health Research, Lancaster.
- Reading CL, Wien F (2009) Health Inequalities and Social Determinants of Aboriginal Peoples' Health. National Collaborating Centre for Aboriginal Health, Prince George BC.
- Reuter L, Kushner KE (2010) Health equity through action on the social determinants of health: taking up the challenge in nursing. *Nursing Inquiry*, 17, 3, 259-280.
- Robinson D, Boyle G, Feighan J et al (2014) Mapping health services to meet the needs of an ageing community: the Local Asset Mapping Project (LAMP). *Irish Journal of Medical Science*, 183, Suppl 1, s300-s307.
- Selamu M, Asher L, Hanlon C et al (2015) Beyond the biomedical: community resources for mental health care in rural Ethiopia. *PLoS One*, 10, 5, e0126966.
- Steenkamer BM, Drewes HW, Heijink R et al (2017) Defining population health management: a scoping review of the literature. *Population Health Management*, 20, 1, 74-85.
- Taylor-Ida DC, Taylor CE (2002) *Just and Lasting Change: When Communities Own Their Futures*. The Johns Hopkins University Press, Baltimore MD.
- Whiting L, Kendall S, Willis WJ (2012) An asset-based approach: an alternative health promotion strategy? *Community Practitioner*, 85, 1, 25-28.
- Whiting LS, Kendall S, Willis W (2013) Rethinking children's public health: the development of an assets model. *Critical Public Health*, 23, 2, 146-159.

Appendix 4: Invitation to participate in qualitative study



Invitation to Participate

Aboriginal Early Intervention for Learning and Physical disability in Early Childhood development Project (The AbLE Project)

Dear _____,

You are invited to take part in a study on early intervention for Aboriginal children with a disability or developmental delay in Western Sydney. We are inviting a variety of health and education professionals, service providers, and other key stakeholders to participate in interviews. By talking with professionals, such as you, we hope to better understand the issues and needs of children and their families to inform service planning and delivery.

I have enclosed some information about the study. Please feel free to contact me (details below) at any time if you would like more information. I will contact you in one week to answer any questions you may have.

Kind regards,

Anna Green
AbLE Project Manager
University of Technology Sydney
Phone: 0416 563 036
Email: anna.green-1@uts.edu.au

Invitation to Participate

Aboriginal Early Intervention for Learning and Physical disability in Early Childhood development Project (The AbLE Project)

Dear _____,

You are invited to take part in a study on early intervention for Aboriginal children with a disability or developmental delay in Western Sydney. We are inviting a variety of health and education professionals, service providers, and other key stakeholders to participate in interviews. By talking with professionals, such as you, we hope to better understand the issues and needs of children and their families to inform service planning and delivery.

I have enclosed some information about the study. Please feel free to contact me (details below) at any time if you would like more information. I will contact you in one week to answer any questions you may have.

Kind regards,

Anna Green
AbLE Project Manager
University of Technology Sydney
Phone: 0416 563 036
Email: anna.green-1@uts.edu.au

Appendix 5: Ethics approvals



AH&MRC ETHICS COMMITTEE

11th December 2014

Mr Frank Vincent
Chief Executive Officer
Aboriginal Medical Service Western Sydney
PO Box 3160
Mt Druitt Village NSW 2770

Dear Frank,

RE: 762/10 - The Able Project: Aboriginal Early Intervention for Learning and Physical Disability in Early Childhood Development

I refer to the email correspondence from Dr Michelle DiGiacomo, Senior Research Fellow, Centre for Cardiovascular and Chronic Care, Faculty of Health, University of Technology Sydney, on 21st October 2014, submitting an annual progress report for the above project, which has been noted with thanks by the AH&MRC Ethics Committee.

The Ethics Committee has agreed to approve an extension for the study until 1st March 2017.

If you require an extension after this time, you will need to provide an annual progress report prior to this date.

In relation to the amendments, the Committee noted that an additional member, Ms Anna Green, has been added to the research team since March 2014 with the addition of Patricia Delaney as her co-supervisor and cultural mentor.

The Committee has agreed to approve the amendments.

Please ensure that additions to the research project including any changes to methodology have the prior approval from the Committee as per the conditions of approval for the project.

