NATIONAL RURAL HEALTH ALLIANCE INC.

National Injury Insurance Scheme: Motor Vehicle Accidents

Submission to the Treasury

May 2014

This Submission is based on the views of the National Rural Health Alliance but may not reflect the full or particular views of all of its Member Bodies.

Introduction

The National Rural Health Alliance is comprised of 37 national organisations. It is committed to improving the health and wellbeing of the more than 6.7 million people in rural and remote Australia.

Members include rural consumer groups (such as the Country Women's Association of Australia and the Isolated Children's Parents' Association), representation from the Aboriginal and Torres Strait Islander health sector, rural and remote health professional organisations (representing doctors, nurses and midwives, allied health professionals, dentists, pharmacists, optometrists, paramedics, health students, chiropractors and health service managers) and rural service providers (such as the Royal Flying Doctor Service and Frontier Services of the Uniting Church in Australia). The full list of Member Bodies is available on the website at www.ruralhealth.org.au.

Each of the Member Bodies is represented on Council of the Alliance, which guides and informs policy development and submissions. With such a broad representative base, the Alliance is in a unique position to provide input on the broader issues relating to good health and wellbeing in rural and remote areas.

The submission

The purpose of this submission is to ensure that consideration of a national injury insurance scheme for motor vehicle accidents comprehends the particular circumstances of people in rural and remote areas.

This submission is comprised of this brief cover note plus existing documents prepared by the Alliance for its work in relation to the National Disability Insurance Scheme (NDIS).

The Alliance has a strong interest in the possibility of a National Injury Insurance Scheme (NIIS) and how it would improve the situation currently faced by people in rural and remote areas upon experiencing a motor vehicle accident, particularly in those jurisdictions currently without a no-fault scheme.

People living in rural and remote Australia who have incurred a catastrophic traumatic brain injury invariably obtain high quality acute medical attention in major metropolitan specialist hospitals. However, after acute management is concluded, and upon returning to their home communities, there is a dearth of capacity for continuing specialist brain injury rehabilitation in most states. NSW is the only jurisdiction which has been able to achieve a state-wide specialist service. This service model has a high degree of collaboration with the NSW Lifetime Care and Support Authority.

It is important that the continuing development of the NIIS reflects the need for rural and remote Australian to have equity of access to specialised services which focus on the cognitive, psychological, behavioural and physical aspects of brain injury rehabilitation. These services provide the strong base and support for successful re-entry to community and relationships, to employment, and to successful navigation for 'living with a changed life'.

We would ask relevant officers in Treasury to make themselves familiar with the facts, figures and opinions in the attached NRHA publications.

One of these documents is the NRHA Position Paper entitled *Achieving best possible outcomes for people with acquired brain injury who live rural and remote communities*. It briefly summarises the national situation with respect to acquired brain injury, particularly as it relates to rural and remote areas. The paper then suggests how it would be possible to effect an improved national approach to rural and remote brain injury rehabilitation and has a set of best practice principles for such work. The paper concludes with some broad recommendations.

The other NRHA papers we commend for Treasury's consideration are:

- The NRHA submission to the Senate Inquiry on the NDIS Bill 2012 (1 February 2013).
- The NRHA's opening statement to a public hearing of that Inquiry.
- The NRHA Discussion Paper on issues relating to the NDIS in rural and remote areas of Australia (21 February 2013).
- The submission to FaHCSIA on the proposed rules for the NDIS (26 March 2013).
- The NRHA/NDCA report on a Roundtable held in Canberra: Implementation of DisabilityCare Australia in rural and remote areas (undated; produced in May 2013).
- The Final Report of the NRHA's FaHCSIA Practical Design Fund Project (7 June 2013).

The National Rural Health Alliance has an ongoing interest in potential developments with a National Injury Insurance Scheme and would be pleased to be involved in further consultations.

NATIONAL RURAL
HEALTH
ALLIANCE INC.

ABN: 68 480 848 412

National Rural Health Conference
Australian Journal of Rural Health

PO Box 280 Deakin West ACT 2600
Phone: (02) 6285 4660 • **Fax:** (02) 6285 4670
Web: www.ruralhealth.org.au • **Email:** nrha@ruralhealth.org.au

Achieving the best possible outcomes for people with acquired brain injury who live in rural and remote communities

Denis Ginnivan

March 2012

CONTENTS

Introduction 3

The Alliance's involvement 3

Current policy opportunities 4

Acquired brain injury – the national picture 4

Acquired brain injury – the rural and remote picture 6

Developing a national approach to brain injury rehabilitation 7

The brain injury journey 7

Post hospital rural and remote brain injury rehabilitation 8

Towards best practice principles for rural and remote brain injury rehabilitation 8

Disability funding 10

Productivity Commission inquiry report 11

NRHA response and call to action 14

References 15

Introduction

Acquired brain injury (ABI) refers to any damage to the brain and its functions that occurs after birth. The injury may be caused by an accident or trauma; a sudden non-traumatic event such as a stroke or aneursym; or by gradual deterioration, for example, by misuse of alcohol or other drugs, or due to degenerative conditions such as Parkinsons Disease. (Brain Injury Australia 2011)

A person with a sudden ABI is most likely to be taken to a major metropolitan hospital or large regional hospital for trauma care and inpatient rehabilitation over several months, wherever they live. Extended hospitalisation for ABI, as for many other causes, comes with particular challenges for rural people due to isolation from the support of their families, friends and communities.

However, people who are discharged from inpatient rehabilitation in metropolitan centres, whether they live in the city or the country, will continue to benefit from well-coordinated multi-disciplinary care to help them reach their full potential and take up their place in their community again over the months and years ahead.

Yet in the rural and remote areas of most Australian states and territories, there is little or no service capacity to support the person with a recent brain injury to maximise the rehabilitation-related opportunities required to 'live well with a changed life.'

The Alliance's involvement

At the National Rural Health Alliance Councilfest in September 2011, it was agreed that the Alliance should develop a position on improving access to specialist post-hospital brain injury rehabilitation for people in rural and remote areas.

The Council of the Alliance agreed to:

- determine the relative importance (frequency, seriousness) of the issue;
- determine the extent to which it may be amenable to a policy response; work to ensure that governments, the public and interested agencies (eg research bodies) are well informed about acquired brain injury as it relates to people in rural and remote areas;
- try to ensure that the interests and characteristics of people in rural and remote Australia are accommodated in new policies going forward so that they get a fair deal in access to existing, modified and/or new services for ABI; and
- consider the elements of the position developed on improving access to ABI services for people who live in rural and remote communities that may be applicable to improving access to health and rehabilitation services more generally.

The Alliance has also undertaken to work to develop a position paper on the proposed National Disability Insurance Scheme, and the National Injury Insurance Scheme, with a particular focus on ensuring that there is equitable access for Australians living in rural and remote areas.

Some of the challenges to be overcome in this particular service area, such as workforce shortages, access to funding, and service model options, make this a valuable case study in providing more specialised services in rural areas for a range of conditions. The importance of this issue for the Alliance lies in two areas:

- ensuring that appropriate models of service and support are available for people who live in rural and remote areas;
- focussing on the current development of a national approach to disability funding, to ensure that Australians living in rural and remote Australia are not disadvantaged by living where they do.

Current policy opportunities

As 2012 begins, the Government's reform of the *health system* has led to the establishment of Medicare Locals with the capacity (if funded properly) to identify regional and local health service gaps, and in conjunction with Local Health (or Hospital) Networks, to play leading roles in the establishment and operation of new health services.

Further, the Government's focus on rural and regional development makes this a good time to propose ways in which rural service deficits can be met. This includes the need for a clear clinical pathway for rural patients with brain injury. In particular, 2012 may be the year for significant progress with much needed investment in disability care and support. The Government has indicated its intention to respond to the Productivity Commission's final report on Disability Care and Support through the establishment of a National Disability Insurance Scheme that provides insurance cover for all Australians in the event of significant disability. Funding of the scheme should be a core function of government (just like Medicare). The main function (and source of cost) of the NDIS would be to fund long-term high quality care and support (but not income replacement) for people with significant disabilities. The Council of Australia Governments has also agreed to a no-fault National Injury Insurance Scheme to fund care and support for all cases of catastrophic injury, drawing on the schemes currently operating in several states and territories around Australia.

Acquired brain injury - the national picture

Approximately 438,300 Australians have a brain injury. This represents 1 in 45 Australians. Three in four are male. Over 60% acquired their brain injury before 25 years of age.75% or 311,800 are aged 65 or less. Of the 311,800 people, 157,500 had a severe or profound core activity limitation activity (eg feeding, dressing, toileting, transport); with 27,000 of these 157,000 people younger than 65 years. (Australian Institute of Health and Welfare 2007)

In addition to the personal and community cost of brain injury, Access Economics (2009) estimated that the total economic cost of neurological injury to the Australian community through direct care and lost productivity is more than $8.6 billion per year. Almost two thirds of that cost is borne by individuals and families, either directly or through insurances.

This position paper specifically focuses on those people who have had a sudden acquired brain injury, and as a result of this injury have required admission into hospital, and subsequent rehabilitation. (it does not focus on those people for whom ABI is gradual –for example drug or alcohol induced ABI). The major reasons for hospital admissions following sudden acquired brain injury, the extent of the rural component of national data, and the broad age groups are outlined in table 1-3 below.

Table 1: National injury causes, and age at hospital separations (2004-05)

	Number	% >/= 65	% < 65
Stroke	48,000	70	30
Motor vehicle accident	51,000	10	90
Assault	20,000	80-85 (1)	15-20 (1)
Falls	127,000	50	50

(1) derived from data in AIHW

Table 2: Sudden brain injury component of national and rural / remote injury hospital separations (2004-05)

	National	Rural / remote	%
Stroke	48,000	16,840	35
Motor vehicle accident	7,200	2,880	40
Assault	3,500	1,575	45
Falls	8,700	2,610	30
Other traumatic brain injury	2,700	1,080	40 (2)

(2) This is an estimate of the proportion of rural remote 'other' traumatic brain injury, based on the rate of motor vehicle proportion

Table 3:
Number of rural people separating from hospital annually, by broad age group (2004-05)

	< 65 years	>/= 65 years
Stroke	5,894	10,946
Motor vehicle accident	2,592	288
Assault	1,418	157
Falls	1,305	1,305

Summary: Nationally, 21,800 people were admitted to hospitals with traumatic brain injury in 2004-05. Approximately 48,000 people were admitted to hospital with acquired brain injury, predominantly due to stroke. Thus there is a total of approximately 70,000 per year admitted to hospital with a recent brain injury, and of this group, approximately 40% are aged less than 65 years. Of those younger than 65 years, 35 % (or approximately 24,000) are from rural and remote areas. Two in five traumatic brain injuries were caused by a fall; one in three by a motor vehicle accident; and one in six by an assault. (AIHW 2008).

Acquired brain injury - the rural and remote picture

Seven million or approximately one third of all Australians live in rural and remote Australia. In 2004-05 people in inner regional areas were 1.25 times as likely to have an ABI, while those living in outer regional and remote areas were 1.42 times as likely to have an ABI, compared with those in major cities ABI. Inner regional males were 1.26 times as likely to have an ABI, while outer regional males were 1.62 times as likely to have an ABI compared with those in major cities. This translates to the comparison that while 32% of the population lives outside major cities, 38 % of Australians with ABI live outside major cities. There was no clear difference between the prevalence of ABI amongst females living in major cities, regional or remote Australia.

Of the national total of 22,000 patients who were admitted to hospitals with a traumatic brain injury in 2004-05, over a third (about 36%) were rural or remote residents.

Hospital admission rates for falls appear to be broadly similar in city and rural areas, so in the absence of other information it is assumed that rates of TBI as a result of falls is also similar in these areas (derived from data in Australian Institute of Health and Welfare 2008)

The rate of hospital admissions as a result of motor vehicle accident was higher in regional areas (1.3-1.5 times) and higher again in remote areas (2.1-2.5 times) compared with major cities. In the absence of other information we assume that rates of TBI as a result of mva is also similarly elevated in these areas, which suggests that almost 40% of TBI due to MVA occurs amongst people living outside major cities.

Compared with major cities, the rate of hospital admission due to assault is similar in inner regional areas, twice as high in outer regional areas, and 4 and 9 times higher in remote and very remote areas respectively. Assuming that the rate of TBI also follows these patterns, 45% of new cases of TBI due to assault occur outside major cities.

The much higher rate of assault related TBI in remote areas is likely to reflect both the high prevalence of Indigenous people in these areas (45% in very remote areas) coupled with the very high rates of assault in these populations. Hospital admission rates for brain injury due to assault are very much higher for Indigenous people (up to 21 times higher in 4 selected jurisdictions in the six year period to 2005). Assault is responsible for about 44% of injury hospitalisations among Indigenous women, compared with 2.3% for non-Indigenous women. (Jamieson et al 2008).

Compared to people living in major cities, people who live in rural and remote areas have a lower life expectancy and are more likely to be injured or die in a motor vehicle accident. (NSW Department of Health 2008)

In terms of treatment facilities available in rural and remote areas, there is a high degree of variability for people with brain injury, by jurisdiction and by degree of remoteness, in the availability of specialised clinical therapy and support following discharge from hospital.

The stages of treatment following brain injury are discussed in more detail in the following sections.

TOWARDS A NATIONAL APPROACH TO RURAL AND REMOTE BRAIN INJURY REHABILITATION

Inpatient treatment and rehabilitation for rural people following brain injury

In the situation of a severe traumatic brain injury, the person is more likely to be transferred to a larger metropolitan hospital for trauma care, and subsequent inpatient brain injury rehabilitation. The person may (depending on severity of injury) be located in the metropolitan hospital for 2-3 months. The resulting isolation from his/her community has major implications for the patient and the family.

For a person who lives in rural or remote Australia, the next stage of rehabilitation is typically provided in a regional base hospital inpatient setting, closer to home and family. The focus of the inpatient strategy is on helping the patient to gain physical strength through standing, walking and moving; to gain in speech and language; to gain in confidence about returning to the home and community, and having a purpose, role, and activity within it. Along with these therapy strategies, there is a parallel monitoring of the patient's medical status, and engaging with the family and community organisations in preparation for discharge from inpatient rehabilitation.

Post hospital rural and remote brain injury rehabilitation

It is after the point of discharge from metropolitan or regional hospitals, when the person returns to their home and community, that availability and access to subsequent brain injury related clinical services for the person with the injury (and their family) will vary widely. This is shaped by a range of factors such as the jurisdictional model of brain injury rehabilitation which varies widely, the insurance/funding model adopted by the state, the remoteness of the place of the person's usual residence, and ethnicity. These factors will also shape the 'rehabilitation culture' of the service provider, and hence the type of clinical service with which the person with brain injury and their family engage.

