

**Impacts on awareness, access and utilisation of early intervention support services for
Indigenous families living in rural and remote areas
The National Disability Insurance Scheme.**

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ABSTRACT

This chapter considers the impact of the National Disability Insurance Scheme (NDIS) on the provision of disability services for families and children with disabilities through non-for-profit organisations (NFPO's). Findings of a large research study confirmed funding difficulties with the provision of services by NFPO's under previous government policies. The impact of NDIS on families of children with disabilities who have three vulnerabilities i.e. they are Indigenous, they live in rural and remote areas and they are unaccustomed to accessing and utilising 'dominant culture' services, are a major area of concern. Two recent research studies are referred to in making recommendations for the conduct of research that examines service provision in Indigenous communities.

Introduction

Government agencies and not-for-profit organisations (NFPOs) have had long involvement in the funding and provision of community services, such as mental health and disability services. Significant change has occurred over the past decade in the way government funds are expended with public sector agencies increasingly using marketplace mechanisms. As a consequence of economic and governance imperatives, funding of services via Not-For-Profit-Organisations (NFPO) has changed significantly with a move away from the provision of grants to the contracting of these organisations for the provision of services. The National Disability Insurance Scheme (NDIS) is going to change this system again within the next two years.

The National Disability Insurance Scheme funding model is based on an Insurance model where individuals approach the National Disability Insurance Agency (NDIA) and an individual plan and budget is developed that is reasonable effective, necessary and beneficial. It is a,What is it you need and how can I deliver it to you in your local community? Model. To qualify for services the individual needs to have a permanent disability which impacts on their ability to participate in the community. To qualify for early intervention there has to be a measurable developmental delay and evidence that early intervention will lead to less support in the future. As yet there is no allocation for Case Management and for families who have not self-identified to be linked to services. The NDIS will not support activities that they assess as being what normal families provide ([http:// www.ndis.gov.au](http://www.ndis.gov.au), 2014) .

Long-reliant on a steady and reliable stream of government funding, organisations large and small will either sink or swim in a newly created market for disability services (NDS, 2013b). Service providers which used to see the government as their customer will now have to view the consumer as their customer. Services providers are becoming aware that they will need to think totally differently about how they relate to their clients, as the funding will be vested in the clients and the families and will essentially be 'portable' (Stubbs, 2013; M. Hawkins personal communication March 7, 2014).

Disability services providers currently rely on what is known as block funding, a fixed government payment to provide a specific service (NDS, 2013 b), but under the NDIS, people with a disability and their families will be empowered to choose the services they want. Instead of justifying themselves to government, organisations will have to convince the clients themselves to come on board. New competitors, both not-for-profit and for-profit, will enter the sector, potentially offering products or services that currently don't exist (NDS, 2013 b). Each person with a disability or family will have a dollar sign above his or her head (Stubbs, 2013; M. Hawkins personal communication March 7, 2014).

All organisations, both for profit and not for profit, will be operating in an environment where they will be paid after delivery of service, and will need adequate cash flow and capital to maintain their existence (NDS,2013a). This will necessarily mean that those services and clients which deliver the best financial outcome will be more attractive to service providers (NDS, 2013a). Government block grant funding, or competitive tender,

with funds paid in advance has, until now, enabled organisations to practice some degree of cross subsidisation for those clients and services which do not 'pay their way', augmented by charitable fundraising (NDS, 2013a). The introduction of the NDIS will put pressure on service providers who are not able to meet the requirements of the new system, either because they do not have the capital, processes and structure to adapt to the significant change that will occur, or because they do not offer those support services that are funded under the NDIS (L. Matthews, personal communication March 7, 2014). This may well mean that some current service providers will amalgamate, go out of business, or be taken over by others (L. Matthews personal communication March 7, 2014). It is also apparent from the current experience in the NDIS launch sites that there will be new entrants into the provision of services, both not-for-profit and for-profit organisations (Productivity Commission Report, 2011, L. Matthews personal communication, March 7, 2014).