Thank you also for the publication titled, '*Cross-sector collaborations in Aboriginal and Torres Strait Islander childhood disability: a systematic integrative review and theory-based synthesis*'.

Supported by the NSW Ministry of Health

Location:
Level 3, 66 Wentworth Avenue
Surry Hills NSW 2010

Postal Address:
PO Box 1565
Strawberry Hills NSW 2012

Contact:
Phone: +61 (2) 9212 4777
Fax: +61 (2) 9212 720
e-Mail: ahmrc@ahmrc.org.au
web: www.ahmrc.org.au

ABN:
ABN 66 085 654 397

The Committee noted that the publication had been approved for submission by two co-authors of the publication and the Board of AMSWS.

The Committee is supportive of Aboriginal researchers and authors and would like to encourage the publication and use of research data that will inform and improve Aboriginal health. The Committee does have concerns when an author is a member of a research team and also reviewer of their own publications or work with the people who may review their written work. This can have broader implications where the academic, publishing and Aboriginal community may perceive this 'review' as a conflict of interest and dismiss or de-value quality research simply because it has not undergone independent and/or non-aligned review. The Committee would like to ensure that this does not occur. The Committee would recommend that any publication or presentation where data or findings are presented, must be provided to the AH&MRC Ethics Committee to be reviewed for compliance with ethical and cultural criteria prior to any submission for publication; and/or any dissemination of the report. As you may be aware, these are part of the standard conditions of approval for any research project approved by the AH&MRC Ethics Committee.

The conditions of approval contained in the original approval letter will continue to apply.

On behalf of the AH&MRC Ethics Committee,

Yours sincerely,



Val Keed
Chairperson
AH&MRC Ethics Committee



AH&MRC ETHICS COMMITTEE

5th May 2015

Mr Frank Vincent
 Chief Executive Officer
 Aboriginal Medical Service Western Sydney
 PO Box 3160
 Mt Druitt Village NSW 2770

Dear Frank,

RE: 762/10 - The AbLE Project: Aboriginal Early Intervention for Learning and Physical Disability in Early Childhood Development

I refer to the email correspondence from Anna Green, PhD Candidate & Project Manager, Centre for Cardiovascular and Chronic Care, Faculty of Health, University of Technology, Sydney, on 10th April 2015, requesting ethics approval for amendments to the above project that has previously been approved by the Aboriginal Health and Medical Research Council (AH&MRC) Ethics Committee.

The amendments requested are:

1. Revised Participant Information Sheet (Professionals)
2. Revised Participant Consent Form (Professionals)
3. Revised Invitation letter (Professionals)

Documents reviewed to support these amendments are:

1. Cover letter dated 10th April 2015
2. Revised Participant Information Statement (clean copy and tracked version)
3. Revised Participant Consent Form (Professionals) (clean copy and tracked version)
4. Revised Invitation letter (Professionals) (clean copy)

The Committee has agreed to approve the amendments.

The conditions of approval contained in the original approval letter will continue to apply.

On behalf of the AH&MRC Ethics Committee,

Supported by the NSW Ministry of Health

Location
 Level 3, 66 Wentworth Avenue
 Surry Hills NSW 2010

Postal Address
 PO Box 1565
 Strawberry Hills NSW 2012

Contact
 Phone: +61 (0) 9212 4777
 Fax: +61 (0) 9212 7211
 e-Mail: ahmrc@ahmrc.org.au
 web: www.ahmrc.org.au

ABN
 ABN 66 085 654 397

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Val Keed', written in a cursive style.

Val Keed

Chairperson

AH&MRC Ethics Committee



AH&MRC ETHICS COMMITTEE

17 December 2015

Dr Michelle DiGiacomo PhD
Senior Research Fellow
Centre for Cardiovascular and Chronic Care
Faculty of Health
University of Technology Sydney
PO Box 123 NSW 2007

Dear Dr DiGiacomo,

Re: 762/10 – The AbLE Project: Aboriginal Early Intervention for Learning and Physical Disability in Early Childhood Development

I refer to the email correspondence from Anna Green, PhD Candidate and Project Manager, Centre for Cardiovascular and Chronic Care, Faculty of Health, University of Technology, Sydney, received on 7 October 2015 requesting ethics approval for an amendment to the above project that has previously been approved by the Aboriginal Health and Medical Research Council (AH&MRC) Ethics Committee.

