



Twelve factors that can influence the participation of Aboriginal people in disability services

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Abstract

Objective: There is limited understanding of the views of Aboriginal and non-Aboriginal workers about the factors that influence the participation of Aboriginal people in disability services. This inquiry identified and explored the factors that influence the participation of Aboriginal people in disability services, as described from the experiences of a sample of paid non-government disability service workers in New South Wales, Australia.

Methods: Interviews and focus groups were conducted with Aboriginal and non-Aboriginal paid employees of an Aboriginal community controlled organisation and a generic disability organisation.

Results: Twelve factors that influenced the participation of Aboriginal people in disability services were identified from the data. These factors are inter-related historically, socially and institutionally.

Conclusions: The study has both identified issues relevant to the participation of Aboriginal people in disability services and has provided indicators of strategies that could ensure greater and more appropriate participation by Aboriginal people. It is imperative that service access barriers are addressed for Aboriginal peoples during the current national government reforms to the disability services sector (NDIS).

Implications: The findings from this study have significant implications for disability service policy and practice relating to Aboriginal people with disability, their families and carers.

Introduction

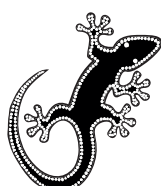
This paper presents research findings from a project [1] that investigated the factors that influence the participation of Aboriginal people in disability services in New South Wales (NSW), Australia. Data were collected from interviews with Aboriginal and non-Aboriginal workers in disability services in NSW.

The prevalence of disability in the Aboriginal population is reported to be over twice the rate of disability in the non-Aboriginal population. The participation rates of Aboriginal people in disability services remain lower than the reported prevalence of disability [2]. Indeed, the disadvantage experienced by Australia's Aboriginal people is reported to be equivalent to that reported in many developing countries [3].

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Recent research [4] found that nearly half of all Aboriginal people with severe and profound disabilities experienced challenges in accessing service providers. Similarly, recent research found that many Aboriginal families did not actively seek information or support from disability services due to a long history of services not addressing disadvantage in crucial areas [5]. Many Aboriginal people do not engage with the disability service system in part due to the legacies of colonial practices and entrenched distrust of non-Aboriginal generic service agencies [6].

The Council of Australian Governments (COAG) [7] is incrementally rolling out national disability service reforms under the National Disability Insurance Scheme Act 2013 (NDIS). Key elements of the NDIS include the opportunity for people with disability to receive individualised, tailored funding to access the supports that best meet their needs. As such, it is proposed that disability services policy will be more focused on individuals as opposed to service systems on a national scale [8]. However, the enactment of the NDIS has been slow and its effectiveness in addressing the needs of remote and rural Aboriginal communities has been brought into question [9].

The Productivity Commission's inquiry [10] that led to the introduction of the NDIS identified a need to further explore ways to address service access and equity barriers for Aboriginal peoples. Similarly, the recent audit of scientific literature focused on disability [11] identified some studies that examined the experience of participating in disability services from the viewpoint of Aboriginal people. However, there is limited understanding of the views of Aboriginal and non-Aboriginal workers in disability services regarding their experience of providing support to Aboriginal people with a disability. This research, led by an Aboriginal researcher, helps to fill this research gap. This paper is written in two parts. Firstly, the research methodology will be discussed. The second section describes in detail the twelve factors that were identified from the data collected. There were similarities and differences between the Mainstream NGO and the Aboriginal NGO in their strategies to address the service participation rate of Aboriginal people. It is important to acknowledge that while factors are being reported separately, these factors were inter-related and inter-dependent. The relationships between the factors are also explained throughout this paper.

Research Design

This research was developed using an Indigenous research methodology. The paradigmatic framework selected for this phase of the research closely aligned with Indigenous Standpoint Theory as a social constructivist approach. The focus of this enquiry was on the cultural interface [12], a complex web of experiences of local Aboriginal and non-Aboriginal service workers and managers of generic and Aboriginal community managed disability service providers.

Participants for this study were recruited from one Aboriginal community controlled organisation and one generic disability service provider in a metropolitan region of New South Wales. Workers varied in their service background, training, experience, expertise and engagement in Aboriginal communities.