The key clinical service elements which constitute this specific phase are identified in italics in table 4 below.

TABLE 4: 'Typical' journey for a patient following traumatic brain injury

Trauma event or sudden medical event in rural / remote location

Retrieval to hospital (metro / larger regional base hospital depending on severity of injury)
- Trauma /emergency management
- Surgery
- Medical care

Referral to inpatient rehabilitation
- medical care, physiotherapy, speech therapy, functional activity
- discharge from hospital
-

Discharge to community / non hospital living setting
(destination is subject to level of care needs required)
- Home and community
- Supported accommodation
- High level care eg nursing home

Or discharge to...
Transitional post hospital brain injury rehabilitation

This phase could commence from one to three months following the injury and could extend (not necessarily continuously) for up to up to three years
This transitional phase could include the delivery of the following services

- *Assessment and review by medical rehabilitation specialist, and neuropsychologist*
- *Clinical treatment of cognitive problems such as memory, planning, concentration, planning and problem solving, flexibility in thinking*
- *Clinical treatment of psycho-social / problems such as depression, emotional instability, impulsive and inappropriate behaviour*
- *Continuing physiotherapy*
- *If returning home, support to family*
- *If not returning to one's home, determining appropriate care and accommodation*
- *Support for vocational re-entry, non vocational activity, and leisure activity*
- *Provision of case management to coordinate the array of services and organisations involved*

Long term general support services

- home care; community support services

Towards best practice principles for rural and remote brain injury rehabilitation

Some specialist brain injury rehabilitation service models have urban and rural based services. Harradine et al (2004) found that similar rehabilitation outcomes can be achieved for rural and urban NSW residents, following a severe brain injury, regardless of the distance from the metropolitan centre, despite the distances involved for rural patients and clinical staff, and the differences in the type of rehabilitation setting. This was attributed to a coordinated approach between metropolitan and rural-based specialist services, with a continuing clinical focus on the brain injury rehabilitation opportunities which exist following discharge from the metropolitan hospital.

It appears that there are key principles which guide the development of improved brain injury rehabilitation service capacity in rural and remote areas. These are outlined below, along with specific strategies by which they can be achieved.

That Australians with ABI have access to the rehabilitation services they require, regardless of where they live
- service models are developed to ensure that there is non metropolitan based capacity to respond to the needs of rural and remote people who have had a brain injury

There is recognition of, and treatment responses to the important continuing clinical challenges faced by people who are discharged from hospital following a sudden brain injury

- regionally based (hub and spoke) brain injury rehabilitation services are integrated and resourced as part of a state-wide approach

- regionally based services providing centre based services for clients who live distantly (eg within a residential capacity in); and outreach services to clients living in more rural and remote areas

There is a service model which enables the delivery of appropriate clinical and support services for people with brain injury living in rural and remote areas.

- specialist brain injury rehabilitation culture is attuned to the clinical needs of rural and remote clients and families
- there is access to assessment and review by a brain injury medical rehabilitation specialist
- there is access to assessment and treatment by clinical neuropsychologist, neuro-physiotherapist, neuro-occupational therapist, and neuro-speech pathologist
- ABI community workers located in smaller communities supporting clients and their families and community to implement rehabilitation strategies
- Rural and remote areas are serviced by fly-in or drive-in outreach staff undertaking specialist clinical assessment and review clinics

There is a model of care which recognises the need for seamless service transition from acute and sub-acute rehabilitation services to transitional and community based services for people who have brain injury

- There is training on brain injury, and support for communities, families and non brain injury specialist workers
- There is care coordination and support to the person and family for managing life at home
- There is case management provided to interface with external services which include eg insurers, places of employment, schools, community services
- There use of tele-health consultant training and support; and e-learning
- There is access to counselling for adjustment to the injury, and managing relationships with others

There is recognition within the service model of the specific clinical needs of children, adults, and older adults with brain injury

Improved support in (most rehabilitation is organised in metro; some in rural; none in remote remote settings (being from remote areas, being sent to the city for rehabilitation can be a devastating experience (Gething 1996) as bing abway from family and cultural experiences

There is recognition of the specific cultural circumstances, and needs of indigenous people who have a brain injury, and their communities

- Location of brain injury rehabilitation workers with aboriginal health services; and the brain injury rehabilitation clinicians work collaboratively with these workers
- Development and use of aboriginal specific ABI resources and training materials
- Brain injury rehabilitation needs of aboriginal people require further investigation (Mitsch 2010)

Achieving best practice post-hospital brain injury rehabilitation as close to home as possible?

Brain injury can happen to anyone, anytime. When a person has a serious brain injury, his/her life is changed, usually permanently. Many of the implications of the changes become apparent well after discharge from hospital care. Brain injury is likely to have major impacts on one's identity in many ways. These potentially include (but are not limited to) physical changes such as reduced mobility; speech loss to the point of incapacity to communicate; cognitive changes such as poor memory, poor concentration and planning and mood control; and challenging behavioural changes that can damage close relationships.

These clinical changes can significantly impact on the person's capacity to keep a job, to drive a vehicle, to return to school or further training, to maintain loving relationships, to make and keep friends, and to have a meaningful role in the community. They could mean that one loses one's pre-injury identity and needs to come to a new sense of identity. This process of adaptation and movement to a new 'self' may occur over many years. It is a difficult journey which can be enhanced through specific support and resources which engage the person with brain injury and their family. There are additional cultural issues faced by Indigenous people which relate to gender, kinship and shame (Mitsch, 2011)

There is no doubting the potential capacity of rural and remote health professionals to support people with brain injury. As with so many other conditions, the issue is how there can be equitable access to the required services for the people of rural and remote Australia.

Funding for the disability 'system'

The current disability system needs to be seen in the context of three major streams: those born with or having a developmental disability commencing before the age of 18; those who have a progressively increasing disability; and those who have a sudden injury or trauma that results in a disability. It is understood that the first and second group would be covered by the proposed National Disability Insurance Scheme; and that the third group would be covered by the proposed National Injury Insurance Scheme.

People born with a disability (eg cerebral palsy) or who have a developmental disability (eg as a result of encephalitis) from an early age require a range of services which are the responsibility of the various state disability service agencies. Over the past two decades funding to those services has come primarily from the Commonwealth/State disability funding agreement. Delivery of the required services has been by state departments and a wide range of non-government service providers. Many of the non government service providers also have tax status as a charity. Services provided for this group include institutional or community based accommodation, special schooling, personal care, case management, supported employment, support for recreation and leisure activities.

People who have a progressively increasing disability through adulthood eg multiple sclerosis, are supported through a wide range of disability specific organisations, and generic community support organisations. Funding comes from both federal and state sources as well as through fundraising. People in this group may periodically be admitted to hospital for inpatient rehabilitation.

People who acquire a disability through a sudden event (eg stroke, or brain injury in a motor vehicle injury) are typically hospitalised initially in metropolitan trauma hospitals or larger regional base hospitals. Where people are admitted for treatment will be dependent on the level of the severity of the injury, and the capability of the specific hospital. In rural and remote areas, people who have had a stroke would typically be managed in a large regional base hospital. There they receive the range of emergency care, surgical and medical treatment, and when it is possible, inpatient rehabilitation. For people who have had a severe stroke, who are older, and who do not have options for community care, nursing home or hostel placement may occur.

Those who have a less severe (and thus more successful) outcome are discharged to home from the hospital. In addition to receiving outpatient rehabilitation (if available) referral can be made to generic support services such as home care and community nursing.

Productivity Commission Inquiry 2011 Report – Disability Care and Support

In 2011, the Productivity Commission released its report on a National Disability Care and Support. The report considers the costs, cost effectiveness, benefits and feasibility of replacing the current arrangements with a properly funded and managed long term disability scheme. The Commission has proposed that there be two sub schemes developed: a National Disability Insurance Scheme (NDIS), to fund the current state government disability service systems; and a National Injury Insurance Scheme (NIIS).This proposed injury insurance model, similar to no-fault motor insurance models which exist in some states, appears to be supported by COAG, and has in-principle bi-partisan support. The Productivity Commission report refers to the need to find creative ways for service provision in rural and remote Australia. The NIIS and the NDIS will have relevance to the development of brain injury rehabilitation in rural and remote Australia. Currently, the no-fault motor vehicle insurers in NSW and Victoria (Lifetime Care and Support, and Transport Accidents Commission respectively) fund hospital, rehabilitation and long term support for their clients who have had a traumatic brain injury. Under NIIS, their brief would be expanded to include all traumatic brain injury.

It is not yet determined how the two schemes will relate to each other, though the NIIS would be implemented as a federated model involving the participation of the current state based motor vehicle insurance organisations. Under the NDIS these organisations would be expanded to have responsibility for all catastrophic injury, irrespective of circumstances in which the injury occurred. At this time there are four jurisdictions which do not have a no-fault motor vehicle insurance scheme in place: WA, SA, Qld and ACT. Minister Shorten is strongly advocating that all states adopt a no-fault insurance model of operation, so that a federated approach can be established.

The Productivity Commission report briefly identified some rural issues, including concerns about the quality, access to and range of services available in rural areas. Challenges to service provider viability, due to the small size of the market, and the availability of specialist services were also noted. A number of potential strategies for overcoming these hurdles included greater use of Telehealth, fly-in visits to regional centres, and periodic visits to remote locations. Notwithstanding, it was noted that people may need to relocate to effectively access services. Issues of servicing Indigenous communities were highlighted, though not solely from a rural and remote perspective (Productivity Commission Report, p538).

Disability funding - NRHA response

A national Advisory Group has been established by the Government for both prospective schemes. The NRHA has been invited to meet with the NIIS Advisory Group in April 2012, to discuss the opportunities for maximising the introduction of the NIIS in rural and remote Australia.

The NRHA has publicly welcomed the prospective development of a national approach to disability funding, and it seeks to ensure that Australians living in rural and remote Australia are not disadvantaged by living where they do. Given the current distribution of rehabilitation resources, the people living in rural and remote Australia stand to benefit significantly from a national disability insurance system. One of its principles would be to deliver appropriate support to maximise a return to independent living to all people, determined only by their clinical need rather than by their location or financial means.

A nationally accessible no-fault insurance model gives certainty to the person with the injury and their family that a timely and planned approach will be supported, effectively immediately after the injury, rather than waiting for an often protracted civil case outcome, through which time there is no certainty the case will be successful, and the person with the injury can clinically regress. The insurance model will legislatively commit the additional financial resources required for provision of rehabilitation and supporting people living in rural and remote areas. It will also introduce a committed funding partner (for state health departments delivering brain injury rehabilitation, and commercial rehabilitation providers) which will increase the likelihood of developing a strategic approach to provision of brain injury rehabilitation services in rural and remote areas. Such an approach will be of particular benefit for the development of a strategic approach to service delivery in rural and remote areas, where the 'market' for services is smaller. The corollary is that a state health department will typically develop services in larger metropolitan centres, which historically is what has happened.

To move from the current situation to one in which there is a national no-fault insurance scheme for both injury and disability will require considerable support and work. There does not appear to be any major objection to the Productivity Commission report, nor to its proposals for the proposed National Disability Insurance Scheme and the National Injury Insurance Scheme. The insurance model was introduced in NSW in 2006, where it was thought there would be strong opposition from the legal profession who represented people in civil compensation claims under the previous fault-based insurance model. Such opposition did not eventuate to any large degree, possibly in view of the fact that after an interim period of participation in that scheme, and where the person was subsequently not deemed to be eligible to continue, there is still provision for civil compensation claims.

The proposed National Injury Insurance Scheme requires all jurisdictions to adopt a no-fault approach to injury insurance. Four jurisdictions (WA, SA, Qld, and ACT) current have a fault based model. The federal government is strongly advocating that they change, in order for the national, federated model to be put in place.

There appears to be an historic opportunity to create major reform in the area of injury rehabilitation. The government is strongly supportive, and there are strong community expectations that it needs to respond to the Productivity Commission report. There is a need to continue to build the public profile of the issue, and to ensure that rural and remote Australia does not miss the opportunity to achieve equity in access to high quality specialist brain injury rehabilitation.

The National Rural Health Alliance calls for

Adequate Disability Funding

That the National Disability Insurance Scheme and the National Injury Insurance Scheme funding models are developed with rural and remote 'in view'; and that rural and remote practitioners have input to the development of the funding strategy for these schemes

Equivalence in service access for people in rural and remote communities

That rural and remote Australians have equivalent access to clinical opportunities for effective clinical recovery from sudden brain injury; and that state (rural specifically) health services work towards developing equitable and best practice approaches to rural brain injury rehabilitation, and support services in the community

That Medicare Locals will be in a position to this monitor issue, and champion strategies for ensuring that their region gets equitable services

Appropriate models of care

That minimum standards be developed for people with sudden brain injury living in rural and remote communities. These should include::

- referral for 'post hospital' specialist brain injury rehabilitation
- referral to age appropriate / positive accommodation care settings
- clinical best practice service standards are implemented

That Indigenous Australians have access to appropriate and effective models of care

That the model of care reflects the differing clinical needs of children, adults, and older adults

That the model of care captures the opportunities for slow stream rehabilitation for people who are very severely injured

Effective workforce strategies

That e-health and telehealth be instrumental and supported for delivery of clinical services.

That there be funding available for visiting (fly-in) clinicians including non medical allied staff.

That rural and remote practitioners be supported by the establishment of a national brain injury health professional network be established, similar to that which exists for mental health

That post graduate education be available for rural remote brain injury rehab professionals

Research and policy development

That there be support for the development of a rural and remote brain injury rehab research and policy development centre; that continuous focus is brought to the cost benefit opportunities which within an disability insurance framework.

That the recommendations of the key recent reports on rural and remote brain injury rehabilitation be considered when developing a strategy.

References

Access Economics Pty Ltd (2009). *The economic costs of spinal cord injury and traumatic brain injury in Australia.* The Victorian Neuro-trauma Initiative

Australina Institute of Health and Welfare (2008) *Hospital separations due to traumatic brain injury 2004-05.* AIHW Injury Research and Statistics Series no 45

Australian Institute of Health and Welfare (2007) Disability in Australia: acquired brain injury Bulletin 55

Harradine P, Winstanley J, Tate R, Cameron I, Baguley I, and Harris R, '*Severe Traumatic Brain Injury in New South Wales: comparable outcomes for rural and urban residents'* Medical Journal of Australia 181 (3) 130-134

Jamieson L, Harrison J, and Berry J (2008): *Hospitalisation for head injury due to assault among indigenous and non indigenous Australians, July 1999 – June 2005.* Medical Journal of Australia Vol 188 no 10; p 576-579.

