8. Key issues for disability service delivery models for remote Indigenous communities

The data and evidence provided and discussed in the earlier chapters have significant implications for the design of a disability service delivery model. Effective screening and assessment of disability will be paramount, and specific approaches are likely to be needed to address the nature of Indigenous disability. In terms of provision of disability services, issues include the training needs of a disability workforce, the extent to which disability support services should be built upon the health system, the implications of significantly higher rates of disability in the Indigenous population, and barriers to accessing services. These issues need to be considered together with the demographic and geographic characteristics of the Indigenous population to develop understanding of how the NDIS should be designed and, equally importantly, implemented.

Screening and assessment of disability

A crucial component which will be required for the successful implementation of the NDIS will be accurate and reliable identification of disability and, in particular, Tier 3 disability. While this is true for the Australian population as a whole, the challenges are likely to be particularly pronounced for the Indigenous population in general, and especially for the Indigenous population in remote and very remote areas. The Productivity Commission's (2011) model involves assessment being conducted by allied health professionals approved or appointed by the National Disability Insurance Agency and trained in the use of assessment tools. In the model, assessments would not be rubber-stamped and deviations of assessed needs outside the norms would require further investigation.

The nature of Indigenous disability is likely to require some specific approaches and strategies. In addition, it is likely that a tailored approach will be necessary in remote communities and perhaps to some extent in regional communities. First, the complex nature of Indigenous disability and the prevalence of dual diagnoses means that the screening for and assessment of disability in the Indigenous population will take additional time and probably require more specialist expertise. Second, the lack of confidence and the level of fear or distrust that some Indigenous people have towards services, particularly those funded or provided by government, means that it will be important to invest

in community relations and building trust within the community. There is extensive practical experience and some research literature about how this can best be achieved.

It appears that in some communities the most effective model will be for local primary health care services to be funded to undertake the assessment. However, not all local primary health care teams are adequately skilled or resourced to undertake such assessments. As will be discussed below, this also raises issues around the fit between health and disability services. Many other communities will not possess the people with the skills required for the assessment of whether an individual meets the NDIS criteria. This means that either people with a disability will need to travel to a larger town for the assessment, or professionals with the requisite skills will be required to visit the communities. The medical model of outreach services which could be hub-and-spoke, visiting services, or fly-in fly-out services, may be appropriate. It appears that there will be some circumstances where technology-based models will be useful in the assessment process.

Provision of disability services

It is possible to think about disability services as falling into three types. The first is services that are associated with meeting the basic care needs of a person with a disability—that is, attendant care and community access. The second is early intervention services which aim to reduce the impact of disability and can cover such things as alleviating the impact of an existing disability or preventing the deterioration of an existing disability. Early intervention services may be provided when the disability is first identified, when there is a change in the disability, or at lifetime transition points. Examples of early intervention services are accommodation support; aids and appliances; behaviour and specialist interventions; case management, local coordination and development; and home and transport modifications. The third type of service is rehabilitation services.

In general, providing attendant care and community access does not require a high level of training, and workers providing this type of care are not highly paid. It is clear that one of the major issues for the success of the NDIS in remote areas is the ability to access a workforce. In the remote context the workforce for the provision of attendant care and community access will almost certainly need to come from within the community. As noted in Chapter 7 on workforce issues, in remote communities there is a large pool of potential workers, many of whom are already providing informal unpaid care (although they may be receiving an Australian government carer payment). There are several issues

that will need to be considered here. In many communities the potential carer workforce will be related to the person with a disability. Consideration must be given as to how to provide basic training and ensure that the work environment for carers is safe. It will be necessary to ensure that the care that is paid for is adequate and periodically monitor the quality of care (as done in other countries like Germany) with consideration given to which organisation would formally employ the carers.

Given that many Indigenous people with a disability also have a range of health problems and that considerable activity has been undertaken in seeking to build an effective health care system in remote areas, a central question is the extent to which disability support services in remote areas should be built upon the health care system. Despite the need to integrate services delivered through the NDIS with the primary health care system, it is clear from the submissions made to the Productivity Commission and consultations undertaken for the research reported in this monograph, that some Indigenous people felt that the health model was not appropriate for providing disability services. This is due in part to the tendency of health services to not fully take into account the broader needs of people with a disability. For example, the submission by the FPDN (2011: 13) suggests that:

> Historically much of the focus on Aboriginal people with disability has been from a health perspective. Whilst this is essential, particularly regarding primary health interventions, it has come at the cost of failing to recognise the social aspects of disability. This has meant that the barriers that produce discrimination against Aboriginal people with disability remain firmly entrenched and the general well-being of Aboriginal people with disability has not improved in any meaningful way.

The social impact of Indigenous disabilities may well differ substantially from disabilities in non-Indigenous social contexts. Careful consideration needs to be given to how to ensure that the services provided are appropriate to the specific needs of people with a disability and are acceptable to them. This area requires further exploration, careful evaluation and monitoring.

