

***'It's quite a complex trail for families now'* - Provider understanding of access to services for Aboriginal children with a disability**

Abstract

Aboriginal and Torres Strait Islander children experience a higher prevalence of disability and socio-economic disadvantage than other Australian children. Early intervention from across the health, education and social service sectors is vital for improving outcomes, but families face a number of barriers to service access which impede intervention. This study aimed to inform ways to improve access to services for families of urban-dwelling Aboriginal children with a range of disabilities. A qualitative approach was taken to explore providers' perceptions of factors that either impeded or enabled families' access to services. In this research the term 'provider' refers to individuals who are employed in a range of sectors to deliver a service involving assessment or management of an individual with a disability. Semi-structured in-depth interviews with 24 providers were conducted. Data analysis was informed by the general inductive approach and then applied deductively to the candidacy framework to generate additional insights. Candidacy focuses on how potential users access the services they need, and acknowledges the joint negotiation between families and providers regarding such access. Our research identified that candidacy was influenced by the historical legacy of colonisation and its ongoing socio-cultural impact on Aboriginal people, as well as funding and current policy directives. Enacting culturally sensitive and meaningful engagement to better understand families' needs and preferences for support, as well as support for providers to develop their understanding of family contexts, will contribute to facilitating service access for Aboriginal children with a disability.

Keywords: Aboriginal and Torres Strait Islander; childhood; disability; service access; candidacy

Background

In Australia, Aboriginal and Torres Strait Islander children with a disability are considered to be ‘doubly disadvantaged’ because they endure not only disparities in disability, but also disadvantage stemming from experiences of historical trauma and racism, as well as socio-economic disadvantage (Bostock, 1991). Aboriginal and Torres Strait Islander peoples are the original inhabitants of Australia and owners of the land (Queensland Health, 2011). They represent the oldest surviving cultures in the world (Aboriginal and Torres Strait Islander Commission, 1998). Colonisation, initiated by the British invasion in 1788, has led to a wide range of health and socio-economic inequities experienced by Aboriginal and Torres Strait Islander peoples (Australian Government, 2009; Sherwood, 2013).

Aboriginal and Torres Strait Islander children experience a higher prevalence of disability than other Australian children (Biddle, Yap and Gray, 2013). For the purpose of this study we used a broad definition of disability inclusive of mild, moderate and severe disabilities, involving physical, intellectual or developmental conditions. Inequitable burden of disability is a pattern seen in Indigenous populations worldwide (Capiello and Gahagan, 2009). Globally, colonisation and associated discrimination and racism has also denied Indigenous people access to the resources to improve socio-economic status (Loppie Reading and Wien, 2009). Other factors such as long waitlists (Gunasekera, Morris, Daniels et al., 2009) and confusion about service pathways can impede timely access to treatment (Aboriginal Disability Network New South Wales, 2007; Australian Bureau of Statistics, 2004; Snodgrass, Groves and South Australia. Ministerial Advisory Committee: Students with Disabilities, 2007). Aboriginal parents/carers of a child with disability report considerable confusion around the existence, role, and accessibility of health and social services, with documented waiting times for treatment ranging from 6 months to 2 years (Author Reference a). Unaddressed disability can negatively

impact outcomes across the life course, meaning that intervention in the early years of childhood is crucial (Australian Institute of Health and Welfare (AIHW), 2014; Baldry, McCausland, Dowse et al., 2015; Goldblatt et al., 2015).

