

Shaping the National Disability Insurance Scheme for rural and remote areas

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Introduction

The imminent commencement of the National Disability Insurance Scheme (NDIS), initially within five trial sites, brings great hope and opportunity for people with a disability and their carers living in rural and remote Australia, and is highly welcomed. It also brings a concern about whether there can and will be an equitable allocation of resources to enable the Scheme to be rightly considered national in its reach to those people and communities.

The National Rural Health Alliance has a proud history of advocating for the needs of people living in rural and remote Australia. It has become more focused on specific disability issues over the past 18 months. 30% of all Australians and 70% of aboriginal people, live outside the major Australian cities. For most people living in rural and remote areas, the quality of one's health is intrinsically related to many other determinants, such as whether someone has a disability, is aged, has employment, has satisfactory access to health, social, physical, educational and cultural pursuits.

This paper describes a National Rural Health Alliance project, funded by the Federal Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA). It commenced in January, and will conclude with a final report in late April 2013. The project seeks to contribute to the development of the NDIS, particularly in its capacity to deliver for people and their carers living outside large urban settings. It has developed an increased awareness of the NDIS, and stimulated engagement by rural and remote people. In particular it has those people living with a disability, their carers, and service providers, to have their say in the development of this 'once in a generation' opportunity.

We hope to have further discussion at the Conference NDIS lunch time workshop today. I wish to thank and acknowledge all the people who are concerned with this issue—people with a disability, carers, and service providers—for their generous input to the project.

What will the NDIS do?

The NDIS seeks to develop a comprehensive 'insurance' approach to assuring delivery of supports to all eligible people with disabilities, irrespective of where they live in Australia.

The Federal Government Bill to establish the NDIS has (? now) passed through the House of Representatives and the Senate, and become law. It is expected that there will be continuing opportunities for further development and refinement of the scheme, as it becomes more 'field tested'.

Below is an excerpt from the Fahscia NDIS website:

The NDIS will take a lifelong approach to providing care and support. The assessment will look beyond the immediate need, and across the course of a person's life.

Rather than funding based on historical budget allocations, a funding pool will be based on actuarial assessment of need. For example, home modifications might be expensive up front, but if they afford a person with significant disability the opportunity of greater independence, or if they mean that a parent or carer can continue to care for their loved one, it's a good investment.

Taking a lifelong approach also means focusing on intensive early intervention, particularly for people where there is good evidence that it will substantially improve functioning or delay or lessen a decline in functioning.

Importantly, an NDIS will support choice for people with disability, their families and carers, and put people in control of the care and support they receive, based on need. Of course, there

will also be safeguards in place to support people in exercising this choice and control, and to help them make informed choices.

An NDIS will ensure people are no longer “shut out” from opportunities and from independence by providing the appropriate and necessary supports that allow people with disability to reach their full potential.

It will nurture and sustain the support of families, carers and friendship groups – the very communities of support that are critical to improving the lives of people with disability.

And it will include a comprehensive information and referral service, to help people with a disability who need access to mainstream, disability and community supports. A National Disability Insurance Scheme will give all Australians the peace of mind to know that if they have or acquire a disability that leaves them needing daily assistance with everyday life, or if they care for someone who has a disability, that they will be supported.

What are the key features of an NDIS

- Provide eligible individuals with the care and support they need when they need it.
- Give individuals decision making power, including being able to choose their service provider.
- Provide high quality, evidence-based services which manage life-time costs of care.
- Be simple to navigate and link to mainstream and community services.
- Recognise the essential care and support of families and carers and support them in that role.
- Facilitate each individual’s community participation, access to education and employment opportunities.
- Be managed on an insurance basis.

The challenge

This project investigates ways in which people in rural and remote Australia can obtain equitable access to the full range of services and resources: the challenge most often cited by our respondents. Other challenges include the usual rural and remote service delivery ‘suspects’—distance; capacity for viability of service providers; communication; lack of full range of services; relatively poorer access to information and suitable services, and a cultural lack of expectation in rural areas of receiving equitable levels of support.

