



NATIONAL RURAL
HEALTH
ALLIANCE INC.



**National Disability
and Carer Alliance**

GETTING TO GRIPS WITH THE NDIS IN REMOTE AREAS

Bulletin from the public Forum held in Mt Isa

Thursday 26 June 2014

Summary

The National Disability and Carer Alliance (NDCA) and the National Rural Health Alliance (NRHA) are working together to promote practical strategies to make the National Disability Insurance Scheme (NDIS) work well in rural and remote areas.

To be effective in such areas the NDIS will need to be funded and operated in such a way as suits the circumstances of people living there. While there is a wide variation in the demographics and needs of different rural communities, there are some common challenges.

This Bulletin summarises the findings from a Forum jointly organised by NDCA and NRHA and held in Mount Isa on 26 June 2014. The Forum was part of a project funded by the National Disability Insurance Agency (NDIA). It was attended by some 50 local, regional and national participants (see list of speakers and attendees at Appendix A). A Communiqué released at the conclusion of the event can be found at Appendix B. Our thanks to Daniela Stehlik for working on this Bulletin with staff of the NRHA.

The Bulletin builds on the following NRHA papers (all of which are available on the NRHA website):

- 1 February 2013 Submission to Senate Inquiry on the NDIS Bill 2012
- 21 February 2013 Issues relating to the NDIS in rural and remote areas of Australia
- 29 April 2013 Roundtable Report on Implementation of DisabilityCare in rural and remote areas

This Bulletin provides further evidence of the need for special arrangements to apply to the NDIS in rural and remote areas, informed by the views of people from those areas who will be directly affected and by the lessons from the launch sites.

Through this Bulletin and related activity, the NRHA and NDCA provide an overview of some of the issues already apparent in operations of the NDIS in rural and remote areas. The two Alliances are describing what needs to be done – now – by all stakeholders, including the NDIA to ensure a fit-for-purpose NDIS for remote Australia. There is anxiety throughout rural Australia about precisely what is intended and, in those areas not due to have the NDIS in operation until 2016-17, a fear of missing out (FOMO).

Eight urgent recommendations are included in this Bulletin to ensure current policy planning remains ‘on target’.

The Transition Challenge for Participant Readiness

As the NDIS extends its trial sites further from 1 July, 2014, it is trialling service delivery into remote communities, through the site in the Barkly Tableland, centred around Tennant Creek. This workshop was held in Mount Isa, central western Queensland, and included a presentation on the Barkly trial.

The Forum focused on the *transition* opportunities and challenges associated with the future expansion beyond trial and into a national system. These transition opportunities and challenges can either enable or delay participant readiness – that is, both client-readiness and provider-readiness.

Although the full roll-out of the NDIS will not reach all of remote Australia until late 2016-17 it is essential that planning begins now for people living with a disability and their families/carers as well as for their service providers.

This transition period of some two years gives a unique opportunity for remote Australia *to get the NDIS right*.

It was also agreed at the Forum that the lessons learned from over three decades of service delivery to remote Australia provides a practical and useful baseline for a deep understanding of how place makes a critical difference outside urban settings, and that these lessons are available now for integration into this transition period. In other words, it is neither necessary nor sensible to wait for trial findings on everything associated with the Scheme in order to get it right for remote Australia.

Agreement on key issues

There were some overarching conclusions from the Forum.

- Remote Australia is not ‘starting from scratch’ in relation to service delivery, or experience. Instead, it proposes to build on the firm base it already has. It does not support ‘parachuting’ in services but rather aims to safeguard what it already has.
- Remote Australia remains committed to working with local expertise, especially Aboriginal Health Workers and Community Workers.
- Because remote Australia continues to experience widespread ‘market failure’, alternative models of disability care and service can and should be developed.

A. People

In regard to **information, education and local capacity building**, the Workshop agreed that:

- there remains a large gap in community understanding of the NDIS generally;
- effective implementation of the Scheme requires whole-of-community involvement;
- different modes of communication are necessary to reach different sections of the population; many people lack of internet access; many are unsure about who to contact; and
- a ‘trip advisor’ portal for services and opportunities in remote Australia should be established as a component of the NDIS web platform.

Recommendation 1:

That a culturally appropriate campaign focusing on information and education specifically to remote Australia, using multiple media platforms and naturally occurring events, be immediately developed.