Service access is vital to the prevention and management of health problems which contribute to health disparities (Australian Bureau of Statistics, 2006; Australian Medical Association, 2005). In the case of managing disability, this usually requires involvement of services which deliver healthcare, as well as services which support educational and social support needs (Cohen and Syme, 1985). Despite the inequitable burden, Aboriginal and Torres Strait Islander persons with a disability are less likely to access services than other Australians (AIHW, 2011; Gilroy, Donnelly, Colmar et al., 2013). Barriers to service access include socio-economic disadvantage, lack of transportation, bureaucratic processes and racism (Australian Human Rights Commission, 2009; Gilroy, 2012; Gilroy, Donnelly, Colmar et al., 2016). Institutionalised discrimination through policies of dispossession and displacement, an ongoing legacy of colonisation, 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 (Author Reference b; O'Neill, Kirov and Thomson, 2004). This fear is influenced by specific policies that legislated the forcible removal of children from approximately 1910 to the late 1960s, creating what is known as the Stolen Generation (National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from their Families (Australia), Wilson and Australia Human Rights and Equal Opportunity Commission, 1997). Aboriginal and Torres Strait Islander people access both Aboriginal Community Controlled Health Services and mainstream services, or non-Indigenous systems, institutions and practices (Dwyer, O'Donnell, Lavoie et al., 2009). Australia has a two-tiered health system. Medicare and the public hospital system provide low-cost or free access to health care services including primary care,

specialists, and allied health. Australians also have the option to pay for private health insurance for health care outside of the public system where they pay out-of-pocket fees to private providers for the amounts not covered by insurance (Department of Health, 2019). The National Disability Insurance Scheme (NDIS) is a recently implemented national initiative that provides individualised funding packages for eligible people with a disability. State and territory governments were previously responsible for the provision of specialist disability services. While the introduction of the NDIS presents 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, careful consideration of issues specific to families' experiences of disability is required for the scheme to be effective (First Peoples Disability Network (Australia), 2016; National Disability Insurance Agency, 2015). For example, recognising that "*disability is a new conversation*" in some communities for a range of reasons including there being no comparable word for disability in traditional language and a reluctance to label people with disability due to already experiencing discrimination based on their Aboriginality (First Peoples Disability Network (Australia), 2016).

The current study aimed to inform ways to improve access to mainstream health, education and social service providers and services for families of Aboriginal children with a disability in an urban area in New South Wales, Australia.

Methods

The study design was informed by the epistemology of pragmatism (Cornish and Gillespie, 2009; James, 1982) and a general inductive approach was applied to analysis (Thomas, 2006) with the candidacy framework (Dixon-Woods et al., 2006) used to further explore the data. The interest of an Aboriginal Community Controlled Health Service in improving service access for

families guided the study design with the methodology and methods selected according to what best suited the purpose of the study (Cornish and Gillespie, 2009). The study design is informed by some of the principles of the general inductive approach as a method (Thomas, 2006). Key principles that informed the design were that the preliminary approach to analysis was inductive, analysis was guided by the research objectives, and qualitative methods were employed (Thomas, 2006). Findings are reported according to the Consolidated Criteria for Reporting Qualitative Research (Tong, Sainsbury and Craig, 2007).

Setting and recruitment

Pragmatism asks the question of whether or not knowledge has served a purpose (Cherryholmes, 1992). The study was part of a larger community-driven project that partnered an Aboriginal Community Controlled Health Service with university researchers to explore service access for Aboriginal families with a child with a disability. Along with exploring family perspectives (Author reference c, Author reference d, Author reference e), the Aboriginal Community Controlled Health Service determined a need to explore mainstream provider perceptions, understandings, and experiences of service provision as important and appropriate. AA and BB were Aboriginal elders from the local community who co-led the project. They had worked with the health service in management and health promotion roles for many years and were also carers of a child with a disability.

A purposive sampling approach was used to guide recruitment of participants. Providers with experience in providing services to Aboriginal and Torres Strait Islander children with a disability and their families were identified via the health service early childhood intervention contact lists, discussions with the child and family health staff at the Aboriginal Community

Controlled Health Service, and research team contacts. Providers were invited to participate via email and direct telephone requests, and asked to forward the invitation to other contacts following a snowball approach. Data collection continued until thematic saturation was reached in analysis.