The amendments requested are:

- Data Collection – Will no longer be interviewing parents and carers of Aboriginal children with a disability
- Team Composition – Removal of AMSWS logo
- Mrs Patricia Delaney's organisational affiliation has changed from the AMSWS to the University of Technology Sydney. She will remain an investigator, cultural mentor, and student supervisor on this project
- Mr John Delaney has been added to the AbLE Project team as a senior Aboriginal cultural mentor
- Mr Frank Vincent and Mrs Joanne Delaney have withdrawn as investigators and members of the AbLE Project team
- To store paper and electronic data in the office of the Chief Investigator at UTS

Documents reviewed to support this amendment are:

1. Participant Information Sheet (Professionals)
2. Consent Form (Professionals)
3. Invitation Letter (Professionals)

Supported by the NSW Ministry of Health

Location
Level 3, 66 Wentworth Avenue
Surry Hills NSW 2010

Postal Address
PO Box 1565
Strawberry Hills NSW 2012

Contact
Phone: +61 (2) 9212 4777
Fax: +61 (2) 9212 7211
e-Mail: ahmrc@ahmrc.org.au
web: www.ahmrc.org.au

ABN
ABN 66 085 654 397

The Committee has agreed to approve the amendments.

The conditions of approval contained in the original approval letter will continue to apply.

On behalf of the AH&MRC Ethics Committee,

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Val Keed', written in a cursive style.

Val Keed

Chairperson

AH&MRC Ethics Committee

Eth: HREC Clearance Letter - UTS HREC 2011-417R

✕ DELETE

↩ REPLY

↩ REPLY ALL

➔ FORWARD

...



Research Ethics

Mon 14/11/2011 3:49 PM

Mark as unread

To: Patricia Davidson;

Cc: Research Ethics;

Dear Patricia,

Re: "Aboriginal Early Intervention for learning and physical Disability in early childhood development (AbLE Project)"
[External Ratification: Aboriginal Health and Medical Research Council Human Research Ethics Committee HREC approval - 762/10 - 14 Jan 2011 - 31 Jan 2012]

At its meeting held on 8/11/2011, the UTS Human Research Ethics Committee reviewed your application and I am pleased to inform you that your external ethics clearance has been ratified.

Your UTS clearance number is UTS HREC REF NO. 2011-417R

You should consider this your official letter of approval. If you require a hardcopy please contact the Research Ethics Officer (Research.Ethics@uts.edu.au).

Please note that the ethical conduct of research is an on-going process. The National Statement on Ethical Conduct in Research Involving Humans requires us to obtain a report about the progress of the research, and in particular about any changes to the research which may have ethical implications. This report form must be completed at least annually, and at the end of the project (if it takes more than a year). The Ethics Secretariat will contact you when it is time to complete your first report. You must also provide evidence of continued approval from the Human Research Ethics Committee you originally received approval from.

I also refer you to the AVCC guidelines relating to the storage of data, which require that data be kept for a minimum of 5 years after publication of research. However, in NSW, longer retention requirements are required for research on human subjects with potential long-term effects, research with long-term environmental effects, or research considered of national or international significance, importance, or controversy. If the data from this research project falls into one of these categories, contact University Records for advice on long-term retention.

If you have any queries about your ethics clearance, or require any amendments to your research in the future, please do not hesitate to contact the Ethics Secretariat at the Research and Innovation Office, on 02 9514 9772.