As shown in Table 1, data were collected through focus groups and individual interviews. A central proposition of the enquiry was that the staff of disability services could identify the main factors from their perspective. All participants were informed of the voluntary nature of the study.

A total of 60 participants from the Mainstream NGO and four participants from the Aboriginal NGO were involved in this study. A total of seven Aboriginal people and 57 non-Aboriginal people participated in this study. It was a significant challenge to obtain more Aboriginal participants from the Mainstream NGO as the agency did not have many Aboriginal workers and did not collect data on the Aboriginality of their staff.

Table 1: Number of Management Staff

Participant type	The Aboriginal NGO	The Mainstream NGO
Non-Aboriginal	1	8
Aboriginal	1	0

Table 2: Number of Worker Participants

Participant type	The Aboriginal NGO	The Mainstream NGO
Non-Aboriginal	0	48
Aboriginal	2	4

A series of trigger questions [13] derived from the literature were used to stimulate discussion in focus groups. All focus groups and interviews were conducted by the first author and audio recorded and focus groups were also scribed by a co-convenor and field notes recorded. All focus group participants were offered the opportunity to participate in an individual interview. This was only taken up by Aboriginal workers.

A number of analytic tools derived from grounded theory were employed [14] in order to analyse transcribed audio recordings and field notes. Situational analysis was identified as the data analytic framework that was most closely aligned with the paradigmatic framework. Congruent with the purpose of this research, conditional elements of the situation are specified in the analysis as they are constitutive of it, not merely surrounding it or framing it or contributing to it [15]. This included consideration of the structural relationships and power elements in the themes and patterns that emerged over the course of the data collection. All identified themes and findings were member checked with a range of participants.

Identified Factors

This section presents the factors that were identified from the research findings. Twelve major factors were identified from the data and these are listed below:

1. Conceptualising Disability
2. Family and Kin
3. Colonisation and Trauma
4. Racism
5. Choice of Workers
6. Choice of Organisations
7. Community Connections
8. Trustworthiness of mainstream services
9. Multiple Agency Intervention
10. Trusting Workers
11. Mobility
12. Affirmative Action Policy

The factors are discussed and presented with direct quotes from the focus group and interview transcripts as exemplars. For ease of reading, all participant quotes are presented in italics.

Conceptualising Disability

The data identified a conflict at the cultural interface in defining and conceptualising disability. Many Aboriginal people perceived the Western scientific biomedical model of disability as culturally inappropriate. Non-Aboriginal workers considered this indicated a lack of awareness among Aboriginal people about disability and the availability of disability services.

The participants pointed out that there was a diversity of conceptualizations of disability in the Aboriginal population. Aboriginal families often used the term *"normal"* to describe how Aboriginal communities conceptualised disability as *"part of living"*. Some participants stated that many Aboriginal families modified and adapted their families to be inclusive of people with disabilities.

The participants reported that *"acknowledgement of disability"* influences participation in disability services. In order to participate in services, Aboriginal people were required to accept the notion of *"disability"* as defined by the disability service provider, including diagnostic tests and labels. Therefore, Aboriginal families may be required to compromise their own cultural and ideological views on disability in order to accept formal disability services and supports that were provided or rationed in a manner more consistent with biomedical views of disability.

Family and Kin

"Pride" and *"family responsibility"* were some of the reasons raised by many of the study participants to explain why some Aboriginal

families preferred not to access disability services. Some Aboriginal workers said that many Aboriginal families did not want to access disability services because they were too *"proud"* to accept support. Some participants reported a number of Aboriginal client cases where the client prioritized addressing family problems above issues relating to a *"disability"*, including attending scheduled meetings. This created difficulties for many disability caseworkers in addressing the needs of people with disabilities.

Many Aboriginal families have never accessed disability services because they have relied on existing resources in their family and kinship networks to support people with disabilities. Some of the participants stated that there was a dichotomous relationship between the *"awareness"* of disability and *"conceptualisation"* of disability services and the expectation that family and kinship networks would fulfil a caring role for all family members, including people with disabilities.