Sample

Participants were 24 providers from health (n=13), education (n=8) and social service (n=3) sectors (Table 1). These participants were social service case managers working in government agencies, early childhood education support workers, disability support workers, special educators, allied health workers, early intervention teachers, Aboriginal health managers, general practitioners, nurses, and paediatricians. These participants were based in health and community services where they interacted with families as a function of their respective professions. Three providers had experience as informal carers or family members of a child with a disability, and two providers identified as Aboriginal.

Data collection

Semi-structured interviews were conducted from June 2015 to July 2016. One female researcher (CC) with a background in social science conducted the interviews. She had no prior relationship to the participants. Interviews were conducted face-to-face at participants' workplaces or via telephone.

A concept map reflecting the findings of previous stages of the larger project including a literature review (Author Reference f) and community forums (Author Reference a) was used to develop the interview guide. The interview guide consisted of eight open-ended questions. The guide was developed iteratively through consultation with AA, BB, CC, DD, EE and FF.

The questions related to 4 key areas which were; background and contextual information, health, education and social service systems, acceptability issues and future outlook. All interviews were audio recorded and transcribed verbatim by a secure professional transcription service. Interviews ranged from 20 to 80 minutes with the majority lasting around 45 minutes.

Data analysis

The analysis proceeded in a two-step approach, as described below. Firstly an inductive thematic analysis was undertaken (Thomas, 2006), followed by further review using the theoretical lens of candidacy to generate further insights. Both these analytic processes determined the final themes.

The preliminary data analysis involved four stages. First, close reading of the transcript and reflexive journaling was undertaken to '*get a sense of the whole*' (Sandelowski, 1995) followed by line-by-line coding of the transcript. Codes were grouped with similar codes. Next, the codes were grouped into preliminary categories. Independent parallel coding of the first two transcripts to crosscheck preliminary codes and categories was conducted by three research team members (CC, DD, EE). DD and EE were university academics experienced with qualitative research. The three researchers had regular meetings with the lead Aboriginal co-researchers (AA, BB) and another member of the research team (FF), a general practitioner at the health service and a university academic. DD and FF had been affiliated with the health service for nearly a decade or more. Discussions at these meetings guided code development and emerging findings; differences in the coding scheme were discussed until consensus was reached.

Categories generated in the preliminary analysis focused on participants' perceptions of accessibility of direct services to families. At this stage, the research team (AA, BB, CC, DD, EE, FF) determined that the candidacy framework (Dixon-Woods et al., 2006) was a suitable sensitizing conceptual framework (Bowen, 2006) to deepen the preliminary themes derived in the first step of the analysis process. The candidacy framework emerged in relation to access to health services for vulnerable populations. Dixon-Woods et al. (2006) 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'* (Dixon-Woods et al., 2006). The candidacy framework enables the identification of a variety of access and utilisation factors, as well as areas to target for intervention. It facilitates the exploration of issues related to trust and power differentials between providers and patients from vulnerable populations (Bristow et al., 2011; Chinn and Abraham, 2016), and has been expanded beyond the healthcare sector (Mackenzie, Conway, Hastings et al., 2013). Six stages of candidacy for accessing services are identified in the original framework: 'identification of candidacy'; 'navigation of services' involves both having an awareness of available services and the ability to mobilise required resources; 'permeability of services' refers to how easily patients are able to use services; 'appearances' at services refers to the requirement that patients must make a claim to candidacy to be considered for eligibility; 'adjudications' are made by providers on whether to grant eligibility based on a range of decisions and judgments; and 'offers and resistance' refers to patients who may choose to refuse offers made by services (Dixon-Woods et al., 2006). Rather than a chronological progression, the six stages demonstrate candidacy as a continually negotiated and dynamic process between providers and patients (Dixon-Woods et al., 2006; Mackenzie, Conway, Hastings et al., 2013). These stages are influenced by the context of 'operating conditions' referring to wider macro factors such as policy imperatives (Dixon-Woods et al., 2006).

