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

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Thesis submitted in fulfilment of the degree of

Doctor of Philosophy

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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.

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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.

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.

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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..

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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.

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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].

Interprofessionality

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

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

Intersectionality

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

Mainstream

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

National Disability Insurance Scheme

The National Disability Insurance Scheme is an initiative by the Australian federal government to provide services and support for people with a disability across

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

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