Despite bipartisan support for the scheme and a momentum towards it that makes it seem inevitable, key questions remain unanswered (M Hawkins personal communication March 7, 2014). The first question is that the people with disability who may have the most complex needs, the most high-support needs or even challenging, aggressive behaviours may be disadvantaged if a market is not created that encourages organisations to offer services to meet their needs. This particularly applies to groups who are three times disadvantaged such as Indigenous families with children who have disabilities in rural and remote areas. These families are disadvantaged already in terms of provision of services. However if

organisations can only deliver services within a market based system they may not provide adequate support for these complex client families (NDS 2013 ab, Productivity Commission Report, 2011). The first trial site in the Northern Territory will not be commencing until July 2014 (NDIA 2014), There has already been recognition that the person-centred funding model based on individual plans, which is the basis of the NDIS, may not work with Indigenous families (M. Hawkins personal communication March 7, 2014) and that innovation will be a very necessary feature of service provision. Also, there is newly emerged evidence (Holden, Johnson & Blakemore, 2014) that there is concern arising from the trial about how to link families that need assistance most into the new system, as all families have to self-identify to the NDIA (M. Hawkins, personal communication, March 7, 2014) .

The not-for-profit organisations that have been providing services before the implementation of the NDIS have already had difficulties maintaining services under previous funding models. A large study conducted in Western Australia included a survey of 300 randomly selected NFPOs (49% response rate); interviews with staff from approximately 30 NFPOs; and an analysis of a sample of contracts and other documentation from State government departments (OAG, 2000). The findings of this study revealed there were issues for the delivery of services where identified needs exceed the scope of contracts and where the costs of delivering services exceed the funding provided. This has flow on effects to institutions such as schools and subsequently students in receipt of such services. It is

common for children with disabilities to receive support from educational, respite services, therapy and specialist medical services. Access to these services in rural and remote areas of Australia has long been acknowledged as a problem for families of children with a disability (Aging, Disability and Home Care, 2012).

The current research literature supports the benefits to families of the support that can be provided by multidisciplinary evidence-based programs (Dunst, 2002; Dixon & Johnston, 2005; Dunst & Trivette, 2009). However, there is evidence that low income families and families who are vulnerable, such as Indigenous families, who are regularly exposed to major life stressors, are the most likely to underutilise intervention services for children with disabilities (Blair, Zubrick & Cox, 2005; Wall et al. , 2005).

Previous research investigating community services in six urban and rural communities in Queensland (McDonald & Zetlin, 2004) found that it was the characteristics and operations of the services providers themselves that erected barriers particularly to Indigenous people. The most prevalent factor, mentioned by the majority of informants in all six of these communities, was lack of knowledge about services on the part of service users. In a similar study in the U.K, Baldock and Ungerson (1994) noted that failure to effectively disseminate information about service availability had a serious impact on utilisation. A school readiness program for Aboriginal children with additional needs conducted by Northcott, a large disability provider, in two sites in NSW, one urban and rural, found that in both communities, parents had received limited information about disability and many found

it difficult to identify their child's support needs (Purcal et al., 2013). This was particularly true in the rural community. In both communities, it took several weeks for the workers to build up a trusting relationship with parents that enabled them to discuss their child's needs, and this was facilitated much more quickly where a relationship of trust already existed, which may have taken many months or years to develop.

The second most prevalent factor for McDonald and Zetlin (2004), was that the 'monocultural or dominant culture (i.e. white culture) orientation of the service providers was alienating to Indigenous people particularly in rural communities. Other families have reported alienation when they feel that the program being offered to them is not relevant to their culture or family structure (Wilson & Watson, 2011). The third factor which also impacted on Indigenous people was the need to engage with a clinical health system. This is particularly salient for Indigenous families with a child with a disability as a diagnosis from a specialist who may be a long distance away can delay access to support and services (Wilson & Watson, 2011).

An example of the impact of isolation on access to services is the Commonwealth Government's Helping Children with Autism package (HCWA). The implementation of this package requires that Indigenous families must be involved in health services in order for their child to be diagnosed and offered an intervention program. Some Indigenous people may have very limited access to specialist health services, particularly those living in remote areas and must wait a long time for a specialist diagnosis. The Purcal et al. (2013) study of

provision of services for Aboriginal families of children with disabilities mentioned previously and also Wilson and Watson (2011) confirmed that it was difficult to obtain support for children due to difficulties in obtaining a diagnosis from a specialist.