The Forum recognised that the costs associated with **transport and accommodation** remain exceptionally high in Remote Australia and therefore:

- better accessibility for all including appropriate equipment (sturdy and robust), better capacity for services, as well as penalty for non-compliance for operators is urgently required;
- people with a disability and their communities should be involved in the design of fit-for-purpose accommodation (and modifications), especially in very remote communities, as a matter of course;
- there should be recognition that people's needs and circumstances change over time; and
- transport costs become higher with increasing distance from service centres and this has to be factored in when determining a client's costs.

Recommendation 2:

Remoteness must be factored in as key variable to ensure that the NDIS equity principle is maintained.

In regard to **carers and informal arrangements**, those at the Forum supported a call to ensure that current carers and informal support systems are safeguarded and that future plans are prepared ensuring that families and carers are included in these discussions. In addition:

- The fear of poorer outcomes following adoption of the NDIS remains very real for aging parents and carers.
- Respite care remains an essential support. This should be flexible using qualified carers and enabling a choice of carer.
- Client care plans should include support for carers and families – "ask them what they want, need and require".
- Carers should be supported in discussions to consider what is needed by any particular client.

Recommendation 3:

Remoteness must not be used as an excuse to ignore or work against the principle of individual support.

The Forum also called for continued recognition that supporting the individual within **Aboriginal and Torres Strait Islander families and communities** means resourcing and supporting those families and communities. In addition:

- whatever solutions are agreed to, they need to be designed and implemented by Aboriginal and Torres Strait Islander and provided with sufficient resourcing;
- supporting the individual must include supporting and resourcing for the client's family and community; and
- while the determination of the prevalence and incidence of Indigenous disability remains unknown, an instrument that can collect the data in a culturally appropriate way needs urgent development.

Recommendation 4:

That the principle of the person before the disability remains critical.

The Forum considered that for **people with high and complex needs**, remoteness remains a considerable challenge. Such individuals can be seen to be caught ‘between systems’ while being at the edge of all of these. Therefore

- Collaboration is essential at three levels – on high order systems where service agreements are a necessity; at the plan level, where urban templates do not work; and at the service delivery level. The plan must be able to capture complexity as clients move within the system. At the plan level, there should also be incentives for providers to collaborate. At the service provision level, there needs to be a one-stop-shop model so that complexity is managed.

Recommendation 6:

Systems must be aligned to ensure people with high and complex needs achieve their potential and quality of life.

B. Providers

In regard to remote workforce issues and the **recruitment and retention of relevant staff, including allied health professionals** those at the Forum agreed that:

- strategies must be implemented for enabling the employment of local allied health assistants and Aboriginal Health Workers;
- support must be provided for professional development for staff and for building inter-agency collaboration;
- there should be a mapping of disability care services currently operating in remote areas, and an urgent input/output analysis of associated costs, including transport; and
- interdisciplinary and graduate practitioner support systems should be established as a matter of urgency.

Recommendation 7:

Culturally appropriate changes to the current (urban) service delivery model be developed and urgently adopted.

In regard to **infrastructure**, the issues associated with accommodation and transport have been discussed above. In addition, people at the Forum were concerned that the assumption that there would be a choice of service, transport mode or aids and appliances in remote Australia was flawed.

- There is no choice when there are no services in place.
- Block-funded services may well have a significant role to play in more remote areas but there is uncertainty about their future and where they might fit into the new Scheme.

Recommendation 8:

That the concept of ‘choice’ as a component or principle of a market-based system for care services may not apply in rural and remote Australia.