The project plan

This National Rural Health Alliance project has undertaken a number of strategies in order to inform and consult with people about the proposed NDIS, and to elicit as many responses as possible, to describe the challenges and opportunities inherent in delivering the scheme in rural and remote Australia. Key strategies include

- development of circulation of discussion papers to our council members, representing 34 member organisations
- email out to the members of ‘Friends of the Alliance’; and to approximately 11,500 subscribers to NRHA
- promotion of the NDIS ‘Your Say’ website and the opportunities to have input to the development of the scheme; assistance with development of a specific ‘rural and remote’ portal
- presentation of a submission to the NDIS Senate Enquiry in March 2013

- meetings with key members of the NDIS advisory groups to draw attention to rural and remote issues
- collaboration with other key organisations, including the First People’s Disability Network; National Disability and Carer Alliance; and the National Young People in Nursing Homes Alliance
- development of an on-line survey (Survey Monkey), the results of which will be incorporated in a Roundtable conference. We are advised that the Minister will be attending this
- presentations at the conference with a number of speakers focusing on disability issues, with further opportunities for discussion.

Project Reference Group

A project reference group has been formed to provide advice to the Alliance on issues relevant to the delivery of the NDIS in rural and remote Australia. The members of the group include people having lived experience with a disability in rural and remote areas, carers, representatives of the NRHA Council and the National Disability and Carer Alliance, and representatives on Indigenous issues. Some of the members of our Project Reference Group are present at this Conference.

The representatives are located all over Australia and we meet by teleconference. Some of the issues that have emerged from our teleconferences include:

- The need for a human rights based approach to the NDIS. This includes ensuring that the NDIS is not delivered in a prescriptive manner, but in a way that reflects the wishes and concerns of the person living with a disability.
- The need to address rural cultural lack of expectations and change them so that rural and remotely based people have the same expectations for disability support as people elsewhere in Australia.
- The importance of providing information about the NDIS to everyone who needs it; particularly about how to navigate the system. The NDIS should be provided very simply so that carers and people with a disability do not need to navigate a multi-layered system.
- The necessity to provide information about the NDIS to Indigenous communities in a culturally sensitive manner. Interpreters will be needed to explain the NDIS to people in some remote communities.
- The affordability of disability services, mobility aids, and assistive technology should be considered so that locality or remoteness is not a consideration in what is delivered by the NDIS.
- Social inclusion of people with disabilities could be increased by providing training for them to increase their employment prospects. Satisfying employment, apart from being therapeutic itself, is also a way to greater social inclusion and to avoiding the poverty trap.
- The importance of not adopting a “one size fits all” approach to delivering the NDIS in rural and remote areas.

National Rural Health Alliance perspectives

NRHA made the following recommendations in its submission to the Senate Inquiry into the National Disability Insurance Scheme:

1. That the NDIS continue to seek input from people and professional bodies with expertise in disability services and the issues in rural and remote areas
2. That the NDIS seek innovative ways to meet special needs of people in rural and remote areas

3. That a 'one size fits all' approach to implementing the NDIS not be used, and that the particular needs of different regions across Australia be paramount.
4. That the NDIS continue to investigate innovative ways to maximise efficiency eg by finding innovative ways to provide personal care packages, and by utilising the expertise of locally based health care providers
5. NDIS should consider the transportation problems and resulting isolation experienced by people living with a disability in rural and remote areas
6. That NDIS should endeavour to establish cooperative relationships with Medicare Locals, and other rural services
7. That NDIS should seek to collaborate with Health Workforce Australia to foster the recruitment and retention of health professionals needed in rural and remote areas to help ensure equitable access to disability services
8. That NDIS should establish collaborative arrangements with the University Departments of Rural Health and other education providers to provide the training needed by additional health professionals located in rural and remote areas
9. That NDIS be cognisant of opportunities to support use of innovations in communication, particularly the NBN to enhance delivery of services to people with disability in rural and remote areas
10. That an NDIS Rural and remote Working Group be established to advise and inform the NDIS of the ongoing challenges and practical solutions for the delivery of the scheme in rural and remote areas
11. That there is a close and formative evaluation of the effectiveness of the scheme in rural and remote parts of the launch transition sites; and that this evaluation helps to inform the further roll out of the scheme.

