

## 6. Existing evaluations of service delivery models

There is very little Australian research on the pros and cons of different models of disability service provision in terms of their impact on Indigenous people. There is, however, some research which provides insights into Indigenous experiences of disability and related service usage, as well as the extent to which this differs to that of other Australians. Much of this has already been touched on in this monograph. This chapter expands upon these issues.

A relatively comprehensive review of Australian research was undertaken for this monograph. While selected international research was reviewed, a more comprehensive assessment of international research was beyond the scope of this exercise. Program and service descriptions were found to be more common than impact evaluations. This reflects to a certain extent the difficulty of evaluating programs that provide services in such a challenging environment. Furthermore, where impact evaluations were attempted, data gaps and discrepancies often limited the evaluation's validity. Therefore, although examples of promising practice and areas of ongoing challenge did emerge from the literature review, findings must be interpreted with a level of caution.

Successful replication or scaling-up of service delivery models often requires detailed knowledge of the context in which models apply, the populations to which they apply, and the specific mechanisms within programs that have achieved the reported results (Pawson and Tilley 2004). Some of the cases of promising practice identified in the review of the literature for this monograph have emerged from overseas models where the contexts are only partially comparable, and the mechanisms may not be fully explicated. Also, some models had been tested only in remote contexts and others only in urban contexts. Service providers were often the focus of research, likely due at least in part to the difficulties of accessing people with disabilities and their carers. Remote and Indigenous populations posed a particular challenge for researchers. In a few cases, research instruments were specifically designed to respond to cultural and remote Indigenous community needs, or to the special needs of Indigenous people with disability and their carers. However, it was difficult to find good examples of evaluations that employed program logic or quantitative impact measures, and even these often struggled with accessing reliable data and reconciling it with qualitative data.

While there have been evaluations of consumer-directed disability models and evaluations of Indigenous-targeted disability services, there is little in the literature that discusses the impact of consumer-directed disability models for Indigenous peoples. The minor exception to this is the Services Our Way program of New South Wales, which shows promise in this regard. Some of the reasons for this gap in the literature will emerge from the discussion below.

There have been several studies of the experience of Indigenous people with disability services. A review of access by Indigenous people to the New South Wales government program Ageing, Disability and Home Care (ADHC) by the New South Wales Ombudsman (2010: 5) found that:

Despite the relatively high rate of disability in Aboriginal communities, the most common theme that emerged during our review was the lack of knowledge and understanding within Aboriginal communities about ADHC and the disability service system—in particular, the services available to Aboriginal people with a disability and their families, and the availability of specific entitlements.

The review by the NSW Ombudsman (2010) also reported that many service providers and community members had told them that the types of support wanted by many Indigenous people with a disability differed to those sought by non-Indigenous people. Specifically, Indigenous people with a disability tended to be more likely to want what one might call practical help. Examples listed included assistance to replace whitegoods, pay for car registration or petrol, or to allow the family to take a holiday together for respite. It was reported that Indigenous people tend to want to take a break with their family members and to be supported by a carer rather than the family member with a disability being placed in centre-based respite care.

While the review of the existing research identified several studies of Indigenous experiences with disability services, this is a question on which there has been relatively little research. Better understanding of Indigenous experiences with disability services and the nature of services which best meet the specific needs of Indigenous people with a disability is an area in which further research is needed in order to inform the design of the NDIS. A study of formal individual advocacy services (paid advocates employed by an advocacy agency, working with people with disability on short-term and issue-specific bases) found that in Indigenous communities advocates assist people with a disability by linking the person with other services and, in particular, helping those who are unable to or would never read information, or who are not aware of the services that are available (Jenny Pearson & Associates Pty Ltd 2009).

A consistent theme in reviews of the experience of Indigenous people with disability services is that there is a lack of knowledge and understanding within the Indigenous community about the disability service system and the services available to Indigenous people with a disability and their families (NSW Ombudsman 2010).

In 2008, the Australian Government released a discussion paper asking community members to respond to a series of questions about their experience of disability. The purpose of the consultations was to inform the development of a national disability strategy. More than 750 submissions were received. An analysis of the submissions has been undertaken (National People with Disabilities and Carer Council 2009). Key themes were identified from the submissions that are directly related to Indigenous people.