Forum participants

First Name	Last Name	Organization
Phil	Barwick	Central and North West Queensland Medicare Local
Alan	Blackwood	Young People in Nursing Homes National Alliance
Valerie	Brown	People With Disability Australia Incorporated
Kay	Cavanagh	Bluecare Respite
Millie	Clery	National Rural Health Alliance
Ara	Cresswell	Carers Australia
Jennifer	Cullen	Brain Injury Association of Queensland / Synpase
Trish	Eerden	Country Health SA Hospital Local Health Network
Alison	Fairleigh	Mental Illness Fellowship of North Queensland Inc.
Deirdre	Finter	Autism Queensland
Alison	Fraser	
Kim	Gillespie	Child and Youth Mental Health Service
Denis	Ginnivan	South West Brain Injury Rehab Service
Gordon	Gregory	National Rural Health Alliance
Nicole	Harvison	Disability Services
Mary	Hawkins	National Disability Insurance Agency
Hugh	Heggie	Department of Health, Northern Territory
Shelley	Howe	North West Hospital and Health Service Aged Care Team
Nicole	Hynes	Disability Services (Townsville Service Centre)
Sarah	Jackson	Mount Isa Centre For Rural & Remote Health, James Cook University
Sabina	Knight	Mount Isa Centre for Rural and Remote Health
Sue	McBryde	
Tony	McGrady	Mount Isa Council
Melinda	McIntyre	Blue Care
Anthony	McIntyre	
Fiona	McKenzie Lewis	North West Hospital and Health Service, Dept. of Allied Health Services
Janette	McLuckie	Mount Isa Community Development Association Inc.
Kate	Mitchell	Central and North West Queensland Medicare Local
Bronwyn	Morkham	Young People In Nursing Homes National Alliance
Dane	Morling	National Rural Health Alliance
Robyn	Mumford	Bluecare Respite
Roland	Naufal	National Disability and Carer Alliance
Christine	Neilson	Disability Services
John	Patullo	Homelessness Services Townsville and Mount Isa
Jamie	Patullo	Riverbed Action Group Outreach Social Service
Pip	Patullo	
Denise	Robertson	People With Disability Australia Incorporated
Liz	Ruck	Mental Health Council of Australia
Robyn	Shaw	Disability Services
Beau	Sheppard	North and West Queensland Medicare Local
Daniela	Stehlik	Rural Industries Research and Development Corporation
Joanne	Symons	Jo Symons Consulting
Joanne	Tencza	Mount Isa Bluecare Community Care
Karen	West	
Alan	White	Frontier Services
John	Williamson	
Wanda	Woods	Centacare North Queensland

Getting to Grips with the National Disability Insurance Scheme (NDIS) in remote areas

A public Forum hosted by National Disability and Carer Alliance, National Rural Health Alliance and the people of Mount Isa

“Equity from Newcastle to Normanton”

Mt Isa Communiqué on Disability Care, Thursday 26 June 2014 **Disability forum charts way forward for disability care in more remote areas**

In Mount Isa today a group of interested individuals and agencies agreed some of the key ways forward to make the National Disability Insurance Scheme work well in more remote areas.

The meeting was organised by the National Rural Health Alliance and the National Disability and Carer Alliance as part of their ongoing work to make the NDIS fit-for-purpose for rural people.

Topics agreed to be of particular importance include disseminating information to people affected by the changes in place, including about things learned from the rural and remote elements of the four trial sites.

Through no fault of the rural and remote community, public and even interest group awareness of the NDIS is still far too limited. An effective information campaign about the NDIS requires culturally appropriate messages to be delivered by means suited to the communication style and capabilities (eg internet access) of rural people. A successful campaign will relieve anxieties about what the new scheme will mean for clients and carers in particular rural or remote circumstances, and the transition to it from current arrangements.

Particular information needs to flow both ways from Aboriginal and Torres Strait Islander people, who have a distinct understanding of ‘disability’ and many of whom live in rural or remote areas, and the managers and supporters of the developing NDIS.

It will be essential for flexible respite care to be funded in the new scheme, provided by qualified workers who must be properly and strongly supported in their work. The conditions must be clarified in which the scheme will fund support provided by members of the client’s family or their friends.

Some clients of the new scheme will need the support of strong, close advocates to ensure that their best interests are met, including through their individual assessment plan.

Given the expectation of a greater volume of client-centred care services, the chronic shortage of professional staff in rural and remote areas, including allied health, is a matter of major ongoing concern. The implementation of effective workforce initiatives across the disability, aged and health care sectors – always more closely inter-related in more remote areas – will remain essential for the rural success of the NDIS. Professional care staff in rural and remote areas are often in their early career, meaning that a culture of interdisciplinary support is particularly important.

Alternative models of disability care practice can and should be developed in more remote areas and, given the widespread existence of market failure, are unlikely to be the result of a commercial or market approach.

Those at the Mt Isa meeting welcomed the adaptive responses of the NDIA to lessons learned in the trial sites about practical matters for clients of the new Scheme.

They agreed to promote additional actions for priority attention by managers and supporters of the NDIS, including in particular the NDIA. These priorities include a range of serious transport challenges, from micro issues such as appropriate aids and appliances, through to the absence of public transport; and responses to housing and accommodation design challenges – which must be met with equity from Newcastle to Normanton, whatever the cost.

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