As a consequence, it has been found that Indigenous children with disabilities are more likely to be identified through the local education system than through the medical system particularly for children at risk of mild intellectual disability (Leonard, Petterson, Bower & Sanders, 2003). The Purcal et al., study (2013) also found that referrals to disability services were frequently made through schools and pre-schools, and less often through the relevant medical services. This was found to be a particular issue for Aboriginal families living in rural communities. This finding is particularly important for those young children (0-6) who may not meet the requirements for a Tier 3 package under the NDIS. For those children who do not have a permanent disability, or do not have a diagnosis recommending early intervention, they may fall into the Tier 2 category under the NDIS (Productivity Commission Report, 2011). At this stage it is unclear how the previous early support services, community development or parental education programs currently funded by State governments as block funded programs will be transitioned to the NDIS system. There is a danger that those children with an undiagnosed delay may fall between the cracks in the system where parents and communities are unaware of how services may assist the child's development. Purcal et al. (2013) found that some preschool and school teachers had

difficulty identifying the support needs of children in their classrooms in the rural site, due to their lack of experience with disability and developmental delay.

Both Commonwealth and State Government in all Australian States have provided services for families of children with a disability and all have included support for Indigenous families and children (Better Start and Help for Children with Autism, Productivity Commission Report, 2011). However, there are barriers to the awareness of, and utilisation of, available services for Indigenous families which are compounded by the families being in rural and remote locations (Kendall & Marshall, 2004). At a time of major change in the whole funding model for services because of NDIS, there is a need for research that can demonstrate how services can empower Indigenous and vulnerable families to access and utilise services that may be offered by new providers under the NDIS. Because of the dominant culture approach and the lack of appropriate information, Indigenous families in the past have needed more support so that they can be empowered to understand the conditions and support the optimum development of their child with disabilities (Kendall & Marshall, 2004) but this is not a recognised need under the NDIS (M. Hawkins, personal communication March 7, 2014). The children themselves are therefore not engaging in programs that could lead to a significant improvement in their developmental outcomes (L. Matthews personal communication March 7, 2014; D. Taylor personal communication, March 7, 2014). Research about the implementation of the NDIS has been commenced at a National level (NILS, 2013) however, there is an urgent need for research which specifically

focuses on how availability, awareness and utilisation of support services for Indigenous families with a child with a disability can be increased and sustained under the NDIS.

Socio Cultural View of Disability

The Western Australian Aboriginal Child Health Survey (Silburn et al., 2006) recommends that to be most effective, health programs need to work within the community's culture, work to build capacity and support community networks, and thus empower the community. This echoes findings in the Indigenous education field, where many researchers see working with and through culture as crucial for Indigenous education to succeed (Enemburu, 1991; Trimble & Fisher, 2006). In low socio-economic and cross-cultural settings, health and education programs developed and implemented independent of the local community and families can also increase the sense of powerlessness and dependence (Kendall & Marshall, 2004) on external providers. This adds to the lack of opportunity for communities to develop the skills, relationships, and self confidence necessary for committed health action (Wilkinson & Sidel, 1991). For Indigenous Australian communities, this approach perpetuates the 'Aboriginal disadvantage' stereotype, the 'solution' being assimilation to Western culture (Keeffe, 1992). In contrast, Community Development theory advocates maximising community involvement, participation and control, in order to ensure initiatives are locally appropriate and sustainable, and work to empower local people (Wiggins, 2011).