Colonisation and Trauma

The disability service workers described European colonization and its associated trans-generational trauma, among other social determinants of health in Aboriginal communities, as access barriers to disability services. Colonisation and ongoing trauma were further participation barriers to disability services. An Aboriginal NGO manager stated that *"trans-generational trauma has left a blot on the psyche of every Aboriginal Australian person"*. Interestingly, no Mainstream NGO participants raised trans-generational trauma as an access barrier.

Racism

Aboriginal workers reported racial discrimination experiences in the disability services sector. There were reports of non-Aboriginal disability workers being judgemental towards Aboriginal clients. Some Aboriginal workers had their Aboriginality questioned by non-Aboriginal workers. The disability services workforce culture has persuaded some Aboriginal workers to ignore racism and not to report racial discrimination as a way of *"staying professional"*.

The Aboriginal participants spoke about how Aboriginal people were merged as another *"cultural group"* with migrants and people who have English as a second language. The Aboriginal participants found this to be discriminatory towards Aboriginal people whose experiences are unique in Australian history and in their ongoing impact on Aboriginal people.

Choice of Workers

The findings indicated that providing Aboriginal people with disabilities with the choices about the Aboriginality of their support workers was a factor in maintaining the service participation of Aboriginal people. The findings indicated that disability service providers, which have a mixture of non-Aboriginal and Aboriginal

workers, fostered cross-cultural interaction amongst the workforce.

Trust was a significant factor in the relationship between disability service workers and Aboriginal families. Some families felt that Aboriginal workers did not maintain client confidentiality due to internal family politics. Therefore, some Aboriginal people preferred to have a non-Aboriginal worker rather than an Aboriginal worker. In contrast, some Aboriginal workers were central to the development of culturally appropriate services. The participants stated that many Aboriginal workers had a high level of knowledge about Aboriginal communities. Non-Aboriginal workers utilised Aboriginal workers to help achieve better service outcomes for Aboriginal clients.

The recruitment of Aboriginal people in the disability services sector can help to improve awareness of disability services in local Aboriginal communities. Many participants used the phrases “connections” and “engagement” to describe how Aboriginal workers have helped Aboriginal people participate in disability services. The participants reported that Aboriginal workers who had established networks with Aboriginal community controlled organisations (ACCOS) have helped disability service staff support Aboriginal families. The Mainstream NGO workers often stated that building “connections” and “networks” with Aboriginal community members took a long time without Aboriginal staff. The issue of taking time also recurred throughout the findings.

Choice of Organisations

Similar to the Choice of Workers factor, giving Aboriginal people with disabilities a choice about using disability services provided by ACCOs or generic disability services helped address access and equity barriers for Aboriginal people. *Trust* and *accessibility* were factors that influenced the service participation of Aboriginal people. Many Aboriginal people preferred to access ACCOs because they did not trust non-Aboriginal workers. This trust barrier is historically and culturally embedded in local Aboriginal communities. Disability service providers utilised ACCOs to help support some Aboriginal clients, such as facilitating meetings and client service planning.

In contrast, the participants also reported that many Aboriginal people did not utilise ACCOs due to Aboriginal community and family politics. As noted above, different views were also expressed, in that some Aboriginal families prefer to work with non-Aboriginal workers.

Differing viewpoints exist concerning these approaches, suggesting the maintenance of both types of services allowed better choice for participants. Some of the non-Aboriginal workers felt that funding ACCOs and Aboriginal specific services fostered *cultural separatism* and fuelled elitism in the Aboriginal population as a form of lateral violence in Aboriginal communities. Some of the participants said that the funding of Aboriginal specific services

and programs provided important avenues, through referrals and shared programs, for connecting generic community service providers and Aboriginal communities.

Community Connections

Relationships between Aboriginal communities and disability service providers opened up Aboriginal client service access pathways. Participants from both NGOs reported that their Aboriginal community networks and relationships have influenced the types and numbers of client referrals. Aboriginal NGO participants reported that most of their referrals were self-referrals and referrals from Aboriginal workers because the organisation was embedded in the local Aboriginal communities. In contrast, most of the Aboriginal client referrals to the Mainstream NGO were through formal referral pathways.