- Few disability service providers seem to grasp the complexity of the issues confronting Indigenous people.
- Mainstream services targeting Indigenous people do not always understand the specific issues facing Indigenous Australians with disabilities and their families.
- The chronic lack of services in regional and remote areas not only restricts choice but sometimes means people are forced to leave their communities in order to access services and support. For some people this means onerous and expensive travel over several days of the week. For others, particularly in Indigenous communities, it has meant the dislocation of families to enable the person to receive treatment.
- The importance of greater availability of transport to improve access to health care and other services and support was a recurring theme.
- The specific needs of Indigenous carers are often neglected, and there is a pressing need for greater availability of respite.
- It is often difficult for people with disabilities to participate fully in important cultural activities. Aboriginal and Torres Strait Islander people with disabilities who want to be full and active participants in the life of their community often find themselves isolated and excluded.

The NSW Ombudsman's review of 2010 identified a range of attitudinal factors that impact on Indigenous people's ability and willingness to seek assistance. These include:

- being unable to relate to the concept of disability
- variable understandings in and among Aboriginal communities about what constitutes a disability

- a belief that there is a cultural obligation to care for a person with a disability within the family
- wanting to avoid the label of 'disability' due to a perception that there is a stigma attached to it
- mistrust of government agencies.<sup>1</sup>

The fear of losing children with special needs to service providers may be particularly acute. One reason given for the under-use of services is negative past experiences with government services, notably where these involve outsiders entering an individual's home. As observed earlier, concerns were raised that care workers who entered an Indigenous person's home, for respite care for example, would be disparaging of the person regarding the cleanliness of their home (King 2010: 205).

The presence of Indigenous staff is said to encourage service access (Western Australia Disability Services Commission 2006). However, one study found that while Indigenous people in urban areas frequently preferred to use services with Indigenous staff members, there were others who preferred other services. Several reasons were given for this. In some cases it was because the person felt that these other services offered better care provision. In other cases people raised the issue of confidentiality, suggesting that they tended to stay away from services that had Indigenous staff members because of the potential that they may have some form of relationship with these individuals.

The importance of consultation with Indigenous people as services are being designed rather than simply imposing a model upon the community is often emphasised. However, consultation fatigue can result, particularly where input does not lead to action. One interesting model for people with a disability gave participants an opportunity to access individual advocacy support so that they saw the engagement as meeting their needs as well as an opportunity to offer information (Aboriginal Disability Network New South Wales 2012). Although consultation may in some cases mean providing input to decision-makers who will then design service models, in a number of cases more collaborative service design models have emerged. True partnership is not easy to achieve; Burton (2012) profiles nine partnerships between Indigenous and mainstream agencies, highlighting elements of promising practice but also noting the challenges involved.

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<sup>1</sup> This issue is discussed in a number of government service planning documents, e.g. Victorian Auditor-General's Office 2011; Western Australia Disability Services Commission 2006.

An additional factor identified in the review was the complex interaction between imprisonment and disability. The rate of imprisonment of Indigenous people is much higher than for the Australian population as a whole. The ABS (2012c: 49) reports that:

The age standardised imprisonment rate for Aboriginal and Torres Strait Islander prisoners at 30 June 2012 was 1 914 Aboriginal and Torres Strait Islander prisoners per 100 000 adult Aboriginal and Torres Strait Islander population. The equivalent rate for non-Indigenous prisoners was 129 non-Indigenous prisoners per 100 000 adult non-Indigenous population.

The same data indicates that some 5–7 per cent of the Indigenous male population aged 20–44 years are imprisoned at any one time. While the evidence on Indigenous prisoners with a disability is limited, research conducted in Victorian prisons has found that Indigenous prisoners are more likely to have an intellectual disability than are non-Indigenous prisoners (Holland et al. 2007). Some types of impairment found particularly commonly in Australian Indigenous populations are over-represented in prison populations, such as cognitive impairments, Acquired Brain Injury, and hearing impairments. These conditions may be disproportionately linked to criminal activity and recidivism, and hence special support may be required to end this cycle. The point though is that it will be important to consider how the NDIS operates for people with a disability who are entering and leaving prison.