Implications of high rates of disability

The NDIS will be particularly important for the Indigenous population given the relatively high rates of disability experienced by Indigenous people. The research reported in this monograph provides an overview of the some of the key issues related to the nature of Indigenous disability, and the types of services and models for the delivery of disability services which are most likely to meet the needs of the Indigenous population. Indigenous Australians

experience profound or severe core activity limitations at more than double the rate of non-Indigenous Australians. This is in part due to socioeconomic disadvantage, and in part to a constellation of other risk factors such as lower rates of education, higher rates of smoking, substance abuse, and poor nutrition.

Not only are rates of disability higher for Indigenous Australians, they also face significant additional barriers to accessing disability planning and support services. In part this is due to a lack of disability services and disability-friendly housing and transport in remote areas. However, there are other demographic and geographic characteristics of the Indigenous population that are likely to impact on how the NDIS should be designed and implemented.

First, the Indigenous population is relatively young. This means that a relatively large proportion of the Indigenous population will be within the scope of the NDIS, as opposed to the aged-care system. Furthermore, the type of disabilities experienced by the Indigenous population will be different to those of the non-Indigenous population. The second demographic characteristic of relevance is that the Indigenous population is growing at a much faster rate than the non-Indigenous population, meaning that the Indigenous population will take on a greater share of services provided by the NDIS over the next few decades. Although all age groups of the Indigenous population are projected to grow over the next few decades, the Indigenous population is ageing and projected to age even faster over the next few decades. Like other populations, Indigenous Australians are shown to have higher levels of disability at older age groups. This means that regardless of any policy changes, the incidence of disability among the Indigenous population is projected to increase over the coming decades.

The Indigenous population is much more likely to live in remote and very remote Australia relative to the non-Indigenous population. In some of the larger remote communities, the introduction of the NDIS may lead to a significant inflow of funds as services that are currently being provided informally begin to be provided on a fee-for-service basis. However, many Indigenous people live in very small communities which in absolute terms will have very few people with a disability. This calls into question the ability of market mechanisms to meet the needs of the Indigenous population with a disability across remote Australia.

Despite this relative concentration in remote areas, the majority of Indigenous Australians still live in urban areas. Furthermore, the Indigenous population is projected to become increasingly urban over the next few decades. Although there are likely to be a range of services available to Indigenous Australians in urban areas, there are still a number of characteristics shared by Indigenous Australians across the country that will impact on the NDIS.

Indigenous people with a disability are relatively more likely to suffer from an intellectual disability than are non-Indigenous Australians. Related to this, there is a higher incidence of complex needs and issues which span health, disability and other aspects. An example is substance abuse combined with cognitive impairment. Furthermore, many Indigenous people with a disability are themselves caring for one or more other persons with a disability. A final issue that arose in consultations and a review of the literature is both a lack of awareness of disability among some groups of Indigenous Australians, and a reluctance of other Indigenous Australians with a disability to identify as such, either in survey data or to service providers.

The reluctance of some Indigenous Australians with a disability to identify as such is likely to make it more difficult to implement, monitor and evaluate the NDIS. The National Disability Insurance Agency will therefore need to raise awareness of disability issues in the Indigenous population. Service providers will also need to become more familiar with Indigenous-specific issues. Data collectors also have a responsibility to ensure that their collections give as accurate an account of Indigenous disability as possible.

We make a number of other specific recommendations for data collection. First, the Disability Module included in the NATSISS and GSS could be modified to correspond more closely with the SDAC. This will have a negative impact on data comparability, but given the importance of the NDIS as a policy initiative, this is a trade-off that may be worthwhile. In addition, the sample size for Indigenous Australians in the SDAC could be increased to enable reliable estimates for the Indigenous population at the national, State/Territory and remoteness levels.

A number of other changes could be made to the NATSISS. It could collect disability information for persons of all ages, not just those 15 years and over, and consider expanding the broader criteria to remote areas to address gaps in coverage. For future NATSISS surveys, 'Disability services' could be added as a specific category to the data item on types of services people have problems accessing in order to provide comparable data on the Indigenous population to that obtained for the total population from the GSS. Finally, there is a need to undertake work to examine methods to assess the level of Indigenous under-identification in DS NMDS data in order to gain a better understanding of the level of under-identification in this collection, as it is not currently known.