Established relationships between Aboriginal workers and Aboriginal communities were essential to opening access pathways to disability services for Aboriginal families. Agency policies and procedures encouraging all Aboriginal workers to be involved in Aboriginal community events, committees and programs helped to embed disability services in Aboriginal communities.

Many non-Aboriginal disability service workers experienced challenges in forging relationships with Aboriginal communities. Many workers did not know who in the local Aboriginal communities to connect with and the right way to go about connecting. Inter-agency networks and Aboriginal consultation groups helped to address knowledge gaps amongst the non-Aboriginal disability workforce.

Trustworthiness of Generic Services

The participants identified a culture of mistrust of non-Aboriginal generic agencies in Aboriginal communities. This culture is historically and institutionally entrenched in Aboriginal communities. Participants spoke about how some of their clients' wariness of services was a result of both being disempowered in the generic community service system and previous negative or even harmful service provider interventions. Disability workers often stated that some Aboriginal clients were “wary” and “distrustful” of services due to previous government community services being “quite directive” and, therefore, they were suspicious that the non-Aboriginal caseworkers would continue to treat them the in the same manner.

The participants reported that many Aboriginal families did not seek assistance from the human services sector, as they did not trust generic services. Many of the participants reported that they had witnessed many referring agencies making discriminatory remarks towards some of their Aboriginal clients. Some participants reported that some Aboriginal people did not trust government officials.

Multiple Agency Intervention

The participants discussed the fact that many Aboriginal people with disabilities experienced interventions from multiple government and non-government agencies. Service workers commented that Aboriginal people with disability were often engaged with many different agencies before accessing their own disability service. This included agencies and interventions unrelated to “disability”. The participants discussed the negative impact that multiple agency interventions had on Aboriginal families. There are a number of implications of multiple agency interventions reported by the participants.

Firstly, multiple service interventions reduced the client’s level of disposable income and increased personal stressors. Consequently, many Aboriginal families missed scheduled appointments, resulting in being labelled as “difficult to engage”.

Secondly, it is sometimes difficult to isolate clients’ “disability” service needs due to the large number of agencies involved in the clients’ lives. The participants provided examples of clients who experienced additional problems and crises as a result of multiple agency interventions.

Thirdly, the participants reported that they had to be flexible around scheduled appointments to prevent over-burdening the Aboriginal clients who had multiple agency interventions. A Mainstream NGO non-Aboriginal worker used the analogy of a “treadmill” to describe the stress that Aboriginal clients experience in meeting the competing expectations of multiple agencies.

Fourthly, many of the participants reported that some health and community service providers were “process focused” and had little regard for their clients as people. A Mainstream NGO non-Aboriginal worker described this focus as the “*treat them and street them kind of attitude where it’s like get them in, tick the boxes, get them out*”.

The fifth impact was that some Aboriginal families struggled to understand the multiple agencies’ processes and requests. This lack of understanding and clarity added to the emotional and financial stress placed on families.

Although multiple agency interventions were causing problems for some Aboriginal clients, the participants also reported examples of clients who had to be “re-connected” or “re-engaged” with the existing services that were already involved. This is a demonstration of the need to empower Aboriginal families to control and coordinate multiple services within the multiple service systems, such as health, children and disability. It is evident that services and support need to be managed carefully and efficiently, acknowledging clients’ wishes as well as planning how best to meet their needs.

Nevertheless, a number of participants reported that some

Aboriginal clients have resisted engaging with caseworkers as a direct result of the stress caused by multiple agency interventions. A Mainstream NGO non-Aboriginal worker gave an account of an ageing Aboriginal client who adopted a “*passive resistance*” strategy against the disability service providers who were involved in his life. Some other Aboriginal clients also resisted by not following through with any of the recommendations and requests made by community service caseworkers or by changing contact details.