The focus of the candidacy framework on access to services for vulnerable populations made it especially applicable to the study findings. In particular, the ‘identification’, ‘navigation’, ‘permeability’, ‘appearance’, and ‘offers and resistance’ stages (Dixon-Woods et al., 2006) of the original framework were particularly pertinent to the final six themes that emerged from the two-step analysis process, as was the overarching concept of the joint negotiation between families and providers of the eligibility of Aboriginal children with a disability and their families for services.

Rigour was ensured through independent parallel coding and regular peer debriefings with the research team to discuss emerging findings (Creswell, 2014). Member checks were carried out through providing the findings to all participants for their feedback (Lincoln and Guba, 1985), although no responses were provided.

Results

The main findings from this study fall into to six themes that represent participants’ perceptions of the phases in a family’s journey towards obtaining care for their child with a disability, as seen through the lens of candidacy theory. The first barrier faced by some carers is in recognising they may benefit from services (‘Barriers to identifying candidacy’). Once they recognise services are needed they can be impeded by the cost and complexity of services (‘Navigate a costly and complex service trail’). Once they have found and decided to access necessary services, the design of service delivery may not suit their particular needs and circumstances (‘Factors influencing the permeability of services’). How families interact with providers at services is a particularly strong predictor of how well services are able to meet the needs of Aboriginal and Torres Strait Islander families (‘Interactions with families who present

at services'). Access to services may be offered but not taken up by families ('Offers and resistance to services'). All of this takes place in the socio-political context of colonisation and the Stolen Generation as well as current funding and policy directives ('Operating conditions'). In Figure 1, the thematic analysis is summarised. The bi-directional arrows between themes represent candidacy as a continually negotiated and dynamic process between providers and carers.

[INSERT FIGURE 1 HERE]

Barriers to identifying candidacy

Some providers perceived that some families may have not been aware of the need to seek support for children's development due to family systems being 'fluid' and advice received from members of their community. Some providers described some families as 'easy going' and accepting of a wide range of behaviours, which they perceived might impede early identification of developmental concerns.

'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".' (Health Provider (HP))

In these cases, it was described as important for providers to support carers, including both parents and kinship carers, by providing access to information around why a child required access to specific services and the support available for early intervention.

Navigating a costly and complex service trail

Providers across all sectors perceived that, once families had identified the need for assessment and treatment, they faced difficulties navigating a complex service landscape. The ability of families to mobilise the competencies and resources required to navigate services was influenced by financial, information and system factors.

Financial

Financial outlay associated with the logistics of accessing services, such as for food, transport, or parking, were perceived to impede the ability of some families to navigate services. Despite universal health care, the out-of-pocket expense required to access was prohibitive for families without the requisite financial resources..

'If Aboriginal families are struggling already, even paying a gap of \$20 is too much for them.'

(Social Service Provider (SSP))

Information

Lack of available information on how to access services was perceived to impede the ability of families to enhance their competency to navigate services. Some providers identified their own lack of understanding of how to locate relevant services to refer families for support. They perceived that for families, this lack of information made navigating services even more stressful and difficult.

'Even for me I'm thinking, where do I go about particular things, there's so many different services...and if you're [a carer] in a very stressful situation and 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.' (HP)

Complex service landscape

Providers across all sectors identified that the complex service landscape impeded accessibility. A key issue raised was the confusion caused by multiple early intervention services. Providers described the number of services involved in early intervention as having increased over time and perceived that the system had become more complex.

'But families have got no chance... there're so many agencies out there putting their hands up...It's quite a complex trail for families now.' (Education Provider (EP))

Factors influencing the permeability of services

In the context of the high proportion of Aboriginal people residing in the area, providers identified low numbers of families who accessed their early intervention services. A key barrier was the need to medically label a child through diagnosis to gain access to services; families did not necessarily want to label their child as having a disability.

'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?...We shouldn't be hounding the families to get a label on their child.' (EP)

It was important for providers that services took a holistic approach when designing their service provision models to be accessible to Aboriginal children with a disability and their families. This approach assisted with providing support to children with disabilities who did not have diagnoses that met eligibility criterion for support services.

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. One provider perceived that for Aboriginal families, case management was particularly important to promoting continuity of care and building trust.