Mitsch, V (2010): Acquired Brain *Injury Rehabilitation Service Delivery Project: Developing a Model of Care for Rural and Remote New South Wales.* New South Wales Agency for Clinical Innovation.

NSW Department of Health Population Health Division (2008): *The Health of the People of NSW* – Summary Report of the Chief Health Officer. Sydney

Australian Institute for Health and Welfare (2007) Disability in Australia: acquired brain injury. Bulletin no.55 Cat no. Aus 96 Canberra.

Australian Government Productivity Commission Inquiry Report, *Disability Care and Support Executive Summary* No 54, 31 July 2011

NATIONAL RURAL
HEALTH
ALLIANCE INC.

ABN: 68 480 848 412

National Rural Health Conference
Australian Journal of Rural Health

PO Box 280 Deakin West ACT 2600
Phone: (02) 6285 4660 • **Fax:** (02) 6285 4670
Web: www.ruralhealth.org.au• **Email:** nrha@ruralhealth.org.au

Delivering equitable services to people living with a disability in rural and remote areas

FaHCSIA Practical Design Fund (NDIS) Project 2013

Final Report

7 June 2013

This report is based on the views of the National Rural Health Alliance but may not reflect the full or particular views of all of its Member Bodies.

Contents

The NRHA and disability services in rural areas **3**

People living with disability in rural and remote areas **5**

What is promised? **6**

National Disability Insurance Act, 2013 .... **7**

Project activities **8**
- Senate Submission 9
- Publicising DisabilityCare Australia 9
- Submission to Senate Hearing 9
- Submission on the NDIS Rules 10
- Papers presented at the 12thNational Rural Health Conference 10
- NDIS Project Reference Group 10
- Collaboration with NDCA on a web survey and Roundtable 11

Themes that emerged in the Project **12**
- Compounding of disability problems by level of remoteness 12
- Need for flexibility in rules and provision of support 12
- Transport issues 12
- Promoting awareness of DisabilityCare Australia 12
- Collaboration between health, disability and aged care sectors 12
- The capacity of the disability workforce in rural and remote areas 13
- Indigenous agencies' advocacy on disability 13

Project recommendations **13**

Case Study **18**

Appendix **20**
- Attachment A. Member bodies of the National Rural Health Alliance 201
- Attachment B. National Rural Health Alliance, *Written submission to Senate Inquiry on the National Disability Insurance Scheme (NDIS) Bill 201,* 1 February 2013 ..203
- Attachment C. National Rural Health Alliance, *Discussion Paper on issues relating to the NDIS in rural and remote areas of Australia,* 21 February 2013 33
- Attachment D. National Rural Health Alliance, *Opening statement presented to Senate Inquiry on the National Disability Insurance Scheme (NDIS) Bill 2012,* 5 March 2013 45
- Attachment E. National Rural Health Alliance *Submission to FaHCSIA on proposed NDIS Rules,* 26 March 2013 49
- Attachment F. National Rural Health Alliance, *Shaping the National Disability Insurance Scheme for Rural Areas* Paper presented at National Rural Health Conference, 9 April 2013 54
- Attachment G. Practical Design Fund Project Reference Group membership list 61
- Attachment H. Delphi Survey questionnaire instrument 62
- Attachment I. National Rural Health Alliance, and National Disability and Carer Alliance - *Final Report of Roundtable Conference,* Canberra, 29 April 2013 63

The NRHA and disability services in rural areas

The National Rural Health Alliance is made up of 34 member bodies, each a national body in its own right, representing rural and remote health professionals, service providers, consumers, educators, researchers and Indigenous health interests. See Attachment A.

The vision of the National Rural Health Alliance is good health and wellbeing in rural and remote Australia, and it has the particular goal of equal health for all Australians by 2020. This goal applies to people living with disability as much as to any others.

Development and implementation of the National Disability Insurance Scheme provides a once-in-a-lifetime opportunity to ensure that disability services are available according to need, wherever people are living with disability, so that they can achieve the best possible health and life outcomes.

This project has brought disability into sharp focus for the National Rural Health Alliance. Thousands of rural and remote people have become aware of DisabilityCare Australia and its work through the Alliance's communication channels, media releases and other publications, the consultative processes in development of discussion papers, and its submission to the Senate in February 2013. This information dissemination has also occurred through the 12th National Rural Health Conference in Adelaide where, for the first time, the program featured a series of presentations on disability and the NDIS; and through the Roundtable held in Parliament House in April 2013 and the report emanating from it.

The most important part of the task, however, is to listen to, discuss and report the issues and challenges faced by people with a disability and their families and carers outside major cities. The lived experience of people living in rural and remote areas is the real truth of the matter.

The National Rural Health Alliance appreciates the opportunity to undertake this valuable work. Within its means, it will continue to consult with its members and people with disability, their families and carers, as DisabilityCare Australia rolls out to become a full scheme over the next few years.

Additional funding to continue the more detailed consultation and sharing of information through rural networks, as outlined above, would add value to the Alliance's contribution. The current project has enabled us to advocate and make representation to government and other parties to maximise the likelihood of people in rural areas having equivalent access to the benefits of DisabilityCare Australia.

The Alliance has identified the significant contribution that health service providers, health professionals and community organisations can and do make to putting people in touch with their entitlements to support even where disability services are scarce. The potential value of the close interface between health, education, disability and employment in rural and remote communities has been identified.

We would welcome the opportunity to be involved in further development and dissemination of practical resources to help inform people living in rural and remote communities about DisabilityCare Australia. Such work would include putting our networks of education, health professional, health service provider and community organisations in touch with the practicalities of the scheme. Not only would this improve rural and regional awareness, it would also provide more detailed and practical input at a national level, relevant across the launch sites and across state borders to people living with disability in rural and remote communities.

Rural people want to be sure that there will be someone with local knowledge who can help with implementing and managing their disability services, adapting the service as their circumstances change and linking in with their health, education and employment needs. In the cities, disability service providers may be able to provide case managers who can do this.

Once a person's plan is established through DisabilityCare Australia, it may be hard in rural areas for them to follow up with people who have local and responsive knowledge. The Local Area Coordinator whose job is to increase community inclusion and develop the necessary capacity within the area may help to build local capacity for this. Over time, if successful, the Coordinator may get disability service providers to come to town – but providing a local case manager for a small number of clients in rural areas is a cost that is not yet factored in. In the interim, local health services, community organisations and others may need to be acknowledged and involved to ensure that people outside the cities can achieve the full benefits from DisabilityCare Australia.

The Alliance intends to work to increase the focus on the relationship between health and disability services in rural and remote areas through all communication channels available to it, including its website, newsletters, e-newsletters and its print magazine Partyline. Other actions in which the Alliance intends to engage include:

- increasing the focus on disability in national forums, such as the National Rural Health Conference, and other conferences;
- promoting awareness among rural and remote networks about DisabilityCare Australia's Advisory Council and its member(s) with rural and remote experience;
- giving attention to the overlap of health, aged and disability services in rural and remote areas, and facilitating opportunities for those closely-related sectors to develop partnerships and work collaboratively;
- continuing to lobby governments for increased health and disability workforce capacity to deliver much needed services and programs in rural and remote areas;
- being a source of advice and feedback from multi-disciplinary health and aged care professionals, consumers, researchers and service providers in the Alliance's networks regarding implementation of the scheme in rural and remote areas;
- promoting awareness of the opportunity to provide input to any reviews of performance of the launch sites, particularly on rural and remote aspects; and
- engaging with rural and remote issues relating to the development of the National Injury Insurance Scheme - the second scheme proposed by the Productivity Commission in its 2011 report.

We would like to continue to be involved during the implementation of the scheme to maximise the likelihood of it fulfilling the promise of a much improved model of service and support for people in rural and remote Australia.

People living with disability in rural and remote areas

About seven million people or 32 percent of the total Australian population live outside what the ASGC-RA classification system defines as Major cities. On average, these people have lower levels of education, lower incomes and worse health risk profiles than people in the major cities. When they are unwell or have sudden health events, there are fewer primary and specialised health services available locally.

Some 70 percent of Australia's Aboriginal and Torres Strait Islander people live outside metropolitan areas and they make up a substantial proportion of the population in rural and especially remote areas. As is well known, on average their health outcomes are substantially poorer than those of other Australians.

The Alliance takes a broad view of health and has a strong interest in the wellbeing of everyone in rural and remote areas, including those who live with a disability. Because there are fewer specialised services in rural areas, local health and aged care services and professionals are likely to be key contacts for people with disabilities. Many people in the Alliance's networks are directly involved in disability, whether as individuals, carers, health educators or researchers. The Alliance therefore promotes an integrated approach to disability, health and aged care.

Our networks and member bodies have highlighted the parlous circumstances which currently confront many people with a disability outside major cities.

In 2009, while the majority of people with disability (2.6 million) lived in Major cities, almost a million lived in Inner regional areas and 436,000 lived in Other areas (Outer regional, Remote and Very remote areas).

The Figure below from Australia's Welfare 2011[1] shows that among people aged less than 65 years, the age-standardised rate of disability in Inner regional (15 per cent) or Other areas (14 per cent) is higher than in Major cities (12 per cent). Severe or profound limitations were more common in Inner regional areas (4.6 per cent) than Major cities or Other areas(3.2 per cent).

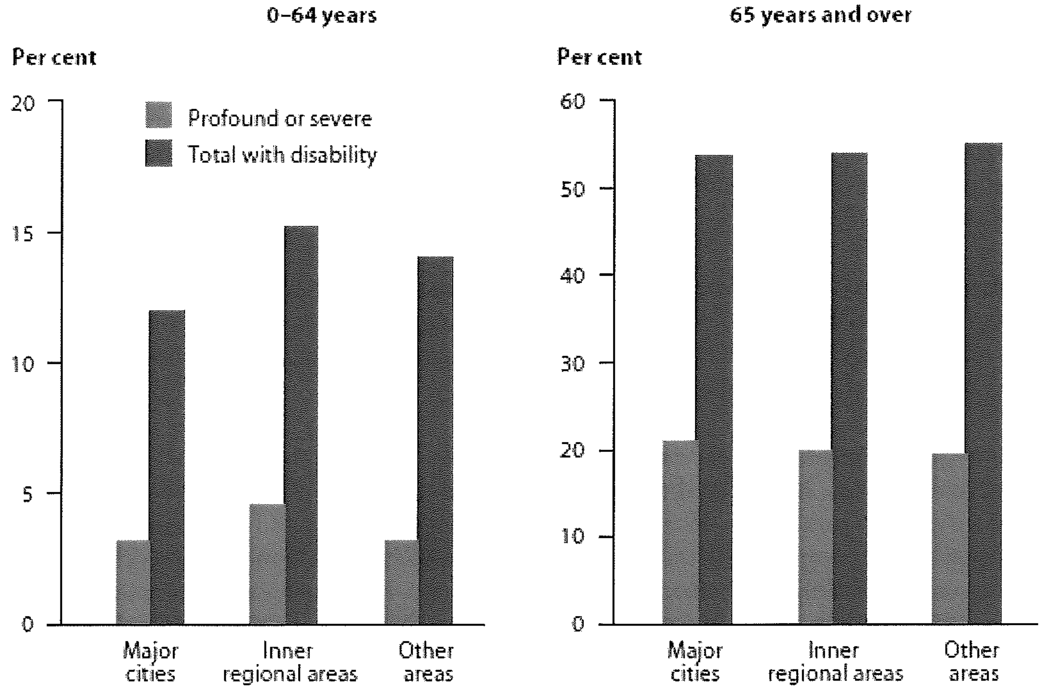
However, among older people (aged 65 years or over) there were no significant regional differences in the prevalence of disability, after population age structures are taken into account.

Regional differences in the underlying prevalence of disability may, in part, be related to the higher rates of injury and a range of health conditions observed in rural and remote areas compared with cities. Disability is 1.2 times more common among men in regional and remote areas than major cities and at similar rates among women[2].

---

[1] Australian Institute of Health and Welfare 2011.*Australia's welfare 2011*.Australia's welfare series no. 10. Cat. no. AUS 142. Canberra: AIHW.

[2] Australian Institute of Health and Welfare 2008.*Rural, regional and remote health: indicators of health status and determinants of health.*Rural Health Series no. 9. Cat. no. PHE 97. Canberra: AIHW.



Note: Rates are age-standardised to the survey population in *Major cities*.
Source: Table A5.5.

Figure 5.3: Prevalence of disability by age group and remoteness of residence, 2009 (per cent of population)

A 2013 report from the COAG Reform Council finds that proportion of people using State or Territory disability support services remains low, but increased nationally from 32.4 per cent to 34.9 per cent from 2008-09 to 2010-11, although with a high degree of variation between jurisdictions.

However increased usage was negligible for people in Outer regional/Remote areas at 1 percent, compared with a 3.5 per cent increase in Inner regional areas and 2.4 per cent in Major cities. Usage rates remain below 30 per cent in Outer regional/Remote areas although the rate of use of these services by Aboriginal and Torres Strait Islander people has increased more rapidly than for the general population. In Outer-regional/Remote/Very remote areas, Aboriginal and Torres Strait Islander people used disability support services at more than double the rate of Indigenous Australians in Major cities - at 61.1 per cent and 26.4 per cent respectively.[3]

It is the unevenness and unfairness of the current situation which makes the successful development of DisabilityCare Australia so vital for rural and remote Australians.

What is promised?

DisabilityCare Australia brings with it the promise of significant new funding, and a new approach for recognising and supporting people with disability and their families and carers.

---

[3] COAG Reform Council.Disability 2011-12: Comparing performance across Australia. 30 April 2013. http://www.coagreformcouncil.gov.au/reports/disability/disability-2011-12-comparing-performance-across-australia

This new approach goes beyond a model that is limited by the available services and places the person with a disability in the 'centre of the picture'- they and their families and carers will be involved in the decision making about how to best use the resources which will be allocated. Thus they will have choice and control over what services and supports will be engaged. There will be a strong focus on supporting the independence and social and economic participation by people with a disability, and facilitating greater community inclusion and every opportunity to maximise the individual's lifestyle and wellbeing.

Being a national scheme, DisabilityCare Australia will ensure a more consistent approach for access to, and planning and funding of, supports for people with a disability. The maturing of the scheme will take seven years or more but it will ultimately mean much greater certainty for people with a disability and their families and carers that they will receive the care and support needed over their lifetime.