Yours sincerely,

Professor Marion Haas
Chairperson
UTS Human Research Ethics Committee

C/- Research & Innovation Office
University of Technology, Sydney
Level 14, Tower Building
Broadway NSW 2007
Ph: 02 9514 9772
Fax: 02 9514 1244
Web: <http://www.research.uts.edu.au/policies/restricted/ethics.htm>

Contact for this correspondence:

Research and Development
Ethics Administration Assistant
Phone: (02) 9845 1253
Facsimile: (02) 9845 1317
Email: SCHN-ethics@health.nsw.gov.au

Corner Hawkesbury Road
and Hainsworth Street
Locked Bag 4001
Westmead NSW 2145
Sydney Australia
DX 8213 Parramatta
Tel +61 2 9845 0000
Fax +61 2 9845 3489
<http://www.schn.health.nsw.gov.au/>
ABN 53 188 579 090

12 November 2015

Dr Michelle DiGiacomo
Faculty of Health
University of Technology

Dear Dr DiGiacomo,

HREC reference number: LNR/15/SCHN/445

Project title: The Able Project

Sites: The Children's Hospital at Westmead

Thank you for submitting the above project for single ethical and scientific review. This project was considered by the Sydney Children's Hospitals Network Human Research Ethics Committee's Executive Committee ("the Committee") at its meeting **9 November 2015**, and subsequently an out of session on **12 November 2015**.

This HREC has been accredited by the NSW Department of Health as a lead HREC under the model for single ethical and scientific review, and by the National Health and Medical Research Council as a certified committee in the review of multi-centre clinical research projects.

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* and *CPMP/ICH Note for Guidance on Good Clinical Practice*.

I am pleased to advise that the Committee has granted ethical approval of this research project. Your approval is valid for three (3) years, effective the date of this letter.

The documents reviewed and approved by the Committee are:

Document Reviewed	Version	Date
LNR Submission Code, AU/6/7932211		30 October 2015
Participant Consent Form	V1	2 November 2015
Invitation to Participate	V1	2 November 2015
Participant Information Sheet	V2	11 November 2015
Project Plan	V1	2 November 2015
The Able Project SCHN cover letter		11 November 2015

J:\PROJECT FILES - Ethics & Governance\Ethics\LNR\2015\LNR_15_SCHN_445 - TRIM E15 0430@16. Correspondence
Out\LNR_15_SCHN_445 - EO 9 Nov 2015 - Ethics Approval Letter - 12 Nov 2015.docx

Please note the following conditions of approval:

1. The Coordinating Investigator will immediately report anything which may warrant review of ethical approval of the project in accordance with the SCHN adverse event reporting policy.
2. All proposed changes to the research protocol, including the conduct of the research, changes to site or personnel, or an extension to HREC approval, are to be provided to the HREC or its delegate for review before those changes can take effect.
3. The HREC will be notified, giving reasons, if the project is discontinued at a site before the expected date of completion.
4. The co-ordinating investigator will provide an annual report to the HREC on the anniversary of this approval letter, and a final report on completion of the study.
5. Your approval is valid for three (3) years from the date of the final approval letter. If your project extends beyond that three year period and you are still actively recruiting you will be required to resubmit your application incorporating any amendments within six (6) months of that approval expiry date. If your project is in follow up on, or analysis, please submit an application for amendment to extend the approval period. Ethics approval can be extended for a period of twelve (12) months at a time.
6. In the event of a project **not having commenced** within 12 months of its approval, the approval will lapse and reapplication to the HREC will be required.

Should you have any queries about the HREC's consideration of your project please contact the Research Ethics Administration Assistant on (02) 9845 1253.

You are reminded that this letter constitutes ethical approval only. You must not commence this research project at a site until separate authorisation from the Chief Executive or delegate of that site has been obtained. A copy of this letter must be forwarded to all site investigators for submission to the relevant Research Governance Officer.

The HREC wishes you every success in your research.

Yours faithfully



Mrs Jillian Bunting (Shute)
Executive Officer
Sydney Children's Hospitals Network Human Research Ethics Committee

Contact for this correspondence:

Ethics and Governance

Name: Eman Nafea
Phone: (02) 9845 3084
Facsimile: (02) 9845 1317
Email: eman.nafea@health.nsw.gov.au

Corner Hawkesbury Road
and Hainsworth Street
Locked Bag 4001
Westmead NSW 2145
Sydney Australia
DX 8213 Parramatta
Tel +61 2 9845 0000
Fax +61 2 9845 3489
<http://www.schn.health.nsw.gov.au/>
ABN 53 188 579 090

Date: 7/01/2016

Dr Hasantha Gunasekera
Paediatrics & Child Health
The Children's Hospital at Westmead

Site Authorisation Letter

Dear Dr Gunasekera,

HREC reference number: LNR/15/SCHN/445

SSA reference number: LNRSSA/15/SCHN/469

Project title: The AbLE Project

Site: The Children's Hospital at Westmead

Thank you for submitting an application for authorisation of this project. I am pleased to inform you that authorisation has been granted for this study to take place at the above site.