Community and family engagement in health and education requires understanding

and working within the world view and values of the community. For example, in many Indigenous world-views, health is not just the absence of disease, but optimal functioning of mind, body, and spirit, and interlinks with the social, emotional, and cultural well-being of the whole family and community (Vass, Mitchell & Dhurrkay, 2011). A health program in an Indigenous community that limits itself to a western medical view of health is thus unlikely to satisfy the collective understanding of health and wellbeing. To address these broader health and family perspectives, a social community approach is necessary (Golds, King, Meiklejohn, Campion & Wise, 1997; Heil, 2008). Health and education professionals need to learn how to collaborate with families and communities, how to learn from families and communities about both their needs and their strengths, and to learn with them about the mechanisms to produce effective disability support services and social change (Smith & Herbert, 1997). The success of health and education support programs is thus dependant not only on the political and social will of the families and the community but also on extra-community workers adopting new work approaches (Wilkinson & Sidel, 1991).

Indigenous researchers working to improve research approaches and outcomes for those being researched emphasise the importance of development of relationships before a discussion of research is commenced (Trimble & Fisher, 2006; Nakata, 2013). Trimble and Fisher emphasise the importance of developing a relationship as equal participants that is based on “trust, respect, integrity, prudence, benevolence and reverence” (2006, p.13). Establishing a quality relationship promotes the process of acceptance as the community

comes to know, through their own cultural rules, whether the researcher is trustworthy. This view is based on recognition that community members will question the researcher, and have a right to do so, given that they hold the knowledge that the researcher seeks. They recommend spending the majority of time in visiting a community to development such relationships prior to commencement of or discussion of research. This approach is aimed at achieving quality research outcomes of greater relevance to the needs of the community. Under these circumstances there is likely to be a positive impact on validity, reliability and quality of data as participants will have greater engagement in the research and share what “they really think” (Trimble & Fisher, p.14). These points have been confirmed in the research experience of the authors also. In a study looking at the awareness and access to social justice the first author had arranged to visit a remote community in the north of Western Australia. An encounter with a cow and car rollover on the way into the community resulted in the author being taken into the health clinic along with many community members also attending clinic day. Talking about and sharing a known experience, how it happened, and listening to others stories commenced a relationship that would not have occurred under the circumstances of more formal discussion about the research. Rather than avoiding involvement, community members and elders were asking to meet the researcher which resulted in a frank sharing of experience and views on the research questions, providing quality valid data that was able to be utilised to attain better outcomes in response to the issues raised (Trimmer, personal communications, November 5, 2013).

The established importance of such relationships is applicable to both conduct of research and provision of services. Nakata (M. Nakata, personal communication, October 25, 2013) indicates that even when Indigenous scholars and researchers work within communities, ways of talking and doing may be at odds with existing community values or practices. He also emphasises the necessity of taking the time to establish trusting relationships based on empathy and respect. This can mean that researchers and service providers need to spend the majority of time getting to know one another before any mention is made of research questions or service provision. The community will want to explore the character and background of the visitor to determine their fit with the values and ethics of the community. Trimble and Fisher (2006) recommend that those wanting to work within such communities be ready to reflect on their own character, values and ethics and to be open in sharing these more personal reflections prior, and in addition to, the factual information about research or programs.

The Purcal et al (2013) study, recently commissioned by the third author for Northcott NSW, evaluated the support provided to Aboriginal families with children with additional needs & what support was required to assist families, what comprised effective early interventions, what empowered Aboriginal families to advocate for support, and what formats for service could provide a sustainable model to support Aboriginal families of children with additional needs. A clear finding with significant implications for the provision of services was the lead up time required to build trusting relationships with local service providers and the Aboriginal community (Purcal et al. ,2013). The development of a trust relationship was essential before parents were comfortable and ready to talk to program staff about concerns for their child, identify support needs and explore options that would directly or indirectly support the child.

The Need for Social and Culturally Sensitive Research Methods to be integrated into any study of the provision of services under the NDIS.

Given that some service providers to date have not provided culturally appropriate services that are utilised by these thrice vulnerable families and children, there is a need to employ innovative research methods to investigate this problem before services are planned and implemented under the NDIS. Whilst the Purcal et al., (2013) report provides some evidence, authentic deep information about the barriers to Indigenous families with a child with a disability which may discourage utilisation of disability support services is incomplete, as is the knowledge of how disability support services can be modified so that utilisation by Indigenous families with a child with a disability will increase and be sustained. Multidisciplinary evidence based dominant culture interventions (Dixon & Johnston, 2005) are available but there is a need for such interventions and services to be developed and implemented in culturally appropriate ways so that Indigenous families will increase their utilisation of and sustain their involvement in the programs.