The promised new scheme brings a welcome change to the current situation in which services for people with a disability differ from one jurisdiction to another - although all of them are generally underfunded. As a consequence of this historical situation people, particularly in rural and remote areas, would sometimes not receive any services or support, and where support was provided, it would usually be simply 'what was on offer' rather than being tailored to the individual.

Historically, if a person with a disability moved interstate or even to a different region within the same state he or she would be likely to be placed at the back of the queue for services. Parents of a person with disability would often have little choice but to devote their lives to the care and support of their family member, thus foregoing career aspirations and inevitably affecting the lives of their other children. Previously the supports received were often focused on more specific and immediate day-to-day care needs, rather than on the aspirations and goals of the person with a disability, and on how they could be achieved.

Australia's journey in disability care has progressed from being charity-based, then a welfare model of service provision, to the new model based on human rights which will support the aspirations of people living with a disability and the steps required to achieve them.

One of the key findings from the consultations was the key role that local health professionals and a range of local health service providers and community groups play in enabling people in rural and remote communities to connect with disability services and education supports where they exist. These health sector people have also extended what support they can where there have been no specialised disability services - again reflecting the reality of close inter-relationships between these sectors in rural areas.

National Disability Insurance Act, 2013

The Act outlines the provisions for eligibility and becoming a participant; processes for assessment and development and reviewing of plans; arrangements for plan management; arrangements for payment of services which are provided; the provision of supports and services, including early intervention; provisions for information gathering and privacy; provisions for nominees to represent a person with a disability; provisions for engagement of service providers; and provisions for review and appeal of decisions.

Importantly, there is also provision for oversight by an independent Advisory Council, the membership of which is to include a majority of people with a disability; at least two members who are carers of people with a disability; at least one member with skills, knowledge and experience in relation to disability in rural or regional areas; and at least one member with skills, experience and knowledge in supply of equipment or services to people with a disability.

Although it was gratifying to be involved in development of the new scheme from the very beginning, it was hard for people to engage with what it would look like 'on the ground' and how it might translate into practice. There was considerable concern that people living with disabilities in rural and remote communities might slip through the cracks due to not knowing about the possibilities opening for them, the current scarcity of services and the potential for legislative arrangements to be impractical for implementation outside the major cities.

Despite the well thought out and informative www.ndis.gov.au website, it was hard for many of those directly involved with disability services to engage with the draft legislation.

The Alliance prepared a detailed discussion paper for its Council about the legislation and how the new system was being shaped. The key concerns that had been raised from informal feedback through articles in newsletters about the NDIS were included in this paper, which formed the basis for key informant interviews with Council members. The feedback to this internal paper was used to inform the submission to the Senate Inquiry and the Alliance's published consultation paper, which are included in the attachments to this report.

Project activities

The Alliance project, *Study to identify ways to deliver services to people with disability in rural and remote areas*, was one of 73 Practical Design Projects funded by FaHCSIA.

Two broad categories of activities were undertaken in the project.

- Development of a knowledge base and support network on the particular circumstances facing people living with disability in rural and remote areas. This involved consulting with Alliance member bodies, Friends of the Alliance, and a wide range of people with a direct interest in the issues.
- Dissemination of information about the NDIS, DisabilityCare Australia and the activity to be undertaken by and through them.

The project included consultations with:

- people with disabilities and their families and carers in rural and remote communities, in order to develop a specific understanding of their needs so as to inform practical strategies for ensuring equity of access to individualised care and support through DisabilityCare Australia;

- rural and remote networks, including health service providers, on ways to deliver services and identify practical solutions that would help to make DisabilityCare Australia 'fit for purpose' in rural and remote areas; and

- representatives of the disability sector including consumers and carers who were engaged through a Project Reference Group.

The Reference Group met by teleconference and advised on particular rural and remote issues, consultation, content, additional communications channels and important elements distinguishing the requirements for delivery of disability care from health care.

In conducting the project, the following undertakings were fulfilled:

- guidance was sought from Indigenous organisations within the Alliance, as well as other Indigenous groups, on ways of ensuring that the new scheme can be culturally aware and respectful; and
- internal project processes were monitored through regular updates to the NRHA Council by email and at meetings.

The specific project activities were as follows.

Senate Submission

On 1 February 2013 the NRHA submitted a paper to the Senate Inquiry on the National Disability Insurance Scheme (NDIS) Bill 2012. This paper was developed after consultation with people in our network and with member bodies. The paper did not attempt to prescribe how DisabilityCare Australia should operate in rural and remote areas on a daily basis; instead it presented higher level recommendations on the principles and philosophy which should be applied to the implementation of the scheme. The Senate Submission included 14 recommendations.

A copy of the submission is at Attachment B.

Publicising DisabilityCare Australia

A number of initiatives were used to publicise DisabilityCare Australia to people living in rural and remote areas. For example, a discussion paper was posted on the website, sent to members of 'Friends of the Alliance' and promoted to approximately 11,500 subscribers to the NRHA. This discussion paper solicited feedback and examples of disability issues in rural and remote areas from the Alliance network. The feedback and stories received helped to shape our thinking on these issues.

A copy of the discussion paper is included as Attachment C.

Submission to Senate Hearing

Following on from the Senate Submission, on 5 March 2013 three staff members of the NRHA appeared before the Public Hearing of the Senate Standing Committee on Community Affairs' Legislation Committee's Inquiry into the National Disability Insurance Scheme Bill (2012). Alliance staff made an opening statement and answered a number of questions from the Committee members. The purpose of our appearance before the Hearing was to further promote the Alliance's position in regard to people living with disability in rural and remote areas, and to answer any questions which may have arisen from our Senate Submission.

A copy of the opening statement to the public hearing is included as Attachment D.

Submission on the NDIS Rules

On 26 March 2013, in response to a call from FaHCSIA for submissions on the proposed NDIS Rules, the NRHA submitted a paper containing a number of recommendations about the proposed rules. These recommendations were informed by our consultations with our network of interested stakeholders. The common theme of our suggested changes to the proposed rules was for increased flexibility to ensure that the disadvantages for people living with a disability in rural and remote areas were not inadvertently exacerbated by over-prescription in the Rules.

The Alliance responded to the draft operational rules for the scheme about some of the practicalities for people living with disability in rural and remote communities with some key recommendations. These are fully listed in the submission at Attachment E.

Papers presented at the 12thNational Rural Health Conference

The 12th National Rural Health Conference was held in Adelaide early in April 2013. This Conference brought together over one thousand people from rural and remote Australia. They comprised rural health professionals, rural residents, health consumers, people with lived experience of disability, and representatives of health organisations. The Conference was an opportunity for the National Rural Health Alliance to include a disability ‘stream’ in the program, which was made all the more topical and relevant due to the imminent commencement of the NDIS and the implications that will follow for rural health professionals. The Alliance presented one of the five papers in this stream and it is included as Attachment F.

The presentation of this paper preceded an NDIS workshop co-convened with the National Disability and Carer Alliance. The Conference also heard Dougie Herd give a keynote address on behalf of the NDIS Launch Transition Agency.

NDIS Project Reference Group

The NDIS Project Reference Group is a group of individuals from all over Australia with a common interest in equity for people living with disability in rural and remote areas.

The group includes:

- representatives of the NRHA Council;
- a representative of National Disability and Carer Alliance;
- people having lived experience with a disability in rural and remote areas, or as a carer of a person with disability;
- representation of relevant Indigenous issues; and
- the NRHA Executive Director.

The role of the Project Reference Group was to inform and support the PDF project by bringing together some key stakeholders to advise on approaches, principles and practical solutions to enhance the implementation of DisabilityCare Australia in rural and remote areas.

The Project Reference Group:

- provided direct links with the disability sector;

- provided advice to the Alliance on issues pertinent to the long term delivery of DisabilityCare in rural and remote Australia;
- engaged in frank discussion of relevant issues and strategies; and
- provided advice on specific matters referred to it, such as development of papers for broader consultation.

Three teleconferences were held during February and March with members of the Project Reference Group. The discussions were very valuable in terms of the information that was provided and the recommendations that resulted. The major recommendations from these discussions are included in the recommendations in this report.

A list of the members of the Project Reference Group is at Attachment G.

Collaboration with NDCA on a web survey and Roundtable

The NRHA collaborated with the National Disability and Carer Alliance (NDCA) to investigate issues relating to people living with disability in rural and remote areas.

Initially an interactive 'Delphi' survey was placed on the Internet and a selected group of people were sent links and invited to respond. This group included the NDIS Project Reference Group, all members of the NRHA Council, and Friends of the Alliance. The purpose of the survey was to establish the issues considered most important for successful delivery of DisabilityCare Australia in rural and remote areas.

The questions included in this survey are in Attachment H.

In all, there were 133 responses to the survey and from these responses a list of the most commonly mentioned issues was drawn up and presented for feedback in a well-attended session at the National Rural Health Conference.

A workshop was held in Canberra to further refine the issues of importance and on 29 April 2013 the Roundtable was held at Parliament House to discuss the findings and to agree upon a set of recommendations to present to Government.

There were about 40 delegates to the Roundtable. They comprised people from a wide range of regions across Australia with a strong representation of rural and remote areas. The delegates included:

- health, allied health and nursing professionals;
- academics with a background in rural/remote disability issues;
- people with lived experience of disability in rural and remote areas;
- carers of people with disability living in rural and remote areas;
- Aboriginal people; and
- representatives of disability support and advocacy organisations.

The final report of the Roundtable Conference contained 15 recommendations. The discussions at the Roundtable Conference provided the NRHA with further insight to advance its development of the recommendations in this report. The report on the Roundtable is in Attachment I.

Themes that emerged in the Project

Compounding of disability problems by level of remoteness

The disadvantages experienced by people living with disability and their families and carers are compounded by living in rural or remote areas. DisabilityCare Australia should be cognisant of this fact when implementing the scheme.

Need for flexibility in rules and provision of support

DisabilityCare Australia should be very flexible in its approach and in the formulation of the rules that are applied when dealing with people with disability, their families and carers, particularly when they are located in rural or remote areas.

When developing support packages for people with disability, DisabilityCare Australia must recognise the key role of families, carers and informal support networks. Support packages must be flexible enough to provide assistance to improve the resilience of families in the face of the unrelenting pressures of caring for a person with disability.

A ‘one size fits all’ policy for implementing the NDIS transition in rural and remote areas should be rejected and the particular needs of different regions across Australia should be paramount.

Transport issues

Transportation is constantly mentioned in relation to the burdens which living in a rural and remote area impose on people with disability. This problem takes many forms, for example:

- transport to attend appointments with health professionals and the cost and time expended when large distances are involved;
- transport within communities where paths and roads are unsuitable for wheelchairs (which relates to lack of suitable access for people with disability, in general);
- the cost and challenges faced by families and carers of people with disability when it is necessary to travel to capital cities or major centres for consultations relating to health, education, disability services and other sectors, particularly if care of siblings is a factor; and
- the transport problems for support providers and medical and allied health professionals who are trying to deliver services in remote regions.

Promoting awareness of DisabilityCare Australia

There is less awareness of disability in rural and remote areas than in metropolitan areas and it is likely that a smaller proportion of those in need have been getting appropriate services. Special efforts will therefore need to be made to promote awareness of DisabilityCare Australia in rural areas to ensure its uptake by all people who are eligible.

Collaboration between health, disability and aged care sectors

Due to the scarcity of resources, in rural and remote areas there are not separate health, disability and aged care sectors. The 'shuffling' of people between agencies was repeatedly mentioned as a problem to be avoided and, given strong will and good organisation, it may indeed be easier to achieve close collaboration between the three in rural areas than in big cities.

The NDIS Transition Agency should promote close collaboration between health, aged care and disability service providers in rural and remote Australia in order to maximise the availability and effectiveness of care in those areas.

DisabilityCare Australia should take steps to establish collaborative partnerships with agencies dealing with health, children's services, disability and other human services and aged care so that integrated service responses can be developed for people of all ages with disability and complex other needs.

The capacity of the disability workforce in rural and remote areas

Determined efforts should be made to overcome the shortages in rural and remote areas of professionals required for disability care. Action to remedy this situation should include broadening the training opportunities available to health professionals (especially in allied health), disability support workers, and locals who can provide non-professional support; consolidation of part-time health positions to full-time; and increased availability of allied health therapy and counselling services.

Some of the additional health professionals who will need to be recruited to rural and remote areas and existing local professionals whose scope of practice might increase will need additional training and support. The NDIS Transition Agency should set up collaborative arrangements with University Departments of Rural Health and other education providers to help provide such training.

Indigenous agencies' advocacy on disability

The NDIS Transition Agency should continue to liaise closely with lead Indigenous disability and health organisations in order to maximise the effectiveness of the scheme within Aboriginal and Torres Strait Islander communities.

The First Peoples Disability Network has a pre-eminent role in developing recommendations for remote Indigenous communities where people are living with disability. The National Rural Health Alliance and the National Disability and Carer Alliance support that Network in its recommendations for the rural and remote roll out of DisabilityCare Australia.

Project recommendations

The purpose of the project was to develop practical recommendations to ensure that DisabilityCare Australia is implemented in a way that is equitable for all Australians with disability, irrespective of whether they live in rural and remote or metropolitan areas.

For those who have been closely and directly involved in the Alliance's PDF project the key concerns include the human rights approach, genuine consultation with those in rural and remote areas who are affected, access and connectedness, quality of service, and continuity and viability of service.

The critical themes in the recommendations can be summarised as follows.

- To ensure improved access for people living in rural and remote areas, and timely, appropriate and good quality care, there need to be mechanisms to enable DisabilityCare Australia to engage local people and services which may not be formally accredited as disability service providers, to enable them to provide a range of appropriate support.

- To ensure 'appropriate cultural access', there must be a requirement that DisabilityCare Australia delivers services and support in a culturally sensitive manner through its communications, publications, and consultation processes. (This is particularly emphasised in relation to Aboriginal and Torres Strait Islander people, who comprise a significant part of the rural and remote population.)

- To ensure that people living with disability in rural and remote areas receive equitable support under DisabilityCare Australia, there needs to be explicit acknowledgement within the rules of the higher costs associated with providing disability support in rural and remote areas. The rules should state that there will be sufficient flexibility to allow for the level of support to be determined, in part, by the remoteness of the place in which the participants live, so that there are no inequities caused by those greater costs.

Detailed recommendations

1. Human rights approach by DisabilityCare Australia

A human rights approach to disability states that:

- all human beings are equal and have rights that should be respected without distinction of any kind;
- people with disabilities are citizens and, as such, have the same rights as those without impairments; and
- all actions to support people with disabilities should be 'rights based'; for example, the demand for equal access to services and opportunities as a human right.