'If they had someone that was there, a 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.' (HP)

Interactions with families who present at services

Interactions between providers and families once families presented themselves at services to make claims to candidacy were influenced by four key factors: 1) focus on supporting carers, 2) awareness of acceptability issues, 3) communication strategies, and 4) provider characteristics and obligations. As seen in the light of the candidacy framework, these interactions were highly relevant to the candidacy concept that access to services was contingent on how interaction and negotiation between families and providers took place. Presentation at services in this context included not just families' initial attendance, but also their ongoing engagement with services and providers.

Focus on supporting carers

Maintaining a focus on supporting carers when providing services to children was seen to increase the effectiveness of interactions. Of particular importance was being mindful of the context within which carers were caring for their children, and ensuring advice aligned with

these contexts was necessary. Some providers also perceived that giving support to carers before implementing programs for children would facilitate engagement with programs.

'We needed support for the parents so that they could support the children to be ready for school...we did a lot of other stuff first before we even got to school readiness for some families.' (HP)

Providing access to supportive resources included linking carers with other carers so that they did not feel as if they were navigating their journeys alone. Facilitating support groups for carers was perceived by some providers to have assisted carers to cope with stress related to caregiving.

Awareness of acceptability issues

Several providers identified the need for non-Aboriginal providers to bring an awareness of social and cultural factors which may influence the extent to which services are acceptable, and their influence on power dynamics, into their interactions with families. Understanding complexities faced by some families, adjusting service provision techniques to accommodate them, and recognising that families and the wider community may have different priorities than providers were perceived as crucial to engaging families with services. For providers, this involved the need to be flexible about families being on time for appointments, and addressing the most pressing priorities for families before implementing programs.

'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.' (SSP)

Providers also felt that it was important to appreciate that the Aboriginal population is not homogenous and 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.

Communication strategies

The use of inappropriate communication strategies by providers impeded effective interactions with families. The use of jargon in communicating with families was observed to be confusing.

'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.'

(HP)

Effective communication strategies included offering the appropriate amount of time to families' needs, particularly when communicating with families who had just received a diagnosis. Adequate time was also important in slowly building 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.

'If I saw a child that was sort of working differently, I'd 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, and just sort of wait for that conversation to begin.' (EP)

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. A bureaucratic style and roles as mandatory reporters were perceived to erode trust. Being obligated by policy to enforce mandatory reporting of cases where child abuse and neglect were suspected was perceived by some providers to influence interactions with families. 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 initiating the involvement of the Department of Family and Community Services.

'I'd say that a lot of the difficulties we've had with Aboriginal children too is around perhaps child protection...that child protection may get involved and then there's a whole new aspect of the service provision.' (SSP)

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 erosion of trust.

Offers and resistance to services

The perception that some Aboriginal families, at times, do not want the services offered by non-Aboriginal providers was prominent. Underlying this perception for some providers was the influence of the Stolen Generation. For one provider, this perception manifested in the context of their service being given a funding directive to target Aboriginal children to increase engagement with these families. The non-Aboriginal provider found it challenging to offer this because she perceived that the family did not feel it was needed. She referred to the 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.' (EP)

Improving non-Aboriginal providers' understanding of ways to work effectively with Aboriginal families was identified as key to overcoming the withdrawal of these providers and their services. Improved understanding involved having a holistic and contextual understanding of the broader situation of a family, beyond the medical needs of the child. 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 I have seen in the last five years many case managers withdraw from supporting families because they feel that "we're here to offer, they don't want any help, we can't do anything".' (SSP)

Operating conditions

Families' journeys towards obtaining care for their child with disability was enacted within the two key operating conditions of the socio-political context of colonisation and the Stolen Generation, and program changes related to current funding and policy directives.