For any research program focusing on the development of services to be successful it would need to include Indigenous perspectives and identify culturally appropriate, community engaging approaches across many fields (Watts & Carson Lecturer, 2002). In a previous successful health related research project in rural and remote Indigenous communities of the second author, these included the concepts of Both Ways Learning, negotiated or generative curriculum, and dadirri (Constable, Dixon, Dixon & Toribio, 2012). Ungunmerr (1993) says of dadirri:

In our Aboriginal way, we learn to listen from our earliest days. We could not live good and useful lives unless we listened. This was the normal way for us to learn – not by asking questions. We learnt by watching and listening, waiting and then acting. Our people have passed on this way of listening for over 40,000 years (p.35).

Dadirri refers to a process of non-intrusive observation, a reflective non-judgmental consideration of what is being seen and heard and a sense of the informed responsibility that comes with knowledge (Atkinson, 2002). It is the first step to meaningful communication, understanding, and relationship building, which form the foundations of appropriate interaction in cross-cultural contexts. It has been demonstrated to be a successful principle and methodology in human health and Indigenous education across many international different cultures and contexts (Constable et al., 2012). In this project the dadirri concepts were classified into the steps of listening, thinking, discussing, and acting:

Listening

As reported in Constable, Brown, Dixon and Dixon (2008), a needs analysis was conducted in each community to clarify the health issues present and the factors influencing them. Semi-structured interviews with community residents in focus groups or individually (as preferred by respondents) were conducted to explore motivation, knowledge of issues, knowledge of solutions, and access to solutions. At the same time in each community, a clinical health survey was conducted to provide baseline quantitative measures of health.

Thinking and Discussing

The results of the needs analysis were reported back to community representatives and discussed. A team of interested community residents and extra-community professionals was formed in each community to consider the issues further. This local health team negotiated the community's health priorities and decided on preparations required for and actions to be implemented in the health program.

Acting

In each of the four communities, on the basis of the health team's considerations and preparatory work, a plan of action was decided upon and instigated, and aspects of the program activities evaluated through further interviews and discussion. This iterative approach kept the program responsive to community feedback and able to adjust to suit new directions and actions.

Throughout every stage of this process, the researchers kept in mind the need for extra-community knowledge to be balanced by community knowledge, and to facilitate rather than direct activities.

More recently, the third author was involved in the delivery of a program for Northcott NSW of a program for Aboriginal children with developmental delays and disabilities. The program being evaluated, worked with the children's families and the community to support school readiness and successful transition to school in two NSW local government authorities – one urban and one rural/regional. Evaluation by the provider and the Social Policy Research Centre, UNSW (Purcall et al., 2013), found that communities and

families often had little information provided to them about disability or the services that could assist the children in preparing for school. It took some time for workers to build a relationship of trust with parents, and this was achieved much more quickly when the community had already recognised the provider organisation as trustworthy, and where Northcott had worked closely with community elders and Aboriginal organisations to gain the trust of families. Northcott also found that families preferred to look at a range of supports for both the family and the child to achieve the best outcomes for the child, rather than deal with the child in isolation of the family and the community. This preference for community based culturally relevant programs is at complete variance with the NDIS individually based model (L. Matthews personal communication March 7, 2014; D. Taylor, personal communication March 7, 2014).

Recommendations for Researching the provision of Services to Indigenous families with a children with a disability under the NDIS.

In light of the previous research projects undertaken by the authors and the literature cited above, any research project which seeks to provide authentic rich information about the provision of services for Indigenous families of children with a disability in rural and remote regions under the NDIS should consider the following research questions and recommendations:

Research Questions

- 1) How do Indigenous families conceptualise disabilities in different communities and cultures?