In all of our discussions it was unanimously agreed that the human rights model of disability is the approach most likely to result in equitable outcomes for people with disability irrespective of their location.

It is recommended that a human rights approach be consistently applied during the implementation and the ongoing application of DisabilityCare Australia.

2. Address lack of expectations of disability support

In rural and remote areas of Australia the historical scarcity of support for disability has led to a lack of expectation of support among both Indigenous and non-Indigenous people.

It is recommended that this lack of expectation be addressed by DisabilityCare Australia providing appropriately targeted publicity and education, so that people in rural and remote areas are given the same expectations for disability support as people elsewhere in Australia.

3. Address how information is provided and the scheme is delivered

It is recommended that for DisabilityCare Australia to be implemented successfully in rural and remote areas, information about the scheme must be provided to everyone who needs it in a comprehensive, simple, clear and culturally respectful manner. Interpreters may be needed to explain the NDIS to people in communities where English is not the first language.

It is recommended that the support of rural and remote communities be obtained in locating people with disability who may not have received support in the past. Information about DisabilityCare Australia, particularly on how to navigate the system, should be provided very clearly and through a variety of media. Simply producing printed brochures, for example, would be unlikely to reach the target audience in most rural and remote communities.

In delivering the scheme the emphasis should be on simplicity, a seamless service for clients wherever they live - one without barriers between various agencies and services - and one that considers the needs of families and carers as well as of the person with disability.

4. *Social inclusion of people with disability*

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.

It is recommended that DisabilityCare Australia facilitate the provision of relevant training and other assistance such as mentoring, to assist people with disability into employment or to start their own businesses.

5. *Culturally appropriate delivery of DisabilityCare Australia*

Culturally appropriate delivery of DisabilityCare Australia and of information about it is essential for it to succeed in Aboriginal and Torres Strait Islander communities. This includes the provision of interpreters to explain DisabilityCare Australia to people in remote communities where English is not the first language.

The First Peoples Disability Network (FPDN) has a pre-eminent role in developing recommendations for remote Indigenous communities where people are living with disability. The National Rural Health Alliance supports the FPDN in its recommendations for the rural and remote roll out of DisabilityCare Australia.

It is recommended that DisabilityCare Australia should recognise the pre-eminent role of the FPDN in its role of advocating for Aboriginal and Torres Strait Islander people living with disability.

6. *Early intervention*

Early intervention is typically seen as a service response for children. However the principle of early clinical intervention can equally be relevant to adults with disability and, if provided in a timely manner, will minimise the likelihood of further clinical decline, and subsequent need for other support services required if the intervention had not been provided.

It is recommended that early intervention should be supported by and considered as a fundamental in the services offered by DisabilityCare Australia.

7. The emotional wellbeing of families

An important aspect of the work of DisabilityCare Australia should be consideration of the emotional wellbeing of families, particularly family-based carers, as well as the needs of the person living with a disability. An approach that does not consider the potential effect on other family members such as siblings would not be appropriate.

8. Support for assistive technology

In some circumstances assistive technologies can play a major role in improving quality of life for people living with disability and their carers. An example might be where a person's participation plan included the purchase of an iPad (or similar device) to help open up that person's opportunities for communications and participation in the community.

It is recommended that the provision of assistive technology and devices be included in the scope of services provided through DisabilityCare Australia.

9. Collaboration between health, aged care and disability sectors

Following their discharge, people who have received in-patient hospital services for a pre-existing disability or following a serious injury are likely to be eligible for support from Disability Care Australia. Depending on their age and care needs, they might also be referred to aged care services.

In such cases a person with a disability can be considered to be on a pathway that traverses all three service sectors. In rural and remote areas, the boundaries between these sectors are less defined, with services being provided by whoever is local and has relevant skills.

It is recommended that there be a high level commitment to improve collaboration between health, disability and aged care sectors to maximise opportunities for the integrated care, rehabilitation and support of people who are moving between these systems with high and complex care needs.

10. Training of allied health professionals and the multi-disciplinary model

A wide range of allied health professionals (AHPs) is needed to deliver equitable services to people living with disability in rural and remote areas, but these services are scarce in those areas. More work is urgently needed to recruit and retain AHPs in rural and remote areas. Such professionals who will be practising in rural and remote areas should have multi-disciplinary training and skills.

Another solution to the workforce challenge is the training of locals (including families) to provide non-professional support to people living with a disability. The family member will need ongoing support, perhaps provided at a distance. This strategy would need to be evaluated regularly to ensure that the service required by the client is matched by the capacity of the support person: for example,whether a person's spouse is able to successfully supervise a physical exercise program.

11. Affordability of services and of assistive technology

The human rights model dictum that every person has a right to be treated equally should be paramount when proposed support packages are evaluated by

DisabilityCare Australia, so that locality is not a consideration in the level of support delivered.

The higher cost of delivering disability support and of providing assistive technology in rural and remote areas should be recognised and provision made for it by providing proportionally greater funding.

12. A flexible approach to administration of DisabilityCare Australia

In numerous discussions with people living with a disability, carers and family members, the call for a flexible approach to delivering disability care was raised. The need for flexibility was seen as being especially important in rural and remote areas due to the scarcity of local resources - especially of a more specialised kind.

The need for flexibility should be recognised by changing the proposed NDIS Rules to enable people living with disability in rural and remote areas to receive care from local people or services that are able to provide timely, appropriate and good quality care, although they may not be accredited disability services, even when the person's funding is managed by the NDIS Agency. The rationale for this is that in rural and remote areas there may be many people capable and willing to provide informal paid disability support, but who due to the part-time nature of the work, do not wish to become registered support providers with DisabilityCare Australia.

13. Limit the use of fly-in, fly-out and drive-in, drive-out for service delivery

Due to the lack of local service capacity in rural and remote areas, it may well be proposed that disability services be provided using a fly-in, fly-out (FIFO) or drive-in, drive-out (DIDO) model. This may be necessary when highly skilled professionals are needed to perform assessments or set up programs that can be supervised by others. However, for regular support services where a high degree of trust is needed between the support recipient and the provider, the model is not suitable.

People with disability and their carers have reported having to deal with a succession of providers who come in for a short time and then leave, often not to return. This leads to fragmented and inconsistent support, with very little trust or rapport emerging. It is therefore inconsistent with the human rights approach which emphasises equity in outcomes irrespective of location.

It is recommended that delivery of disability support using a FIFO or DIDO model be limited to where it is completely appropriate or absolutely unavoidable, such as in accessing health professionals who do not need to deliver services to the same client on a regular basis. Effective coordination with ongoing local providers must be part of the arrangements.

14. Extending Second Year Australian Working Holiday Visa Scheme

The Second Year Australian Working Holiday Visa Scheme enables people who are already on working visas and who are prepared to undertake specific types of employment in rural or remote areas for a set period, to apply for a second 12 month working visa if they wish to remain in Australia for a longer time. At present the types of work that people may engage in to become eligible for the scheme include farm work and some types of work in forestry and mining.

It is recommended that DisabilityCare Australia investigates the feasibility of extending the Scheme to include appropriate work supporting people living with a disability and their families and carers, particularly in rural and remote areas.

Case Study

During our consultations with various stakeholders, the NRHA was provided with a number of case studies which illustrate the additional problems faced by people living with disability in rural and remote areas.

This particular case study is given as an example since it describes the experience of an Aboriginal health worker who has a child with disability, and it vividly illustrates typical problems encountered by people from rural and remote areas.

> *In 2002 at 12 months of age her son was diagnosed with autism and dyslexia. She had tried putting her son into main stream childcare for around 3 months, but after receiving numerous phone calls and having to leave work early on numerous occasions to attend to her child, felt they lacked the qualified staff to cope with children with disabilities. She found that as an Aboriginal parent of a child with disabilities it was hard to get help both mentally and physically as many professionals put it down to a behaviour issue.*
>
> *She suggested that a full-time support centre set up for parents with disabled children would help provide a place to gain help and support around developmental needs, pre-school and education needs. She would also like to see the placement in schools of specially trained staff who can advocate for and support students with disabilities.*
>
> *She expressed her frustrations regarding the education system's assessment process for children with a disability, with children having to wait anything up to 2 years to get a disability assessment.*
>
> *Some childcare centres decided that her son was too high maintenance to continue in their system.*
>
> *Because she and her husband worked full-time they were not eligible for any help from the Government and therefore had to pay out for Speech Therapy sessions, Physiotherapy sessions, eye checks and glasses and ongoing monthly medications which caused financial strain.*
>
> *She spoke of the feelings of isolation and difficulties as an Aboriginal family trying to deal with a child with a disability.*
>
> *She spoke of her experiences trying to obtain dental work for her child which usually required him having surgery in Adelaide which is not covered by Government funding or the Patient Assisted Travel Scheme. She spoke of the costs of obtaining overnight accommodation at the Women's and Children's Hospital and that they usually only allow 2 Parents and 1 extra child to stay in the Hospital overnight wing, which is not conducive for larger Aboriginal families. Should a child need to go to Adelaide for Orthopaedics or Ear Nose and Throat (ENT) issues the RAH and*

> *Women's and Children's Hospital's do not approve accommodation for Out-Patient Appointments.*
>
> *This can be difficult for families who don't have access to a car and rely on public transport. The Port Augusta Hospital Medical Bus does not take children under 5 years to Adelaide for an appointment.*
>
> *Due to these issues many children from Leigh Creek, Copley, Marree, and Nepabunna can go years before they have a dental or an ENT consultation which then impacts further on ongoing treatment and medications for ENT issues and can lead to further hearing, eye and dental Issues.*
>
> *She feels that it is important for the government to take into consideration the financial, mental and physical strain that parents of children with a disability face on a daily basis.*
>
> *She also suggestedthat a Mobile Child Health Medical Bus like the Rainbow Bus in Port Pirie could visit outback towns on a regular basis (6 to 12 monthly - max) alternating from Port Augusta to Marree and Port Augusta to Coober Pedy.*

Prominent amongst the issues brought out by this case study are:

- the additional burden on families having a child with disability associated with being located in a rural or remote area;
- the lack of appropriately qualified support providers in rural and remote areas;
- the need for flexibility by health professionals, organisations and support providers when delivering support for people with disability from rural and remote areas; and
- the problems caused by lack of appropriate transport in rural and remote areas.

Appendix

Attachment A. Member bodies of the National Rural Health Alliance

Attachment B. National Rural Health Alliance, *Written submission to Senate Inquiry on the National Disability Insurance Scheme (NDIS) Bill 201,* 1 February 2013

Attachment C. National Rural Health Alliance, *Discussion Paper on issues relating to the NDIS in rural and remote areas of Australia,* 21 February 2013

Attachment D. National Rural Health Alliance, *Opening statement presented to Senate Inquiry on the National Disability Insurance Scheme (NDIS) Bill 2012,* 5 March 2013

Attachment E. National Rural Health Alliance *Submission to FaHCSIA on proposed NDIS Rules,* 26 March 2013

Attachment F. National Rural Health Alliance, *Shaping the National Disability Insurance Scheme for Rural Areas* Paper presented at National Rural Health Conference, 9 April 2013

Attachment G. Practical Design Fund Project Reference Group membership list

Attachment H. Delphi Survey questionnaire instrument

Attachment I. National Rural Health Alliance, and National Disability and Carer Alliance - *Final Report of Roundtable Conference,* Canberra, 29 April 2013

Attachment A

Member Bodies of the National Rural Health Alliance

ACHSM	Australasian College of Health Service Management
ACN (RNMF)	Australian College of Nursing (Rural Nursing and Midwifery Faculty)
ACRRM	Australian College of Rural and Remote Medicine
AGPN	Australian General Practice Network
AHHA	Australian Healthcare and Hospitals Association
AHPARR	Allied HealthProfessions Australia Rural and Remote
AIDA	Australian Indigenous Doctors' Association
ANF	Australian Nursing Federation (rural members)
APA (RMN)	Australian Physiotherapy Association Rural Member Network
APS	Australian Paediatric Society
APS (RRPIG)	Australian Psychological Society (Rural and Remote Psychological Interest Group)
ARHEN	Australian Rural Health Education Network Limited
CAA (RRG)	Council of Ambulance Authorities (Rural and Remote Group)
CHA	Catholic Health Australia (rural members)
CRANAplus	CRANAplus – the professional body for all remote health
CWAA	Country Women's Association of Australia
ESSA (NRRC)	Exercise and Sports Science Australia (National Rural and Remote Committee)
FS	Frontier Services of the Uniting Church in Australia
HCRRA	Health Consumers of Rural and Remote Australia
ICPA	Isolated Children's Parents' Association
NACCHO	National Aboriginal Community Controlled Health Organisation
NRF of RACGP	National Rural Faculty of the Royal Australian College of General Practitioners
NRHSN	National Rural Health Students' Network
PA (RRSIG)	Paramedics Australasia (Rural and Remote Special Interest Group)
PSA (RSIG)	Rural Special Interest Group of the Pharmaceutical Society of Australia
RDAA	Rural Doctors Association of Australia
RDN of ADA	Rural Dentists' Network of the Australian Dental Association
RHW	Rural Health Workforce
RFDS	Royal Flying Doctor Service
RHEF	Rural Health Education Foundation
RIHG of CAA	Rural Indigenous and Health-interest Group of the Chiropractors' Association of Australia
ROG of OAA	Rural Optometry Group of the Australian Optometrists Association
RPA	Rural Pharmacists Australia
SARRAH	Services for Australian Rural and Remote Allied Health

Attachment B

NATIONAL RURAL HEALTH ALLIANCE INC.

ABN: 68 480 848 412

National Rural Health Conference
Australian Journal of Rural Health

PO Box 280 Deakin West ACT 2600
Phone: (02) 6285 4660 • **Fax:** (02) 6285 4670
Web: www.ruralhealth.org.au• **Email:** nrha@ruralhealth.org.au

Submission to Senate Inquiry on the National Disability Insurance Scheme (NDIS) Bill 2012

1 February 2013

This Submission is based on the views of the National Rural Health Alliance but may not reflect the full or particular views of all of its Member Bodies.

Submission to Senate Inquiry on the NDIS Bill 2012

About NRHA

The National Rural Health Alliance is made up of 34 member bodies, each a national body in its own right, representing rural and remote health professionals, service providers, consumers, educators, researchers and Indigenous health interests(see Attachment). The vision of the National Rural Health Alliance is good health and wellbeing in rural and remote Australia, with the particular goal of equal health for all Australians by 2020.