Socio-political context

The ongoing impact of Australia's history of colonisation on the Aboriginal population, in particular around the Stolen Generation, was identified as a key factor that impeded effective interactions with families. This awareness manifested particularly in a lack of trust of

mainstream services. 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 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 maybe reluctant to trust in a system that's been imposed on them.' (HP)

Program changes related to funding and policy

Long-term investment was key to effective service provision to families and necessary to build sustainable and effective programs to empower families. It 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. 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. Some providers perceived discontinuation of funding in short funding cycles as an inevitable precursor to withdrawal of providers and their services.

'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?' (HP)

Providers also identified the rollout of the NDIS as a policy directive characterised by uncertainty over the impact it might have on families. A key concern involved the impact that

the withdrawal of government services from disability service provision might have on families with the most complex cases. One provider perceived that the increased role of non-government organisations in this space might lead to families with complex cases falling through the gap in service provision, as they believed that non-government organisations were not as committed to supporting these cases. An Aboriginal health provider identified particular concern around the change to services for families. They perceived that the large shift in the service landscape might lead to lack of continuity for families. An associated concern was that families would need to familiarise themselves and feel comfortable with a new set of providers.

'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...I think it's going to be daunting to the families.' (HP)

Discussion

This study ascertained the areas that providers perceive Aboriginal families are most vulnerable in accessing services for their children. The findings highlight potential areas where future interventions and research might be targeted to improve both families' access and providers' service provision.

In their refinement of the candidacy framework, Mackenzie, Conway, Hastings et al. (2013) present the concept of multiple candidacies whereby different identities of an individual may intersect to create multiple vulnerabilities in negotiating the stages of candidacy (Mackenzie, Conway, Hastings et al., 2013). The influence of financial factors at the stage of 'navigating a costly and complex service trail' 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 status. Intersectionality refers to categories of identity which mutually construct each other to inform experiences of discrimination and oppression (Collins, 2015; Hankivsky and Christoffersen, 2008). Application of the theory of intersectionality in health is relatively new and continually emerging (Bowleg, 2012). 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-Aboriginal Community Controlled Health Service 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 (Author reference e). Intersectionality theory advances 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 (Bowleg, 2012). Acknowledging multiple intersecting identities enables appreciation of the multidimensional complexity of health disparities (Hankivsky and Christoffersen, 2008). 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.

The perception that some Aboriginal families, at times, resist the services of non-Aboriginal providers was prominent in providers' descriptions of interacting with families. This is an area that has been overlooked in research on access to services for vulnerable populations (Dixon-Woods et al., 2005). Providers linked this perception to the ongoing legacy of the Stolen Generation influencing a negative association between non-Aboriginal providers intervening in families care for their child and the destructive child removal policies. The influence of past negative experiences interacting with mainstream systems on the resistance of offers of services by vulnerable populations has been reported elsewhere (Bristow et al., 2011; Chinn and

Abraham, 2016). However it is important to recognise the ongoing effects of colonisation on interactions between mainstream providers and Aboriginal families today. Reflection is needed as to whether Aboriginal families are resisting the ‘help’ they need, or whether service and provider interventions are in fact not meeting the needs of the child and family. Parents accessing health care for their children with disabilities in England have similarly described service access as a ‘battleground’ characterised by frustration over needing specific diagnoses to access services and loss of trust in current providers from past negative experiences engaging with other providers, suggesting the need to redesign disability service delivery to meet the specific needs of the child and family is also an imperative for other populations (Whiting, 2012). For Aboriginal families, rather than assuming interventions can be transferred cross-culturally, non-Aboriginal services and providers need to reconceptualise their service provision according to existing cultural strategies and strengths (Lowell, 2013). A strengths-based focus is essential in highlighting existing assets and strengths within communities which otherwise may be invisible to mainstream services with a focus on implementing a bio-medical western health agenda. Bond (2005) argues that public health approaches, such as health promotion through ‘educating’ Aboriginal communities, can be disempowering in positioning Aboriginal people *‘as nothing more than a group of people who just don’t know what is good for us’* (Bond, 2005). Rather than let an assumption guide behaviour, providers should strive for culturally sensitive and meaningful engagement with families to understand their needs and preferences for support. The Strong Women, Strong Babies, Strong Culture (Lowell, Kildea, Liddle et al., 2015) and Indigenous Early Years Intervention (Bond, 2009) programs are examples of strengths focused community-based interventions for supporting early childhood development in Aboriginal communities. Key to the effectiveness of these interventions is the privileging of culture as integral to health and well-being, community control, identifying

existing community strengths, and reframing discussion from focusing on problems to asking how families can be supported by the community (Bond, 2009; Lowell et al., 2015).