Trusting Workers

Trust was identified as a major access barrier to disability service providers for Aboriginal people. Similar to the previous factors, the terms “*trust*” and “*judgement*” were used to describe the development of trusting relationships between caseworkers and Aboriginal clients. The study has identified eight strategies that were employed to build a trusting relationship between non-Aboriginal disability workers and Aboriginal clients.

Firstly, more time was required to build trust and rapport with Aboriginal clients than non-Aboriginal clients due to the culture of mistrust of generic service providers and non-Aboriginal service providers in Aboriginal communities. In contrast, the Aboriginal NGO workers stated that overcoming trust barriers was not a challenge for them in building relationships with their clientele.

Secondly, service workers commenced service planning only after a relationship with the clients had been established. Aboriginal families often did not feel comfortable talking to disability service workers about personal issues until trust was established. A non-Aboriginal worker suggested that staff “... *actually [go in] with a clean slate and not say what they would do ... [Aboriginal people] don’t want you just to [commence] planning or anything like that for quite some time*”.

Thirdly, typically disability was often not the underlying factor for many Aboriginal families. A Mainstream NGO non-Aboriginal manager stated that “... *it isn’t necessarily ... the case ... [that] we’re going to address issues about disability ... even though there is [a person with a] disability in the family ... [it] may not be the dominant thing that makes a difference to people getting on better*”.

Fourthly, taking time to learn about how the family’s Aboriginality was a factor in understanding the client’s service needs. The non-Aboriginal workers reported that they built a trusting relationship with Aboriginal clients by taking time to learn about how their client’s Aboriginality and history had impacted on their engagement with past community service organisations.

Fifthly, it is also vital to choose a location for client meetings in a family friendly setting, such as at a cafe or an ACCO. For example, the non-Aboriginal workers reported that Aboriginal clients and family members commonly requested not to have service meetings at their home.

Sixth, the disability workers had demonstrated that they were not like other government officials. This often took multiple visits over a long time.

Aboriginal families had to be empowered in the intervention. The participants of both agencies shared a similar definition of empowerment. Participants used phrases, such as “*families in the driver’s seat*” and families controlling the “*decision making*” process. Some of the study participants said that empowering clients required caseworkers to have an “*open minded*” and “*non-judgmental*” attitude.

The Mainstream NGO non-Aboriginal participants stated that some Aboriginal families opted out of the service enrolment process due to caseworkers requiring forms to be completed. A Mainstream NGO non-Aboriginal worker described the paperwork process as “... *a very western concept*”. A Mainstream NGO non-Aboriginal worker stated that “*there was something to do with their traumatic past ... [or] there was quite a degree of suspicion [in Aboriginal communities] around signing documents*”.

The participants provided four indicators that trusting relationships between caseworkers and Aboriginal clients had been successfully established.

1. Caseworkers and Aboriginal clients had open and honest discussions.
2. Aboriginal clients contacted organisations requesting support for a problem.
3. Clients did not resist disability service workers and responded “positively” to the advice and recommendations provided by the disability workers.
4. Existing or past clients referred new people to the organization.

Mobility

Remoteness and travel mobility was an access barrier. Lack of affordable transport was a significant challenge for people who depended on government income support. Many Aboriginal families had to travel vast distances or relocate to metropolitan regions to access disability services. This was further compounded by complex bureaucratic processes affecting access to services, such as intake arrangements and waiting lists in different areas.

Affirmative Action Policy

The study identified ineffective policy frameworks that aimed to address access and equity barriers for Aboriginal people with disabilities. The Mainstream NGO that participated in this study developed their Aboriginal policies in response to pressure from government and philanthropic agencies. Interestingly, only the Management staff of the Mainstream NGO discussed their agency’s policies at length. The Mainstream NGO was not actively implementing initiatives or actions under their Aboriginal affirmative action policies. There was a lack of knowledge about

the Mainstream NGO’s Aboriginal affirmative action policies in the agency’s workforce.

Discussion

This study has identified twelve factors that influence the participation of Aboriginal people in disability services. The factors identified have implications for disability service delivery for Aboriginal communities under the COAG disability service reforms. The findings of this study may assist the Australian Government, disability service providers and Aboriginal communities to progress the relevant national reforms in the disability services sector.