Introduction

The Alliance welcomes the opportunity to comment on the National Disability Insurance Scheme Bill 2012. We note that the Bill reflects a national approach, and as such makes no specific reference to the operation of NDIS in rural and remote settings. Our submission broadly reflects a belief that the needs of people with a disability, their carers and service providers in rural and remote Australia will have specific characteristics, and as such warrant a targeted and flexible approach to make the NDIS 'fit for purpose' in rural and remote areas.

About seven million people or 32 percent of the total Australian population live outside what the ASGC-RA classification system defines as Major Cities. On average, these people have lower levels of education, lower incomes and their health risk profiles are worse than people in the major cities. When they are unwell or have sudden health events, there are fewer specialised health services available locally.

Some 70 percent of Australia's Aboriginal and Torres Strait Islander people live outside metropolitan areas and they make up a substantial proportion of the population in rural and especially remote areas. As is well known, on average their health outcomes are substantially poorer than those of other Australians.

The Alliance takes a broad view of health and has a strong interest in the wellbeing of everyone in rural and remote areas, including those who live with a disability. Because there are fewer specialised services in rural areas, local health and aged care services and health professionals are likely to be key contacts for people with disabilities. Many people in our networks are directly involved in disability -as individuals, carers, health educators or researchers. The Alliance therefore promotes an integrated approach to disability, health and aged care.

Our networks and member bodies have highlighted the parlous circumstances which currently confront many people with a disability in rural and remote areas. It is the unevenness and unfairness of the current situation which makes the successful development of the National Disability Insurance Scheme so vital for rural and remote Australia. For example:

- Consumers and carers express concerns about where to turn for specific support and education around the needs of children with disabilities.
- Transport for health care is a particular challenge for many people with disabilities in rural or remote areas, where public or specialised transport is less readily available. Transport issues extend beyond health care to daily living and social needs.
- Health professionals know that parents caring for a son or daughter with a disability worry about how their child will be cared for when the parent ages and becomes infirm.

- In the absence of more appropriate options, young people with high personal care needs are not infrequently stuck in a nursing home.

- Even though they are in short supply in rural and remote areas, allied health professionals play a major part in maintaining the wellbeing and independence of people with long term disabilities, including those resulting from chronic conditions. The demand can be compounded where there is little or no appropriate rehabilitation for example, following stroke, brain injury trauma, or long-term alcohol overuse.

The Alliance is keen to ensure that the NDIS is designed in such a way that services are not just an entitlement but a realityfor people with a disability who live in rural and remote areas.

Optimising the NDIS in rural and remote areas

The Productivity Commission Report, *Disability Care and Support*, released on 10 August 2011, asserted that disability care and support in Australia was "underfunded, unfair, fragmented and inefficient". The report stated that the current provision of support is fragmented and inconsistent across Australia, and that these problems are compounded for people with a disability who live in rural and remote areas. For this reason it is vital that the NDIS Launch Transition Agency carefully considers the practicalities of how it works with people with disabilities in rural and remote communities and with service providers and other organisations.

For example, during the transition to the NDIS, participant plans will need to be developed for existing clients of disability services. However, in country areas it may well be that there are people who do not access disability services at present, due to a longstanding lack of availability of information about the services that are available, or the knowledge that there are not any services locally. The Agency will need to be cognisant of these people and provide them with opportunities to become participants in the NDIS. This may require extra targeted publicity for the scheme in rural and remote areas to ensure that people become aware of its opportunities.

The Agency should take every opportunity to work with local resources in rural and remote areas to ensure that people who are entitled to participate in the NDIS are firstly identified, and then supported to obtain their participant's plans in a timely and efficient manner.

Transitioning to the NDIS in rural and remote areas should include the identification of local resources such as people and professional groups that are already aware of the particular needs and care shortcomings in the region. The advice offered by these resources should be carefully considered in relation to the NDIS transition.

The provision of financial advice and counselling support has been an important part of responses to environmental disasters. Various strategies have been used to meet this need, such as the 'drought bus' and many others. These ideas might be transferable to the introduction of the NDIS to help people with disabilities and their carers make choices about managing the funding for disability supports.

Recommendations:

- The NDIS Transition Agency should, as a general policy, actively seek and carefully consider suggestions from appropriate resources such as people and professional bodies with expertise in disability services and issues in rural and remote areas.

- The NDIS Transition Agency should seek innovative ways to meet the special needs of people with disabilities in rural and remote areas. Strategies that have worked in other or similar contexts may be found to be applicable and should be considered.
- A 'one size fits all' policy for implementing the NDIS transition in rural and remote areas should be rejected and the particular needs of different regions across Australia should be paramount in consideration.

New models of care

There may be very good opportunities for unmet needs in rural and remote Australia to be addressed, as the NDIS brings a statutory insurance funding commitment for eligible participants, rather than a service availability approach.

The experience of the National Rural Health Alliance networks with flexible funding arrangements such as Multi-Purpose Services, specialist outreach programs and other approaches to make the best use of the health professionals and services available locally may help to inform the development of effective rural models for the NDIS.

The aim of the NDIS to assure "reasonable and necessary funded supports" may provide the opportunity to apply innovative ways of providing personal care packages for the person with the disability, such as a funding source for local people to provide some aspects of care, or for a scheme similar to the live-in carers programs that exist in the UK.[4]

Particularly in rural and remote areas, people living with a disability may be disadvantaged when it comes to obtaining necessary care and services due to lack of transport. Under the NDIS it may be possible to fund improved transport arrangements locally or within a region to better serve people who live with a disability.

Similarly, in rural and remote areas, people living with a disability may find it difficult or impossible to participatein community or regular social activities. Local means for involving people with disabilities in community and social activities, such as help with transport or through a drop-in centre,could be further developed.

The NDIS Transition Agency may be able to establish or fostercollaborative relationships involving Medicare Locals, Local Health Networks,and other local services such as aged care, disability services and paramedics. Its work should also be seen as a major new opportunity for better coordination of care involving multidisciplinary teams, and improved access to mental health care and after hours care.

The NDIS Practical Design Fund project being conducted by the National Rural Health Alliance from December 2012 to April 2013 will provide important initial input on some of these questions (see page 7).

Recommendations:

- The NDIS Transition Agency should seek ongoing engagement with rural and remote health care providers and broader National Rural Health Alliance networks to gain an understanding of the needs in rural and remote areas that are currently not being met. The cost of delivering the NDIS in rural and remote areas may be reduced by finding innovative ways to provide

---

[4] For example, information about Able Community Care's Live in Carer Service for Elderly or Disabled Adults in the UK was sent to the Alliance in response to a *Partyline* article about the NDIS. http://www.uk-care.com/

personal care packages for people living with a disability and by utilising the knowledge and expertise of locally based health care service providers.

- The NDIS Transition Agency should consider transportation problems and resulting isolation experienced by people living with a disability in rural and remote areas as a fundamental problem to be alleviated.
- The NDIS Transition Agency should endeavour to establish cooperative relationships with Medicare Locals, Local Health Networks, and other local services such as aged care, disability services and paramedics.

New approaches to building health workforce and service capacity

Allied health staffare likely to be significantly involved in the assessment and local delivery of services funded by NDIS, but the recruitment and retention of allied health professionals to rural areas is already a major challenge. The NDIS may provide opportunities to develop new programs developing allied health service capacity in rural areas.

When people with a disability who live in rural and remote areas are assessed for participation in the NDIS, the needs discovered by these assessments may provide the opportunity to create more sustainable private practices or to justify public appointments for allied health professionals.

Services designed around the needs of the person living with disability, rather than the availability of service providers,could encourage not for profit service providers to expand in and to rural and remote areas.

In addition, the increased demand for timely assessment and planning, especially during the launch stages, may help to justify public employment of additional allied health workers or to extend existing part-time positions.

Recommendation:

- The NDIS Transition Agency should seek to collaborate with Health Workforce Australia, Commonwealth and State and Territory Health Departments to foster the recruitment and retention of health professionals needed in rural and remote areas to help ensure equitable access to disability services.

Rural and regional educational opportunities

The demand for local training of allied health professionals through University Departments of Rural Health may increase. The UDRHs may also be able to engage through service learning and clinical placements in building capacity to provide needed services for people with disabilities. It has been suggested that academic coordinators, by working with local health professionals who may be too stretched to take on teaching responsibilities alone, may help to facilitate this approach. Expectations of higher education and effective social networks for people with disabilities living in rural and remote communities may also increase with the focus on goals and aspirations.

Recommendation:

- The NDIS Transition Agency should set up collaborative arrangements with University Departments of Rural Health and other education providers to provide the training needed by additional health professionals located in rural and remote areas.

Communications and infrastructure

NDIS is also likely to increase the need for good communications and information technology solutions to keep track of the services being provided, the wellbeing of the clients and links between people living with disabilities and their carers and wider networks. Tablets and mobile phones are already part of the equipment for some community aged care providers on outreach visits from regional centres to ensure that all care needs are met within the visit. Tele-monitoring for veterans with chronic conditions is part of NBN trial sites.[5]

The NDIS may present another focus for ensuring that the NBN and the technological solutions it supports are accessible in rural and remote locations.The work of the NDIS should be informed by the view that technological solutions are complementary to but do not replace face-to-face care and interactions.

Established rural health professional and other networks have been instrumental in supporting the implementation of technical innovations such as the implementation of the MBS items for telehealth. These include theAustralian College of Rural and Remote Medicine (ACRRM), Rural Doctors Association of Australia (RDAA) andMedical Specialist Outreach Assistance Program support officers, CRANA Plus, the Royal Australian College of General Practitioner (RACGP), and other professional nursing and allied health bodies.

Medicare Locals are currently involved in supporting the roll out of eHealth records through the Practice Incentive Program.

Recommendation:

- The Agency should be cognisant of opportunities to support the utilisation of technological innovations, in particular the opportunities offered by the NBN, to enhance the delivery of services to people with a disability who live in rural and remote areas.

Rural and remote consultation opportunities

NDIS launch sites

In discussions with stakeholders, it seems that the launch sites will provide opportunities for testing new service models for rural and remote areas.

The launch sites will also help to identify the variations in cost forproviding services for people who live outside the regional centres. At present, viability supplements to aged care services are in place to partly address the higher costs of maintaining the service due to greater distances, higher staff costs, higher transport and running costs and smaller, fluctuating numbers. With the NDIS approach to funding around the person's needs, the highercosts of providing services may need to be addressed in a different way.

It will also be important to ensure a seamless transition from launch site to the NDIS to avoid any loss of capacity or personnel developed to provide the services during the launch phase.

National Disability Insurance Scheme website and 'Have Your Say' portal

The Alliance is concerned that engagement and feedback received through the 'Have Your Say' portal maynot adequately reflect specific rural and remote issues. We believe that there are further opportunities to do this by having a rural and remote 'Have Your Say' portal. The Alliance has indicated its willingness to assist in the development of its content, and to actively promote this opportunity to people living in rural and remote Australia

---

[5] Australian Government Department of Broadband, Communications and the Digital Economy.In home telemonitoring for veterans.http://www.nbn.gov.au/nbn-benefits/health-and-aged-care/government-initiatives/telemonitoring-for-veterans/

Recommendations:

- The Transition Authority should develop and maintain opportunities for specific rural and remote feedback on the design, operation and review of the scheme.
- That an NDIS Rural and Remote Working Group be established to advise and inform the NDIS on the ongoing challenges and practical solutions for the delivery of the scheme in rural and remote areas.
- That there is close and formative evaluation of the effectiveness of the scheme in the rural and remote parts of the five launch transition sites; and that this evaluation helps to inform the further roll out of the scheme.

FaHCSIA NDIS Practical Design Project 2013

The Alliance has recently been funded by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) to consult with its networks on the best way toconnect and deliver equity of access to services for people with disabilities living in rural, regional and remote areas. The study will identify some of the challenges facing people in those areas, and their carersand service providers. It will seek practical solutions to enable the scheme to be effective in those areas.

Issues raised in these consultations to date include the following.

- “There must be a concerted publicity effort to ensure that service providers are knowledgeable about the NDIS and are able to inform their clients. A major issue in rural areasis that people are unaware of what is available to them, or have given up trying to access services which they would be in theory eligible to obtain. This can lead over time to enormous stress for family carers trying to manage by themselves, recourse to permanent institutional care away from home, or even premature and preventable death. People in such situations are sometimes cared for by their families until they require hospitalisation or institutionalisation, at great distances from their place of abode and away from their families. This model of health care is very expensive and disempowering. The expansion of community based primary health care services, including disability services within primary health care, and publicising of what services are available could actually save money by reducing hospitalisation.”

- “It is expected that the service model for rural and remote areas will require a non-market approach, given the poor prospects of viability in areas of low population and isolation. This would therefore deter privately provided services, and as a result the only services available (if any) would be government services or government funded NGOs.”

- “In rural areas where disability services do already exist, they may be improved by the implementation of the NDIS. However in some areas no such services currently exist. The NDIS Transition Agency should be aware of this problem and find ways to ensure that basic access to disability services (and other necessary health care services) is as much a consideration as improvements to existing services in rural and remote areas.”

- “Health care providers may be key to delivering aspects of the NDIS in rural and remote areas, but some form of monitoring will be necessary to prevent possible rorting of the system by a minority.”

- “Having relatives as carers, which may well be the only available option for some people, can be interpersonally difficult and disempowering to both parties. This is a subset of the important issue of monitoring the suitability of carers.”

- “Perhaps surprisingly, there are still issues associated with access to buildings in rural and remote areas for people living with a disability. Many buildings in these areas are relatively old and less likely to have had access ramps added.”

- “The NDIS should be inclusive and focussed on skills required rather than prescriptive of qualifications for health professionals. This is particularly relevant in rural and remote areas where, for example, a person with a disability may have access to an Exercise Physiologist, but not an Occupational Therapist or vice versa. While most health professionals have particular strengths, there is a great overlap in many of the skills of different health professions and health professionals have capacity for further professional development in specific areas to meet a local need.”

- “It is unfortunate when health professionals are unable to provide a service in a rural and remote area because of prescriptive regulations. This often means the client has to incur greater travel costs or is unable to participate. It also exaggerates the problem of health professional retention, recruitment and workforce shortages.”

- ”It is important to ensure that the case managers/assessors working within the NDIS Transition Agency manage and develop participant plans that are fully cognisant of the services available within an area. NRHA believes that it is important to ensure that services provided to a participant in a rural or remote region are equal to what participants in a major city would experience. It would be infeasible for the Transition Agency to place a case manager in all rural and remote locations; however, the Agency could contract local health care providers or suitably skilled workers to provide assistance in developing and reviewing participant plans. This would ensure that the participant receives advice from a person with sound local knowledge of services available.”