## **Examples of disability services models**

This section provides some examples of disability services models. Each is a different model, but all offer findings relevant to service provision to Indigenous Australians with disabilities. The first is a program operating in Canadian Aboriginal communities, most of them remote. The program has been extensively evaluated, and has been found effective in building services and a workforce in areas where none previously existed. The second is an Australian program of individual funding packages targeted at Aboriginal people with disabilities in New South Wales, including metropolitan areas.

### **First Nations and Inuit Home and Community Care Program**

The First Nations and Inuit Home and Community Care (FNIHCC) Program is a Canadian program targeted at that country's Aboriginal population. In terms of the models set out above, it offers block funding through contribution

agreements and is administered by Aboriginal governance bodies, using funds pooled from two different government agencies that enable staff to work across service boundaries. It is targeted in large part at building service provision capacity in regions where there have historically been few or no services.

FNIHCC is available only to Inuit living in an Inuit settlement, to First Nations people living on reserves south of 60° North latitude, or in First Nations communities north of 60°. Designed to work in partnership with Aboriginal communities to maximise the ability of people requiring care to remain in their own homes, FNIHCC was first established in 1999. It has since been extensively evaluated, with evaluations released in 2001, 2005, and 2008; examples of particularly promising practice within specific FNIHCC programs were published in 2010 (Canadian Home Care Association 2010; Health Canada 2008). FNIHCC clients can be of any age, but must have been formally assessed to require one or more essential services, and it must be determined that the services can be provided with reasonable safety to both the client and caregiver. Funds are held by the local Aboriginal governance body, such as a Band Council, and are allocated based on assessment of need.

Early reports and evaluations of the program focused on establishment processes such as need assessment, funding formulas, community education and workforce training. Issues identified in this stage included the difficulties experienced by smaller more remote communities. Smaller communities (i.e., those under 1 000 people) had greater difficulty in finding the human resources to conduct needs assessments and felt disadvantaged by fixed funding formulae. Remote communities experienced difficulty in securing personnel, and found that resourcing did not take into account the additional transport costs they faced. Furthermore, one of the key issues identified was the challenge involved in implementing a nationally consistent model over a diverse set of communities. Again, smaller and more remote communities faced greater challenges.

The most recent evaluation (Health Canada 2008) found once again that FNIHCC had achieved much, continued to be needed, and recommended that its funding continue. It has built a workforce and provided services in regions where none had previously existed. According to some types of data, hospital admissions were down and costs decreased due to improved local care (e.g. lower numbers of amputations). Aboriginal community members appreciated being able to stay in their home community for services delivered in their own language. However, half of those interviewed responded that the program was not entirely culturally appropriate, particularly where off-reserve providers were involved. Some wanted traditional healers included in the program.

Aboriginal communities in the southern regions, closer to major metropolitan areas, experienced better outcomes than more northerly, remote communities.

Band Councils sometimes had fixed ideas about which types of disability services were most important. In one case (Durst, Gay and Morin 2006), a woman left for an urban area when she was unable to get funding allocated for a ramp to her house. In some communities, where aged care was assumed by the Band Council to be the priority need, there was concern that children's disabilities were being under-served.

One important finding was that the model had changed over time. Acute care, particularly transitional care after hospital discharge, was becoming more frequent. The same personnel and procedures were typically required for transitional care and for long term disabilities, so this model appeared to be cost-effective. It indicates, in fact, that adhering to a strictly disability focused model may not be as cost-effective in remote communities as a more flexible model, perhaps redefining disability to encompass short-term as well as longer-term conditions. However, while this improved service and cost effectiveness, it complicated the accountability requirements, as it was not easy to distinguish between services delivered from each pool of funding, and both government agencies required reporting for their own funds.

Finally, it was not easy for the evaluators to reconcile data from the qualitative and from the quantitative sections of the evaluation, demonstrating the importance of setting up data systems from the outset that allow for improvement as well as accountability.