Site-specific approved documentation	Version	Date
Participant Consent Form	V1	3 Dec 2015
Invitation to Participate	V1	3 Dec 2015
Participant Information Sheet	V1	3 Dec 2015

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Please advise us of the date when the project starts at this site.
2. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are copied to the research governance officer.
3. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project are to be submitted to the research governance officer.

Yours sincerely,



Eman Nafea, PhD
Research Governance Officer

Appendix 6: Participant information sheet and consent form



The AbLE Project **Participant Information Sheet (Professional)**

Project Title:

The AbLE Project: **Ab**original Early Intervention for **L**earning and physical disability in **E**arly childhood Development

Project Team:

University of Technology Sydney

Dr Michelle DiGiacomo

Prof Patricia M. Davidson

Prof Rosemary Johnston

Mrs Patricia Delaney (Cultural Mentor)

Mr John Delaney (Cultural Mentor)

Western Sydney University

Dr Penelope Abbott

Mount Druitt Hospital/Western Sydney University

Dr Patrick Patradoon-Ho

Sydney Children's Hospital Network (Westmead)

/University of Sydney

Dr Hasantha Gunasekera

What is the purpose of this project?

We aim to improve early detection and support services for developmental delay or other disability in preschool-age Aboriginal children.

'Why have I been invited to participate in this study?'

You have been invited to participate in this study because you are working in the area of early childhood, primary care, health promotion, education, health education, or disability and/or developmental delay services.

What does the AbLE project involve?

You may be invited to take part in an interview to discuss your experiences or thoughts on disability, developmental delay and/or early childhood services. These will last approximately 30-60 minutes. We are interested to hear your thoughts on how we can improve early detection of disability and developmental delay in preschool-age Aboriginal children.

Are there any risks?

Talking about your experience with early childhood disability or developmental delay may be upsetting. If at any time you become distressed, you should contact the research team as soon as possible. They will assist you in arranging appropriate care.

Are there any benefits?

This study aims to improve the support and services to help young Aboriginal children and their families in the Western Sydney areas, however, it may not benefit you or your work directly.

Confidentiality / Privacy

All aspects of this study, including results, will be strictly confidential and only the researchers will have access to your personal information. This will be stored securely and is only accessible to the lead researcher. Your name and personal details will be removed and will not be used in any presentations or publications arising from this study.

'What will happen to my interview after it has been used?'

Only with your permission, will we audio record the interviews. These audio recordings will be transcribed and then stored securely on a password protected computer at the University of Technology Sydney. Hardcopy materials will be stored in a locked cupboard. This computer and cupboard is only accessible to the lead researcher, Dr Michelle DiGiacomo. Data will be securely stored for a minimum of 7 years after the study is completed, as required by the Aboriginal Health and Medical Research Ethics Committee (AH&MRC).

Do you have a choice?

Your participation in this study is voluntary. You can stop being a part of this study at any time without having to explain. Your current and future relationship with the researchers will not be affected.

How is this study being paid for?

The study is funded by the Australian Research Council (ARC).

How will the information be used?

General, non-identified information gathered from the interviews will be reported back to the ARC. This information will be used to inform improved support services for early childhood disability and developmental delay identification in Aboriginal kids. Your name and identifying information will not be shared with anyone outside of the project team.

This study has been approved by the AH&MRC. If you have any concerns or complaints about this study, you can contact them at:

The Chairperson
AH&MRC Ethics Committee
P.O. Box 1565
Strawberry Hills NSW 2012
Telephone: (02) 9212 4777.

Further information:

You can get additional information about the project from Anna Green (ABLE Project Manager) on 0416 563 036 or anna.green-1@uts.edu.au.