- “Communication between health providers is essential for continuity of care. The eHealth initiative should be considered as an approach to minimising the inconvenience to clients of continually having to provide the same information to health care and disability service providers.”

- “It is imperative that ‘case managers’ are educated on all health services available to ensure optimal treatment referral pathways. Consideration should be given to creating a central registration site for health providers to provide their details, practice information and information about areas they service, particularly rural and remote areas.”

- “Will the NDIS launch sites be representative of rural and remote regions around Australia? For example, will approaches used to ensure equitable access to services/support in rural South Australia be able to be replicated in remote regions of Queensland or the Northern Territory? If not, what steps are being taken to ensure that remote regions of Australia receive equal access and services?”

- “The NDIS Transition Agency should consider how to enable people who don’t work in the disability sector, but who have skills that may aid a person with a disability, to have the opportunity to become providers of services.”

- "The NDIS Transition Agency should be aware of the importance of supported employment and strategies to improve inclusive work places: for example, tax concessions for those businesses which provide employment for those with disabilities. So many positive outcomes result from having a paid job especially in terms of emotional and mental health. Where disability plans are being developed they should include an employment component."

Other comments received include the following:

On Aboriginal and Torres Strait Islander people living with a disability

- "The overwhelming problem for Indigenous people living with a disability is availability of culturally appropriate and effective facilities. The NGOs may have the funds for care at some local facilities, but none for infrastructure."
- "The lack of compatibility amongst the different groups results in these people having individualised needs. Often the outcome is for them needing to be housed in the public hospitalsystem, due to lack of funds or the will to provide suitable housing."
- "The number of second and third generation Foetal Alcohol syndrome young people means that we will be overwhelmed especially in central Australia. Many of the babies born today will become young people with a disability because of the familial Alcohol abuse."
- "Through non-compliance with treatment and management regimes there is a large population of poorly controlled diabetics requiring amputation of limbs with or without co-morbidities of blindness and chronic renal disease. There is little or no help for these people once they leave hospital and return to the community."
- "Significant levels of thought, planning and funds need to be directed towards the specific needs of Indigenous people with a disability living in central Australia."

Recommendation:

- That the NDIS continues to liaise closely with lead Indigenous disability and health organisations in order to maximise the effectiveness of the scheme within Indigenous communities.

On people living with dementia

- "One particular rural issue is the need for services and care for people with dementia living on quite remote properties. These people are not always elderly and are often fairly fit and physically healthy, however the decline in brain functioning makes it likely that farming accidents may occur. Family members are not always available to provide supervision. People with dementia who do not qualify for aged care assistance should be eligible for assistance under the NDIS."
- "Wherever they live, people with a disability should have access to basic entitlements such as adequate nutrition and hygiene. In more remote areas these fundamental needs must be met if the clients concerned are to remain in their own home."

Recommendation:

- The NDIS Transition Agency should promote close collaboration between health, aged care and disability service providers in rural and remote Australia in order to maximise the availability and effectiveness of care in those areas.

Conclusion

The National Rural Health Alliance welcomes the introduction of the NDIS and is highly motivated to work with key organisations to ensure that people living with a disability in rural and remote areas of Australia, obtain the best possible life outcomes. There are specific characteristics of rural and remote Australia that require creative and practical solutions to providing effective and cost efficient disability services.

We urge careful consideration of the issues outlined in this document and look forward to providing further input based on rural and remote consultations as the NDIS unfolds.

Attachment C

NATIONAL RURAL HEALTH ALLIANCE INC.

ABN: 68 480 848 412

National Rural Health Conference
Australian Journal of Rural Health

PO Box 280 Deakin West ACT 2600
Phone: (02) 6285 4660 • **Fax:** (02) 6285 4670
Web: www.ruralhealth.org.au• **Email:** nrha@ruralhealth.org.au

Discussion Paper

on

Issues relating to the NDIS in rural and remote areas of Australia

21 February 2013

Discussion Paper

Issues relating to the NDIS in rural and remote areas of Australia

Introduction

This paper seeks to promote discussion on the issues of living with a disability in rural and remote areas of Australia.

The NRHA wishes to ensure that the National Disability Insurance Scheme (NDIS) is equitably implemented for all Australians, including those who live in rural and remote areas. We are interested in your views and ideas about the issues raised in this paper and we need your responses to ensure that the recommendations we make to the NDIS Transition Agency are based on the lived experiences of rural and remotely based people. With each issue listed, there are a number of related discussion points. Many of these discussion points reflect direct quotations from submissions sent in by people in the NRHA network.

The set of issues for discussion

- Lack of availability of services in rural and remote areas
- Transportation and mobility aids
- Recruitment, training and retention of Health Professionals in rural and remote areas
- Stroke rehabilitation
- Publicising the NDIS
- Identifying people who could benefit from the NDIS
- Identifying resources, people with skills and knowledge, potential carers
- Financial Counselling
- Community and Social Involvement
- Collaborative relationships between health care providers and between organisations
- Cost reduction by utilising local expertise
- Avoiding inequalities based on location
- Educating people with a disability
- Advocacy for people living with a disability
- Culturally appropriate delivery of the NDIS
- Human Rights model
- Need for more supported accommodation and respite care in rural and remote areas
- Review and Quality Control

Please also feel free to bring other issues relating to disability in rural and remote areas to our attention if they are not mentioned in this paper.

Issues

1. Lack of availabilityof services in rural and remote areas

Lack of health, aged care and disability services availability in rural and remote areas.

Below is a correspondent's view on this issue:

> *The Healthlink[6] program that was funded federally in our area has been quite successful. Services that did not exist prior to this funding being made available are now established and well integrated. There is room for improvement as traditional carers (doctors and nurses - and some allied health professionals) resist any departure from the medical model of care. Local knowledge is a great advantage. Allied health assistants help greatly to coordinate allied health services where service providers are a very limited resource.*

Discussion points

- How to get more services made available in rural and remote areas?
- Provide the same services by different means? eg telehealth care? Fly in fly out? RFDS?

2. Transportation and mobility aids

Transport is a particular challenge for many people with disabilities in rural or remote areas, where public or specialised transport is less readily available. Transport issues extend beyond health care to daily living and social needs.

At the individual level, the issue is mobility, with people in rural and remote areas potentially having poorer access to mobility aids, higher costs and needing different types of aids (for instance for use over rough ground).

> *I have a friend who when she had Chemo for Leukaemia and her immune system was wiped out , developed toxoplasmosis with five tumours growing in her brain. She is severely disabled and overweight. She needs an injection of Botox in the muscle in her ankle as her foot is turned inward, making it very hard for her to walk.*
>
> *To have this injection she has to travel to Royal North Shore Hospital on 1st March. To do this she has go by Community Transport from Molong. She has to have a Carer go with her (that is me - 77 years of age).We have to stay overnight and travel back the next day. All this costs a considerable amount of money. Here is the crunch line: If she had had a stroke, she could have the injection at Orange Base Hospital - one hour away.*

Discussion points

- Are there cost effective ways to overcome these disadvantages?
- Can eligibility rules be relaxed to provide transport assistance to a wider range of people with disabilities?

---

[6] http://www.healthlink.net/index.htm

- What are the prospects for more and better use of community buses, school transport systems (during the day), and community taxis?
- Video communications to link in with service providers in major centres.
- Community transport needs to be subsidised for specific cases, maybe in the form of vouchers.
- Volunteer carers (not receiving carer's pension/payment) should be reimbursed for their expenses incurred when helping people with a disability – the actual cost of fuel and accommodation when necessary, as some specialist appointments are 350km or more away.

3. Recruitment, training and retention of allied health professional[7](AHP) staff in rural and remote areas

Can innovative and cost effective ways be found to encourage the recruitment, training and retention of allied health professionals in rural and remote areas? Retention of allied health professionals in more remote communities is a huge problem.

> *"Even in major regional areas, health professionals are often working at their first job and then they leave for the cities at the end of the year. Hospital Administration will often delay advertising their jobs to save money, and for months there may be no service available."*
>
> *"A common issue associated with rural and remote areas is that the lack of trained staff in the area inhibits people from receiving hands-on rehabilitation. Community services may come to an area, but if a weekly service cannot be provided then the patient will not really progress with their 'rehab'."*
>
> *"A more global degree in allied health for rural areas. For example, if a worker had the skills to do Occupational Therapy, Speech and physio, perhaps as a first degree followed by sub specialisation into either stroke, paediatric, autism etc, or into traditional streams. The multi skilled staff would be ideal for small communities which may struggle to provide enough work in a single specialty. So long as there was good dedicated video support for such generalists, it would give them the back up to carry on and they would need plenty of respite to stay sane. Perhaps additional holidays earned by being a solo practitioner would prove attractive? The Colleges have to change to allow training in rural practices which often have part time practitioners with young children, or job sharing. This makes it hard to work full time with one person, but a placement that covered multiple specialties/ practitioners would be perfect."*
>
> *"It should be remembered that scholarships and other inducements for rural students only work if the overall number of places at university and in rural areas is increased in line with the requirements for more allied health workers."*
>
> *"Allied health assistants are working well in the areas in which I work. They streamline the day when allied health professionals visit remote locations and coordinate services as well as following through with basic programs or*

---

[7] An allied health practitioner is a tertiary trained professional who works with others in the health-care team to support a person's health care. Examples include physiotherapists, osteopaths, chiropractors, speech pathologists, podiatrists, dietitians, social workers, medical scientists and medical radiation practitioners.

interventions that they are competent with under the instructions of the AHP. Excellent program to support allied health professionals in rural areas."

"These allied health professionals need access to a panel of experts. People with a disability often have very specialised needs and care requirements during acute episodes. The local AHPs are well-placed geographically to provide long-term follow-up care. They may need advice, assistance and support from time to time. This should be made available through networks, professional supervision and mentoring in a formal way."

"Local kids need to be supported through the training pathway to become an AHP."

"Existing AHPs need to be well-supported to take on students so that trainee AHPs who may want to return to rural areas, gain experience and confidence in these specialised locations."

"Recognition as specialists in rural health – as other career pathways are blocked by staying in rural areas. Years of experience must count for something!"

"Most people who live in rural areas have a connection to the agricultural calendar of events that predominates in that region. Often training courses or annual meetings coincide with a major event such as wheat harvest which prevents attendance at the annual conference or district meeting ....that automatically excludes those people – not just once but every year. So not only is there the barrier of distance, cost, arranging time from work, no back-fill for work, etc... it is very challenging to stay in the professional loop."

"A dedicated rural health careers website should include information about scholarships, financial assistance and incentives that are available for all health career paths. There are anecdotes of Health Faculty Heads who are not aware of the HECS reimbursement scheme for medical students. Such information needs to be readily accessible and well publicised to anyone considering or studying for a health career to make rural practice more attractive and achievable."

Discussion points

- What ways can be found to overcome this problem of recruitment, training and retention of health professionals in rural and remote areas?
- Is there a role for generic allied health assistants or similar?
- Should carers be trained in massage?
- More scholarships for allied health students and professionals?
- Compulsory rural placements during training of health professionals similar to what is required of medical students, with the same level of support?
- HECS reimbursement for those agreeing to work in rural or remote areas on graduation?
- Special entry arrangements for rural school leavers?
- Can University Departments of Rural Health play a role?

4. Strokeand Brain Injury rehabilitation

Stroke rehabilitation is a particular problem in rural and remote areas, partially due to the difficulty in getting appropriate medical intervention within the critical time period of three hours.

> *Prior to the Healthlink funding being made available in the Hillston area, there was only private physiotherapy for follow-up rehab available to people after stroke, cardiac event, or major surgery once discharged home from hospital. As the larger hospitals aim to send people home early, often people were missing out on follow-up treatment. The closest outpatient rehab/cardiac rehab or pulmonary rehab was in Griffith and was often fully booked. This required patients to arrange transport the 110km to Griffith and commit time and energy to this when they had not long returned and were often still not well. Many therefore chose to manage without any rehab. There is now an inpatient slow-stream rehab service available, an outpatient clinic for stroke rehab, falls prevention, cardiac rehab, pulmonary rehab as required. As numbers are small, it is person-centred rehab but based on guidelines set at larger centres within the Local Health district. The Healthlink program and chronic disease model of care also allows for follow-up at home with exercise programs and health coaching to support people in the optimal management of their disease. This is also happening in Hay in a slightly different way that optimises the services of the visiting allied health professionals. There are small towns nearby who are not so fortunate such as Lake Cargelligo and Coleambally.*

Discussion points

- Stroke prevention: can high risk individuals be identified early?
- Service models must be developed to ensure that there is capacity in non-metropolitan areas to respond to the needs of rural and remote people who have had a stroke or brain injury.
- Should regionally based (hub and spoke) brain injury rehabilitation services be integrated and resourced as part of a State-wide approach?
- The specialist brain injury rehabilitation culture needs to be attuned to the clinical needs of rural and remote clients and families.
- There must be regional services, with residential capacity, providing centre-based services for clients who live distantly, and outreach services to clients living in rural and remote areas.
- Access to assessment and review by a brain injury medical rehabilitation specialist must be available.
- There need to be ABI community workers located in smaller communities supporting clients and their families and community to implement rehabilitation strategies.
- Rural and remote services could also be provided by fly-in or drive-in staff undertaking specialist clinical assessment and review clinics.

5. Publicising the NDIS

The NDIS must be effectively publicised to:

a. people living with a disability in rural and remote areas;
b. their families and carers; and
c. health professionals who work in rural and remote areas.

If people don't know about it, they can't benefit from it.

> *There must be a concerted publicity effort to ensure that service providers are knowledgeable about the NDIS and are able to inform their clients. A major issue in rural areas is that people are unaware of what is available to them, or have given up trying to access services which they would be in theory eligible to obtain. This can lead over time to enormous stress for family carers trying to manage by themselves, recourse to permanent institutional care away from home, or even premature and preventable death. The expansion of community based primary health care services, including disability services within primary health care, and publicising of what services are available could actually save money by reducing hospitalisation."*

Discussion points
- What are some innovative ways in getting this publicity out there?
- Is television an option? Eg Channel 600 (Rural Health Channel), NITV (National Indigenous TV)?

6. Identifying people who could benefit from the NDIS

How will people from rural and remote areas who are living with disability be identified to ensure that they obtain benefits from the NDIS? Some of these people may not be aware that they are eligible. Innovative ways to bring people into the Scheme need to be found.

Discussion points
- Could networks like Country Women's Association, ICPA, Shire councils, school systems, and Frontier Services be utilised?
- Maybe DVDs and other materials need to be made available through these agencies?

7. Identifying resources, people with skills and knowledge, potential carers

How can the NDIS Transition Agency identify resources it can utilise in rural and remote areas: for example, people with useful skills and knowledge, potential carers?