## Services Our Way

Many Australian jurisdictions have instituted individual funding models for people with disabilities, but few appear to have been targeted specifically at Indigenous Australians. One relatively recent exception is the Services Our Way (SOW) program of New South Wales. While the program is too recent to have been formally evaluated in as much detail as the FNIHCC, there are a number of features of SOW that are worth noting.

The program commenced in the Shoalhaven in 2010–11 as a demonstration project. The program is available to Aboriginal people with a diagnosed intellectual or physical disability, including Acquired Brain Injury and Multiple Sclerosis. SOW principles state that the program is family-centred, strengths-based and culturally appropriate, working collaboratively with other human service organisations and with Aboriginal communities. It encompasses prevention and early intervention, with a deliberately broad interpretation of disability.

In terms of the models set out above, it is an individual support funding package with the funds held by the agency. A key component of SOW is that it is an

Aboriginal program delivered by Aboriginal Support Specialists for Aboriginal people with a disability, their carers and families. Aboriginal people with a disability and their families are able to choose how much help they get from Aboriginal Support Specialists in terms of the level of support and assistance. This Aboriginal Support Specialist is available to provide as much or as little support in developing a 6–12 months Support Plan as desired. However, the Aboriginal Support Specialist always manages funding, with all invoices and receipts sent to them.

Not only is disability interpreted broadly, but so are the types of supports that can be purchased. While there is still a focus on traditional supports (such as respite, personal care, day programs, and therapy) clients are encouraged to think in creative ways in term of service provision. Carers within the scheme can have a range of relationships with the person with a disability, including as a parent, grandparent, family member, extended family member or other person with cultural obligations to provide care for the person. There are a number of constraints on spending, including prohibitions on using the funds for gambling or for support of family members other than the person with a disability and their primary carer. These constraints aside, there are a range of possible supports listed in the guidelines which include:

- support for access to community and recreation opportunities, e.g. transport and tickets/entry fees
- supplementation of the transport costs of the person with a disability, where these costs are not fully covered by other schemes
- goods or supports from other community or government programs if the person is otherwise unable to access these goods or supports in a timely manner
- selected household items that are otherwise not affordable and will relieve stress and/or enhance capacity
- supports or resources to increase networking, caring skills, communication, access to ideas and/or improving lifestyle routines
- a service that can build access and inclusion to specific places/activities by addressing physical, attitudinal, and skill barriers.

While there have been few formal evaluations of the program, storytelling and action-based research are being used to assess and improve the program. According to comments from relevant New South Wales government officials, implementation of the demonstration project in the Southern Region thus far has presented a number of consistent findings. These findings provide insight into Aboriginal people with a disability and their families' interaction with the disability service system.

- Many of the clients, approximately 90 per cent, are young children, and have been diagnosed with either autism or an intellectual disability.
- Some clients have not accessed disability services previously and therefore do not have a legitimate medical diagnosis to ensure eligibility, which can delay access to services.
- Many of the clients are reluctant to access structured overnight, centre-based respite services, continue to have difficulty accessing such services, and are confronted with an inflexible and culturally inappropriate service response.
- Significant funding otherwise used for individualised support packages is being unnecessarily diverted to access centre-based respite services.
- A Parents of Children with Autism Support Group has been established and the families have benefited positively from group forums to discuss their experiences and thoughts about disability and caring, and have suggested innovative solutions to respite services.
- Many of the clients and their families were unfamiliar with these services and the technologies available to support their adolescent children, e.g. automated wheelchairs, voice recognition technology, and the use of computers in developing support plans.
- Parents have commented on the difference it makes working with an Aboriginal Support Specialist who understands the cultural complexities of Aboriginal families.
- The clients and their families are innovative with the individualised disability plans.

Given the similarities between the SOW program and the way in which the NDIS is likely to be applied, it will be important to learn from identified strengths and weaknesses of the program.

This text taken from *Indigenous Australians and the National Disability Insurance Scheme*, CAEPR No. 34 Research Monograph, by N Biddle et al., published 2014 by ANU Press, The Australian National University, Canberra, Australia.