The AbLE Project Participant Information Sheet (Professional)

Project Title:

The AbLE Project: **A**boriginal Early Intervention for **L**earning and physical disability in **E**arly childhood Development

Project Team:

University of Technology Sydney Dr Michelle DiGiacomo Prof Patricia M. Davidson Prof Rosemary Johnston Mrs Patricia Delaney (Cultural Mentor)	Western Sydney University Dr Penelope Abbott Mount Druitt Hospital/Western Sydney University Dr Patrick Patradoon-Ho
Mr John Delaney (Cultural Mentor)	Sydney Children's Hospital Network (Westmead) /University of Sydney Dr Hasantha Gunasekera

What is the purpose of this project?

This study is being conducted by researchers from the Faculty of Health at the University of Technology in conjunction with Mt Druitt Hospital, the Children's Hospital at Westmead and the Western Sydney University. The purpose of this project is to aim to improve early detection and support services for developmental delay or other disability in preschool-age Aboriginal children.

'Why have I been invited to participate in this study?'

You are being asked to consider participating because you are working in the area of early childhood, primary care, health promotion, education, health education, or disability and/or developmental delay services and will be able to provide us with perspective on early detection and support services to this group.

What does the AbLE project involve?

If you consent to participating in this research project, you will be asked to sign the consent form. Following that, you will be invited to take part in an interview to discuss your experiences or thoughts on disability, developmental delay and/or early childhood services. We are interested to hear your thoughts on how we can improve early detection of disability and developmental delay in preschool-age Aboriginal children. Interviews are expected to take approximately 30-60 minutes.

Are there any risks?

Talking about your experience with early childhood disability or developmental delay may be upsetting. If at any time you become distressed, you should inform the research team member conducting the interview. They will assist you in arranging appropriate care.

Are there any benefits?

We do not anticipate there to be any direct benefits to you as a result of participating in this study. The aim of the study is to improve the support and services to help young Aboriginal

children and their families in the Western Sydney areas. This being the case, you may experience some benefit in being able to contribute to that.

Confidentiality / Privacy

All aspects of this study, including the study results, will be kept strictly confidential and only the researchers will have access to your personal information, unless as required by law. All data collected will be stored securely and accessible only to the principle researcher. Your name and personal information will be de-identified and will not be used in any presentations or publications arising from this study.

'What will happen to my interview after it has been used?'

With your permission, will we audio record the interviews. These audio recordings will be transcribed and then stored securely on a password protected computer of the principal researcher, Dr Michelle DiGiacomo, at the University of Technology Sydney. Hardcopy materials will be stored in a locked cupboard. Data will be securely stored for a minimum of 7 years after the study has been completed.

Do you have a choice?

Your participation in this study is entirely voluntary. You can decide not to participate or to withdraw from participation during the study. If you wish to withdraw, any information collected from you will be destroyed and not used in any analysis or publication. Your current and future relationship with the researchers will not be affected regardless of your decision to participate or not.

How is this study being paid for?

The study is funded by the Australian Research Council (ARC). You will not receive any payment for participating in this study.

How will the information be used?

General, non-identified information gathered from the interviews will be reported back to the ARC as well as possible presentation in journals and at conferences. This information will be used to inform improved support services for early childhood disability and developmental delay identification in Aboriginal kids. Your name and identifying information will not be shared with anyone outside of the project team.

This study has been approved by the Aboriginal Health & Medical Research Council Human Research Ethics Committee, the Sydney Children's Hospitals Network Human Research Ethics Committee and the University of Technology, Sydney. If you have any concerns or complaints about the conduct of this study, please do not hesitate to contact either of these committees at the details provided below.

The Chairperson
AH&MRC Ethics Committee
P.O. Box 1565
Strawberry Hills NSW 2012
Telephone: (02) 9212 4777

Executive Officer, Research Ethics
Sydney Children's Hospitals Network HREC
Phone: (02) 9845 3066
Email: SCHN-ethics@health.nsw.gov.au

All enquiries will be handled in the strictest of confidence.

Further information:

Should you require any further information about this study, please contact the ABLE Project Manager, Anna Green on 0416 563 036 or anna.green-1@uts.edu.au.

This Information Sheet is for you to keep.

The AbLE Project: Aboriginal Early Intervention for Learning and physical disability in Early childhood Development

Participant Consent Form

I, _____, agree to take part in the AbLE Project.