Case management was perceived as key to enhancing the permeability of services for families. Providers valued case management in assisting families to gather information to successfully navigate services. The World Health Organisation (WHO) also recognises case management as a key element to achieving person-centred and integrated health services for complex health problems through service coordination (WHO, 2015a). 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 (Drennan, Wagner and Rosenbaum, 2017; Schwaderer and Itano, 2007; Wells et al., 2008). The key worker model has been employed in a number of programs related to Aboriginal and Torres Strait Islander childhood disability (AIHW, 2015; Johnston and Pilkington, 2015). Reported benefits of the model are the development of trusting relationships with families and local communities, and the help provided to families to navigate care across sectors (Johnston and Pilkington, 2015).

Highlighting strengths and support networks, linking carers with other carers, and providing information, were considered by providers as key to supporting carers. Providing support and information in a way that is grounded in understanding of the context of these families is vital. The important role providers play in making information about supportive resources available to carers has been identified elsewhere (National Academies of Sciences Engineering and Medicine, 2016). The need to build the capacity of providers to support carers (especially linking carers) in this way, is an important area for further research (National Academies of Sciences Engineering and Medicine, 2016). 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 (WHO, 2015b). The First Peoples Disability Network (FPDN) (Australia) (2016) advocate the need for increased awareness about rights and entitlements under the NDIS and how to navigate the new system through face-to-face consultation (FPDN (Australia), 2016). Sukkar, Dunst and Kirkby (2016) 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*" (Sukkar, Dunst and Kirkby, 2016). Consideration of this issue is particularly important for Aboriginal childhood disability due to additional challenges faced by families related to acceptability issues when presenting to services.

Strengths and limitations

The key strength of this research is that it was driven and guided by an Aboriginal Community Controlled Health Service. Participants were purposefully sampled to obtain in-depth and information-rich perspectives to address the study aim as it related to the specific community, however the small sample size along with self-selection bias means that the findings are not necessarily generalisable to providers working in the area of Aboriginal and Torres Strait Islander childhood disability nationally or Indigenous childhood disability internationally. 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 (Commission on the Social Determinants of Health, 2008). Yet, the issues identified in this study likely have resonance to other marginalised populations and, in particular, individuals who have experienced historical trauma.

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. Providers have identified cost and service complexity as barriers to service access for Aboriginal families. They have described key facilitative strategies to successful engagement with Aboriginal families. These include enacting culturally sensitive and meaningful engagement with families to better understand their needs and preferences for support and gaining an understanding of families' contexts to be able to provide the right support at the right time. Support for providers to develop their understanding of family contexts and skills in engaging with families will contribute to service access for Aboriginal children with a disability.

List of abbreviations

National Disability Insurance Scheme (NDIS); Health provider (HP); Social service provider (SSP); Education provider (EP); World Health Organisation (WHO).

Ethics

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Competing interests

The authors declare that they have no competing interests.

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Table

Table 1 Demographic characteristics of providers (N=24)

Characteristic	% (N)
<i>Sector:</i>	
Health	54 (13)
Education	33 (8)
Social service	13 (3)
<i>Organisation:</i>	
Government	46 (11)
Non-Government	29 (7)
Private practice	25 (6)
<i>Role type:</i>	
Practice	83 (20)
Administrative	17 (4)
<i>Gender:</i>	
Female	75 (18)
Male	25 (6)

Figure 1 Provider understanding of candidacy for Aboriginal children with a disability and their families accessing services