All of the identified factors were inter-related historically, socially and institutionally. Furthermore, the factors were entrenched in the disability services sector and each local Aboriginal community involved in the study. These findings demonstrated that disability service workers face many challenges in working with Aboriginal people. For example, racism and discrimination were experienced by both Aboriginal workers and by Aboriginal clients in disability services. In addition, a lack of trust was a barrier to accessing services that was inter-related with the legacies and experience of colonisation and racial discrimination [16]. Consequently, Aboriginal families may prefer Aboriginal workers or ACCOs because they felt safer and more fully understood than with non-Aboriginal workers but the choice should also be available to access non-Aboriginal staff and services.

A major finding was that disparities in how disability is conceptualised have a profound effect on disability service access and equity policies, and on how government funded disability programs are designed and implemented. Aboriginal people were required to accept and conform to the disability service provider’s definition of disability in order to obtain formal supports and services when traditional family and kin resources were unavailable. The term “disability” centres on the power of Western colonial institutions to define, control and categorise people’s circumstances typically through controlling access to resources. The conceptualisation of “disability” has been historically imposed on Aboriginal communities.

The historic distrust of government agencies has continued to influence suspicion in Aboriginal communities of generic disability services and non-Aboriginal disability workers [17]. The Aboriginal communities’ conceptualisation of disability among Aboriginal communities seems to be more aligned with principles of person-centred practice [18] and the social models of disability [19]. However, many non-Aboriginal participants viewed this as a lack of awareness of disability in Aboriginal communities. Non-Aboriginal workers need to better understand the views of local Aboriginal communities in order to improve access and participation rates.

Flexibility in the interpretation of agency policy has permitted

some disability workers to establish more trusting relationships. Non-Aboriginal workers reported that it took them more time to build relationships with Aboriginal families than non-Aboriginal families. The study found eight strategies that were adopted by the participants in building trusting relationships with Aboriginal families. However, disability service providers' Aboriginal access and equity policies are only likely to be effective if the agency management is committed to addressing disadvantage in Aboriginal communities and ensuring that their workers know and understand their policy [20].

The disability services sector must pay greater attention to addressing the social structures underpinning the social determinants of health and disability in Aboriginal communities. The continuing experiences of racism and the economic, health and educational legacies of colonisation continue to underpin the disadvantage experienced by Aboriginal people with disabilities and the rates of disability in Aboriginal communities. The cycle of multiple agency intervention can exacerbate disadvantage in many Aboriginal families.

Conclusion

The study aimed to identify the factors that influence the participation of Aboriginal people with disability in disability services from the perspective of Aboriginal and non-Aboriginal disability workers. The study used an Indigenous research methodology. Twelve factors were identified from the study [1] at the cultural interface. These factors are inter-related historically, socially and institutionally [16]. The study has both identified issues relevant to the participation of Aboriginal people in disability services and has provided indicators of strategies that could ensure greater and more appropriate participation by Aboriginal people.

The NDIS may provide an opportunity for an historical shift in how people with disabilities are supported. It is imperative that service access barriers are addressed during this reform, particularly the enduring systemic access barriers experienced by Aboriginal people with disability identified in this inquiry. The findings from this study have significant relevance for policy and practice under the current national reforms.

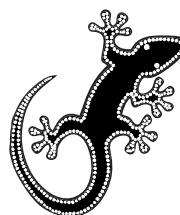
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The Australian Indigenous *HealthBulletin* (ISSN 1445-7253) is the electronic journal of the Australian Indigenous *HealthInfoNet*.

The purpose of the Australian Indigenous *HealthBulletin* is to facilitate access to information of relevance to Australian Indigenous health. Reflecting the wide range of users – policy makers, service providers, researchers, students and the general community – the *HealthBulletin* aims to keep people informed of current events of relevance, as well as recent research. Research information is provided in two ways – the publication of original research and the presentation of abstracts of research published or presented elsewhere.

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