- ☐ I have read [or had read to me] the Participant Information Sheet.
- ☐ I understand what will happen during the interview and what I will be asked to do.
- ☐ I asked a member of the project team if I did not understand any part of it, or if I had any other questions.
- ☐ I understand that the interview will be audio-taped and I agree that I am happy for this to happen.
- ☐ I understand that the research team will use our stories in their work and share that with others, but they will make sure no one knows exactly what I said.
- ☐ I know that I can stop taking part in the project at any time by contacting a member of the project team.

Once you have read and consented by ticking each of the boxes above, please complete the section below.

Signature: _____

Name: _____

Date: _____

If you have any questions about taking part in the study, please contact Anna Green (AbLE Project Manager) on:

Phone: 0416 563 036

Email: anna.green-1@uts.edu.au

The Able Project: Aboriginal Early Intervention for Learning and physical disability in Early childhood Development

Participant Consent Form

I, _____, agree to take part in the Able Project.

- ☐ I have read (or had read to me) the Participant Information Sheet.
- ☐ I understand what will happen during the interview and what I will be asked to do.
- ☐ I asked a member of the project team if I did not understand any part of it, or if I had any other questions.
- ☐ I understand that the interview will be audio-taped and I agree that I am happy for this to happen.
- ☐ I understand that the research team will use our stories in their work and share that with others, but they will make sure no one knows exactly what I said.
- ☐ I know that I can stop taking part in the project at any time by contacting a member of the project team.

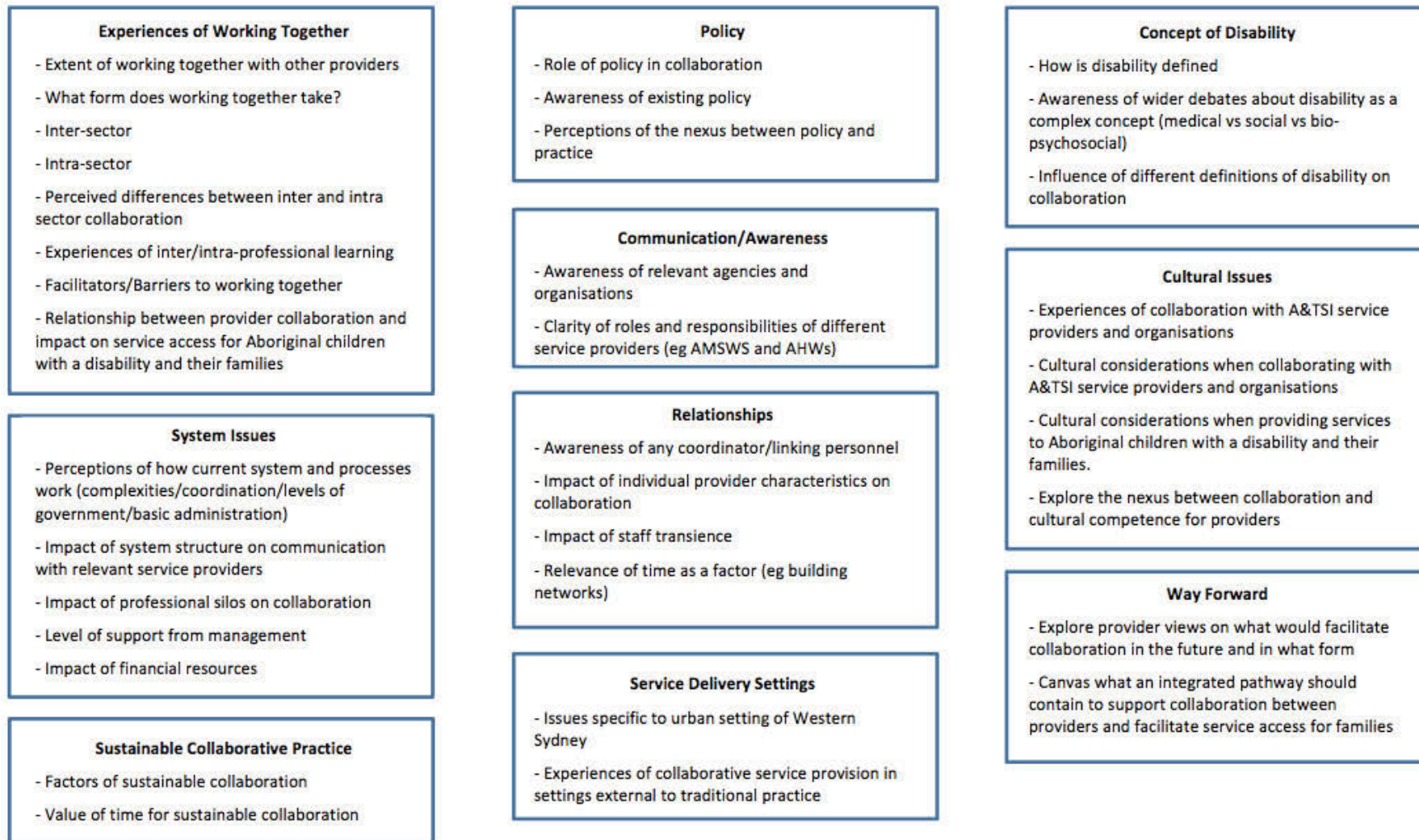
Once you have read and consented by ticking each of the boxes above, please complete the section below.