- 2) What are the implications for Indigenous communities and families of having a child (0-12) disability on awareness access to and utilisation of services in rural and remote areas?
- 3) Do barriers exist to utilisation of specialist services as a consequence of existing government policy and models for service provision?
- 4) What is the preferred model of services that would increase utilisation and sustainability of support services for Indigenous families with a child with a disability?
- 5) How can other ways of knowing and community values, such as Aboriginal extended family relationships, be incorporated into service delivery?

Recommendations

Following on from the above discussion and the experience of the authors in conducting research in Indigenous communities, it is recommended that the following principles are incorporated into the methodology for research projects undertaken in rural and remote Indigenous settings:

- a) Become known to the families and communities before commencing the project.

Previous to setting up the focus groups or interviews, it is necessary to contact the local councils and services to arrange visits to meet the community and families. If possible the researchers, project manager and research assistants should attend community days, fair days and perhaps sporting events. It will then be necessary to contact schools, parenting groups and local Aboriginal Education Consultative

Groups to get to know the parents. Also it would be useful to gain knowledge of the dominant family groups in the community, preferred names and language groups.

- b) Recruitment of families with a child with a disability may be problematic given the issues discussed earlier. Barbeques and Family Fundays are good ways of contacting families and increasing participants.
- c) The research project would need to include qualitative methods so that Indigenous families can be given an authentic voice (Brantlinger, Jiminez, Klingner, Pugach & Richardson, 2005; A. Howard personal communication March 7, 2014).
- d) Review of literature to investigate successful culturally appropriate support programs for other Indigenous populations from International research needs to include what has been called the grey literature, government reports etc.
- e) Ensure a needs analysis is conducted with each family and community. Semi-structured interviews with families in focus groups or individually (as preferred by respondents) should be conducted to explore motivation, knowledge of issues, knowledge of solutions, and access to solutions.
- f) The demographics of the communities in which the families are situated should be assessed using a tool such as The Accessibility and Remoteness Index of Australia (ARIA) and the Index of Relative Socio-economic Disadvantage (IRSED). Family characteristics including living arrangements and caring arrangements of the child

with disabilities should also be gathered if the families are willing to share this information.

- g) Other demographic information related to diagnosis/ no diagnosis and time of diagnosis for the children should also be gathered as relevant and available.
- h) Community-based Indigenous research assistants should be employed to assist with the running of all aspects of the project. It is preferable for these assistants to be community residents.
- i) Research projects conducted in participation with service providers could be combined with service delivery to Indigenous communities and families. Particularly where resources are scarce, inclusion of some funding to enable the provision of specialist therapy or other family support services could assist in addressing individual issues as they are identified.
- j) Ensure that the project gives something back to the communities. You could supply morning and afternoon tea and some remuneration and arranging transport to and from the venues.

Northcott has spent a number of years establishing services in a rural location in NSW with a particular focus on Aboriginal services. This involved many false starts, changes of staffing, and attempts to engage the local community elders in supporting the services and encouraging local people to access them. One measure of success was when the local lawn bowls team, led by one of the Aboriginal elders in the community, asked for Northcott sponsorship of the team. For two years the team, which includes the local Northcott area

manager, has proudly worn its Northcott shirts in the regional competition. This is a symbol of Northcott's acceptance in the local community, and has assisted in developing deeper and richer relationships with local families. (Stubbs, personal communication, October 31, 2013).

Conclusions

If the development of services can be based on the findings of culturally relevant research, then these services have the potential to improve relationships and communication between service providers and Indigenous families of the child with a disability. More widely, the support programs that the families utilise can potentially impact on social determinants of disability by improving engagement, employment and empowerment if implemented in a culturally appropriate manner and provide much needed information for all of these stakeholders to increase awareness and understanding about services and about Indigenous families with a child with a disability.

The development of culturally appropriate information resources and the development of culturally appropriate services can inform policy, specifically in the areas of medical therapy educational and social support services. Also finally it is envisaged that the improvement will lead to better long-term outcomes for the family and the children themselves Australia is a better place for Indigenous people with disabilities than it once was but not as good as it might become. The NDIS has the potential to improve long term outcomes for Indigenous families with young children with a disability but it will need to be implemented in a innovative, creative and community appropriate way to achieve these..

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