Aboriginal disability perspectives

The First Peoples Disability Network is the peak national aboriginal disability organisation, and it has developed a 10 point plan for the implementation of the NDIS in aboriginal communities. Further information can be obtained from its website. The key elements of the plan are:

1. Recognise that the starting point is the vast majority of Aboriginal people with disability do not self-identify as people with disability. This occurs for a range of reasons including the fact that in traditional language there was no comparable word for disability. Also that many Aboriginal people with disability are reluctant to take on the label of disability particularly if they may already experience discrimination based on their Aboriginality. In many ways disability is a new conversation in many communities therefore with regard the NDIS we are starting from an absolute baseline position. And as a consequence change in this area may evolve on a different timeline to that of the main part of the NDIS.
2. Awareness-raising via a concerted outreach approach informing Aboriginal people with disabilities, their families and communities about their rights and entitlements. And as well informing Aboriginal and Torres Strait communities about the NDIS itself and how to work this new system effectively. There is simply no other way to raise awareness than by direct face-to-face consultation. Brochures and pamphlets will not do the job in this instance as this will be as stated earlier a new conversation in many communities.
3. Establish NDIS Expert Working Group on Aboriginal and Torres Strait Islander People with disability and the NDIS. In recognition of the fact that there is a stand-alone building block for

the NDIS focused upon Aboriginal and Torres Strait Islander people with disabilities the FPDN views it not only as critical but logical that a new Expert Working Group be established focused upon Aboriginal and Torres Strait Islander people with disabilities. The new working group would operate in the same way the 4 current working groups do—it would be chaired by 2 members of the National People with Disability and Carers Council. To ensure its effectiveness but also critically to influence prominent Aboriginal leaders as well as the disability sector, members would be drawn from Aboriginal leadership as well as involving prominent disability leaders. The FPDN believes such an approach is warranted not only because of the degree of unmet need that is well established but also because this has the potential to be a very practical and meaningful partnership between government, the non-government sector and Aboriginal and Torres Strait Islander communities.

4. Build the capacity of the Non-Indigenous disability service system to meet the needs of Aboriginal people with disability in a culturally appropriate way. Legislate an additional standard into the Disability Services Act focused upon culturally appropriate service delivery and require disability services to demonstrate their cultural competencies.
5. Research including into the prevalence of disability and into a range other relevant matters. Critically this work must be undertaken in partnership with Aboriginal and Torres Strait Islander people with disabilities to ensure a culturally appropriate methodology. There remains very little reference material about disability in Aboriginal and Torres Strait Islander communities this needs to be rectified to ensure that we are getting a true picture of the lived experience of Aboriginal and Torres Strait Islander people with disabilities.
6. Recognise that there already exists a workforce in many Aboriginal communities that continues to do important work often informally. This work needs to be valued and recognised with the potential being the creation of employment opportunities in some communities.
7. Recognise that it's not always about services. Many communities just need more resources so that they can continue to meet the needs of their own people with disabilities. There may be perfectly appropriate ways of supporting people already in place, however what is often lacking is access to current technologies or appropriate technical aids or sufficient training for family and community members to provide the optimum level of support.
8. Recruitment of more Aboriginal people into the disability service sector.
9. Build the capacity of the social movement of Aboriginal and Torres Strait Islanders with disabilities by supporting existing networks and building new ones in addition to fostering Aboriginal leaders with disabilities. These networks play a critical role in breaking down stigma that may exist in some communities but are also the conduits for change and will be integral to the successful implementation of the NDIS in Aboriginal and Torres Strait Islander communities.
10. Aboriginal 'Launch' sites focused upon remote, very remote, regional and urban settings. It is critical that this major reform be done right. Therefore it is appropriate to effectively trial its implementation. To this end the FPDN can readily identify key communities that would be appropriate as trial sites.

Ref: First People's Disability Network www.fpdn.org.au

Conclusion

All the issues and opportunities identified in our consultations will be considered and incorporated into the final report to FaHCSIA, and thus assist in the further development of the NDIS. The NRHA will ensure that peak aboriginal health organisations have an opportunity to consider and make comments regarding the final draft, prior to it being adopted.

The NDIS will commence on July 1 in a limited form. When it is in operation, there will be further opportunities for it to be refined. It is important to take the opportunity to voice concerns and extend the rural remote voice into the 'mix' of federal and state government policy development. These are exciting times.