Signature: _____
Name: _____
Date: _____

If you have any questions about taking part in the study, please contact Anna Green (Able Project Manager) on:

Phone: 0416 563 036 Email: anna.green-1@uts.edu.au

Appendix 7: Brainstorm map for topic guide development



Appendix 8: Interview topic guide

Background and contextual information

On a daily basis what does your role look like?

- Determine level of contact with Aboriginal and Torres Strait Islander families
- Level of contact with Aboriginal and Torres Strait Islander service providers/organisations
- Understanding of disability

Health, education and social service systems

Level of contact with [health services/schools/Centrelink]?

Can you tell me one or more things that work well in working with the [health/education/social service] system? One or more things that don't work well?

- Draw out factors that influenced either way

What are your views of the role personal and professional relationships may play between service providers?

Acceptability issues

***Note:** Introduce the concept of Acceptability as a dimension of service access.

Is this your first role where you have worked with Aboriginal and Torres Strait Islander families or service providers/organisations?

- Determine if they have had any support/formal training around working with Aboriginal and Torres Strait Islander families or service providers/organisations

What are your thoughts on how Acceptability issues relate to your interactions with Aboriginal and Torres Strait Islander families or service providers/organisations?

- Determine what has worked well
- What hasn't worked well
- Influence on their routine

What do you understand about the impact of the Stolen Generation on your interactions with Aboriginal and Torres Strait Islander families or service providers/organisations?

Future outlook

Findings from the stakeholder and carer forums were that the health, education, and social services somehow work in a streamlined way to address some of the service access issues. Do you have any comments on these suggestions?

- Unpack ideas in relation to how they would work in practice

Appendix 9: Self-care plan

Potential risk	Self-care strategy
Encountering expressions of racism from a participant during an interview.	- Attempt to draw out the meaning behind the racist comment instead of reacting as suggested in the 2015 FoH Yarning Circle facilitated by Jennifer Newman. - Maintain ongoing de-briefing sessions with supervisors and cultural mentors.
Encountering expressions of racism from participants during a group interview.	- At the start of the group interview make a statement that it is a safe space and each participant should be respectful of one another. - Attempt to draw out the meaning behind the racist comment instead of reacting as suggested in the 2015 FoH Yarning Circle facilitated by Jennifer Newman. - Maintain ongoing de-briefing sessions with supervisors and cultural mentors.
Encountering expressions of racism during analysis of interviews.	Maintain ongoing meetings with supervisors and cultural mentors during the analysis stage to mitigate potential feelings of isolation.
General impact of research that could involve sensitive cultural issues.	- Be aware of the free counselling service offered at UTS through the health clinic. - Maintain a reflective journal throughout the data collection and analysis stages to help with self-awareness. A journal entry will be made after each interview regarding my thoughts about the interaction flow, rapport, technique ect. to improve my skills in handling subsequent interviews.