There is much that governments and other service providers can undertake do to maximise the chances of a successful implementation of the NDIS for Indigenous Australians. Issues related to the incorporation of the Indigenous population into the NDIS are summarised in Fig. 8.1 in order to highlight the interrelationships.
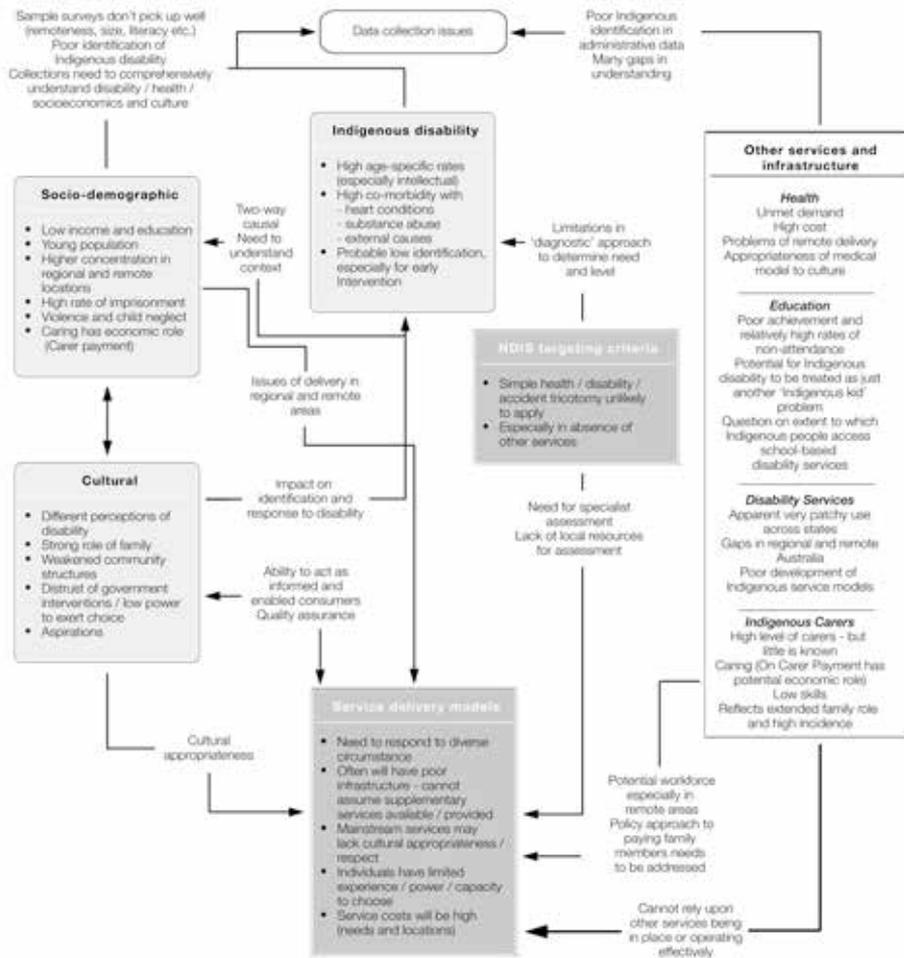
Fig. 8.1 Key issues for Indigenous Australians and the National Disability Insurance Scheme

Source: Authors' own conceptualisation

In many regional, rural and remote communities what is often needed are broad-based generalist services which will support the specialist services delivered through the NDIS. To the extent to which people with a disability will need to travel to larger towns for assessment or to access services, it will be important to consider access to transport needs alongside the provision of disability services. Another area which needs to be considered is the interaction between disability services provided through the NDIS and the criminal justice system.

While this is relevant to both the Indigenous and non-Indigenous population, it is particularly important for the Indigenous population, given the relatively high rates of incarceration of Indigenous Australians.

The NDIS presents an opportunity to improve the employment prospects and level of community infrastructure in remote and regional communities. As observed earlier, providing attendant care and community access does not generally require a high level of training. In the remote context the majority of the workforce for the provision of attendant care and community access will almost certainly need to come from within the community. As noted in Chapter 7, in remote communities there is a large pool of potential workers, many of whom are already providing informal care which is unpaid or remunerated through an Australian government carer payment.

Given that many Indigenous people with a disability also have a range of health problems and that the health care system in remote areas is in general far better developed than disability services, it seems likely that disability services in remote areas will need to be built upon the health care system. This would appear to differ from the general approach outlined in the Productivity Commission Report, which advocates a greater separation between disability and health services. This does not appear to be a feasible approach, given the difficulties of delivering services in remote areas and the relatively small number of people who are expected to be covered by the NDIS in most discrete Indigenous communities. Also, integrating disability and health services could address short-term disabilities (such as those experienced by people discharged from hospital into remote communities after surgery) as well as the long-term disabilities targeted by NDIS.

For reasons of scale, including accessing expensive and limited infrastructure in many communities, and for providing professional support and backup to service workers, the option of building disability services on the health care system is one which may need to be considered, especially where these community health services have developed strong community bonds. However, careful consideration would need to be given to the means of ensuring that the services which are provided are appropriate to the specific needs of people with a disability and are acceptable to them, that disability support does not follow a simple 'medical model', nor that inappropriate stress is placed on already stretched services which often cannot fully meet existing demand.