Discussion points
- Local organisations that know the area and can provide valuable local knowledge.
- What are some of the other sources of information?

8. Financial Counselling

People with disabilities and their carers in rural and remote areas may need financial counselling to make best use of the funding they are provided with under their plans. How can financial advice be sensitively delivered to ensure that the best possible use is made of funds?

Discussion points
- Learn from the Rural Financial Counsellors[8] program?

---

[8] See: http://www.daff.gov.au/agriculture-food/drought/rfcs

- What is the role of counselling by telephone, webinar, social media?

9. Community and Social Involvement

How can people with a disability become involved in community and social activities in their local regions?

Discussion points

- Can existing organisations or organisational models that are already providing employment/training/social inclusion in some regions of Australia be copied or cloned to other rural and remote areas?
- Arts and disability?
- By encouragement, training and assistance to get into the workforce?
- Government funding for regional arts programs?
- Crossover with the strategic framework for arts and health?
- Australia Council?

10. Collaborative relationships between health care providers and between organisations

Can outcomes for people with a disability in rural and remote areas be improved by fostering collaborative relationships between Medicare Locals, local health networks, mental health facilities, aged care and disability services, and paramedics?

It is necessary to ensure, particularly in rural and remote areas, that the health, aged care and disability sectors work together **collaboratively** to avoid fragmentation of care and to avoid 'shuffling' people around the system.

> *The NDIS Transition Agency should endeavour to establish cooperative relationships with Medicare Locals, Local Health Networks, and other local services such as aged care, disability services and paramedics.*

Discussion points

- How can these relationships be encouraged?
- Should these groups be treated collectively by governments, funding bodies etc?
- Can the NDIS Agency play a role?
- Relationships between these agencies are critical for the future of health and aged care and disability services on the ground.
- What role can the National Rural Health Alliance play?
- What role for AMLA[9] (Australian Medicare Locals Alliance)?

11. Cost reduction by utilising local expertise

Can the cost of delivering the NDIS in rural and remote areas be reduced by utilising the knowledge and expertise of locally based health care service providers?

Discussion points

- Could the cost be reduced below what it otherwise might be? What about in comparison with major cities?

---

[9] See http://amlalliance.com.au/

- How can locally based health and disability care service providers be most effectively utilised to implement the NDIS?

12. Avoiding inequalities based on location

The higher cost of delivering disability services in rural and remote areas must not cause inequalities in the life outcomes of people with a disability who live in rural and remote areas compared with those based in city and metropolitan areas.

The following is part of a submission received by the NRHA on this issue:

> *I think there are other areas in which support could be useful. In Victoria most allied health professionals type their own reports. This is inefficient. A secretary could do it more cheaply to free up more appointment spaces.*
>
> *Similarly, many hours are spent travelling to outlying communities. Organising mentors to visit and check on progress of clients and perhaps also checking by video link would be helpful. Alternatively, since some patients are difficult to transport, and often with no useful public transport, a minibus/ Special school bus etc. that brings several clients to the local outreach clinic, may be useful. Ideally a clinic might include neurology, psychiatry, orthopaedics along with specialist nurses and allied health plus social worker, flown in to see local clients over a two day period, for example. This might be a good model for implementation by Medicare Locals etc. Importantly it should also include the local allied health and doctors by way of up-skilling, and communication.*

Discussion points

- Is there merit in the above submission?
- Could not-for-profit service providers be encouraged to expand into rural and remote areas by designing services around the needs of a person with a disability, rather than about the availability of service providers?
- Will the commercial viability of disability services be enhanced by providing people with a disability the means to bid for such services?

13. Educating people with a disability

What are the problems associated with providing appropriate education to children with a disability who live in rural and remote areas?

The following related submissions were received by the NRHA.

> *"As 'security and familiarity' are extremely important factors to children with disabilities, removal to urban/regional centres is not always the best option: that is where such professional / specific facilities and accommodation exist. Such accommodation needs to be structured; but to date such accommodation for rural students is very limited, particularly for children with marginal mental disabilities.*
>
> *Without suitable accommodation, educational and workplace opportunities, a move to urban /regional centres makes the experience of the students with disabilities more traumatic than it should be and often leads to social and emotional disorientation.*

> *Should the option to return the student to familiar home and school environments be taken it is essential that one to one Student Support Officer (SSO) assistance be available and provision be made for specialized training and ongoing support for the SSO. This alternative, selected by many rural families and schools, means that a sympathetic staffing formula (ratio) needs to be applied to allow for the required SSO support. Experience has shown that the welfare of students with disabilities can be greatly enhanced when they are able to be resourced to remain in familiar surroundings."*
>
> *"Particular issues in smaller country towns relating to support and education for children with disabilities include:*
>
> - *Small numbers*
> - *Access to service providers – specialists far away as well as local service providers needing support from experts.*
> - *Uncertainty about which programs are available for these people when service coordinators are not working with these younger people all the time (much more chronic disease and aged care work) and networks are not well established. Also, who administers what service seems to change often."*

Discussion points

- Should Student Support Officer assistance be made available more widely?
- What experience has the School of the Air with education for children with a disability?
- What about the Isolated Children's Parents' Association (ICPA) – this is one of its specialty areas.

14. Advocacy for people living with a disability

The NSW Council for Intellectual Disability included the following in their Senate Submission regarding the NDIS.

> *Whilst the NDIS will deliver a fundamental change in the nature of the relationship between individuals with a disability, service providers and the community, people with a disability will still be reliant on the NDIS to provide the funding and the mechanism by which the funding is provided, in order for them to exercise their rights. People with intellectual disability have the right to, and need for, independent advocacy to enable them to overcome these barriers in order to exercise these rights in the context of the NDIS.*
>
> *NSW CID believes that legislative effect should be given to the Productivity Commission's recommendation that "advocacy would make an important contribution to the effective functioning of the NDIS and to the overall effectiveness of the NDIS in delivering on its key objectives"*[10]

Discussion points

- What potential role does advocacy have in relation to the NDIS?

---

[10] Productivity Commission Report

15. Culturally appropriate delivery of the NDIS

How can the NDIS be delivered in a culturally appropriate manner, particularly for Aboriginal and Torres Strait Islander people located in remote communities?

Discussion points

- Should trained and culturally appropriate interpreters be provided to assist people in remote communities for whom English is a second language, to understand their rights under the NDIS?
- What culturally appropriate services and supports should be available for Aboriginal and Torres Strait Islander peoples with disability and their carers?

16. Human Rights model

In essence,the human rights perspective on disability means viewing people with disabilities assubjects and not as objects. It entails moving away from viewing people withdisabilities as 'problems' towards viewing them as holders of rights. Importantly, it means locating problems outside the disabled person and addressing the manner in which various economic and social processes accommodate the difference of disability - or not, as the case may be.[11]

Discussion points

- Is the human rights model the appropriate model for the NDIS?
- How to adopt and build on a Human Rights model for delivery of the NDIS rather than a welfare model.

17. Need for more supported accommodation and respite care in rural and remote areas

Should the NDIS address the need for more supported accommodation and respite care for people living with a disability in rural and remote areas?

> *Hi – I've just returned to Adelaide after 17 years of Remote Area Nursing and health care for Aboriginal people in WA and communities around Broken Hill. The most significant thing that I saw re helping people care for someone with a disability was good respite care via the local/nearest hospital for the person with the disability. If the family felt as though the hospital understood the needs of their loved one and that they could receive respite as needed, this made a huge difference in their ability to care.*
>
> *I think having respite care booked in advance rather than waiting until they felt totally worn out seemed to work best, i.e. for 1 week 3-4 times per year, or a few weekends throughout the year.*

Discussion points

- Should supported accommodation and respite care be within scope of the NDIS?

---

[11] Human Rights and Disability – United Nations Geneva 2002

18. Review and Quality Control

Should the NDIS Transition Agency provide some form of review and quality control for the services that are provided to people with a disability?

Discussion points

- The views of the person receiving the service should be paramount.
- Some type of objective assessment of service quality should be performed on a regular basis?

Attachment D

NATIONAL RURAL HEALTH ALLIANCE INC.

ABN: 68 480 848 412

National Rural Health Conference PO Box 280 Deakin West ACT 2600
Australian Journal of Rural Health Phone: (02) 6285 4660 • Fax: (02) 6285 670
Web: www.ruralhealth.org.au • Email: nrha@ruralhealth.org.au

NRHA Opening Statement

Public hearing of Senate Standing Committee on Community Affairs' Legislation committee

Inquiry into the National Disability Insurance Scheme Bill (2012)

Thank you for inviting the National Rural Health Alliance to appear before you.

Most of you have come across the NRHA before, so perhaps all I need to do is to update you about how many national organisations are currently in the Alliance. The current number is 34: all of them national organisations; some representing rural and remote health consumers, some service providers, and some health professional groups. These last include four allied health, four medical and three nursing organisations.

As I hope you understand, the vision of the Alliance is good health and wellbeing in rural and remote Australia, with the particular goal of equal health for all Australians by 2020.

We are delighted to appear before you on this matter - but just a little surprised. Until the past 18 months the Alliance had little involvement with issues relating to disability. We have become more and more engaged,since there seems to be no other specific national voice representing those living with a disability and their carers who live in rural and remote areas.

This reflects two important points worth making to your inquiry. The first is that, through its very existence, the plans for the National Disability Insurance Scheme (NDIS) have increased public discussion about a very important matter and increased the number of organisations that have become involved. This is a good thing. Whatever else happens through the NDIS, the processes of which your inquiry is a part will mean that the issues of concern to people living with a disability are better understood, so that the individuals and their families and carers are less marginalised than would otherwise be the case.

The second point the Alliance's close involvement reflects is that, in rural and remote areas, there is arguably no such thing as a discrete, stand-alone disability sector. Where populations are sparse, economic markets are thin, specialised workers are fewer, and everything tends to be related to everything else. This has two important implications for the NDIS in rural and remote areas. The first is a very positive thing. The joined-up nature of individuals and agencies in rural areas is one of the main causes of the greater sense of community - the stronger social capital - that exists in rural areas than in large cities. It will be critical for the NDIS to recognise, make use of and build upon this social connectedness by using the networks and the human resources currently available. At the same time, however, it is critical that the existence of this social capital is **not** used as (or seen as) a reason for setting any lower standards or expectations of the NDIS in rural and remote areas.

The second implication of the fact that there is no discrete disability sector in rural areas may also be a good thing. It is that, in those areas, the NDIS must not be seen as a stand-alone entity but as something which will be an integrated part of health, disability, ageing, rehabilitation, community and general wellbeing care and services.

We note that the Bill reflects a national approach, and as such makes no specific reference to the operation of NDIS in rural and remote settings. People living with a disability in rural and remote areas have specific characteristics and as such warrant a targeted and flexible approach that will be necessary to make the NDIS 'fit for purpose' in those areas.

With funding from FaHCSIA under the Practical Design Fund, the Alliance has a project in train to seek practical solutions to the problems that are going to affect the implementation of the NDIS in rural and remote Australia. We have been consulting with rural stakeholders about their hopes, fears, and ideas about the NDIS. They have highlighted the parlous circumstances which currently confront many people with a disability in rural and remote areas. It is the unevenness and unfairness of the current situation which makes the successful development of the NDIS vital for rural and remote Australia.

The take-home message for your Inquiry is that a fairer system that is based on a commitment to eligible participants, rather than on the availability of services (or lack thereof), will provide major opportunities and benefits for rural and remote people. The Alliance therefore supports the scheme very strongly.

For this reason we are pleased that there is bipartisan support for the NDIS and its purposes. We would be very disappointed if there was to be any retreat from the current aspirations - especially if they were occasioned by short-sighted fiscal targets of dubious real value.

Without doubt there are challenges in making the NDIS work in rural and remote areas as well as will be required for it to be truly universal. Many of these challenges are familiar to us all, because they are the same challenges as face health and aged care services. As I have said, markets are thinner, so that a system which is based on providing individuals with the wherewithal to bid for services which are appropriate for and commensurate with their disability status, will be inherently challenging where there are small numbers and wide spatial distributions of those people.

Many of the other more specific challenges have been briefly described in our submission to you. Chief among them are the fact that, on average, people in rural and remote areas have lower levels of education, lower incomes and worse health risk profiles. Some 70 percent of Australia's Aboriginal and Torres Strait Islander people live outside metropolitan areas, so that the characteristics of the NDIS in rural and remote areas must include those which will make it culturally safe and appropriate. And overall the proportion of people who live with a disability is higher in rural than metropolitan areas.

To ensure take-up of the NDIS by all eligible people living with disability in rural and remote areas, extra targeted publicity for the scheme may be necessary to ensure that everyone with an interest is aware of its opportunities. The development of participant plans for people with disability would be greatly enhanced by the provision of a website that showed comprehensive details of all available services that are approved for take-up by NDIS participants.

Other challenges for such a scheme in rural areas relate to transport and personal mobility; engagement in the workforce; the cost of services; those who may not currently be on the disability services radar; and workforce issues, including the availability of allied health professionals.

The Alliance encourages the NDIS Launch Transition Agency to consider and accommodate these issues from the very beginning so that the scheme can get off to a good start. On the ground, much will depend on the involvement of Medicare Locals, Local Health Networks and local aged and community services. There will also be the need for good communications with people in rural areas, in an appropriate language and style, and social media will have a role to play. On the technological front, telehealth and related systems will no doubt also have an important and growing contribution to make.

Feedback the Alliance has already received indicates that workforce issues, flexibility, teamwork and scopes of practice are certain to be issues of importance in delivering assessment and services to people living with a disability. Permit me to read two of the quotations from rural people that are in our written submission to you.

> "It is unfortunate when health professionals are unable to provide a service in a rural and remote area because of **prescriptive regulations**. This often means the client has to incur greater travel costs or is unable to participate. It also exaggerates the problem of health professional retention, recruitment and workforce shortages."
>
> "The NDIS Transition Agency should be aware of the importance of **supported employment** and strategies to improve inclusive workplaces: for example, tax concessions for those businesses which provide employment for people with a disability. So many positive outcomes result from having a paid job, especially in terms of emotional and mental health. Where disability plans are being developed they should include an employment component."

Overall, we are optimistic. The NDIS brings with it significant opportunities to strengthen the rural workforce for care of the unwell, the ageing and those living with a disability. The opportunities for improving the sustainability of rural communities and regional development through better care across health, community, aged care and disability services should not be underestimated. The basis for regional training of nursing, allied health and medical students is already in place through UDRHs and Rural Clinical Schools, along with increased local skills-based training through TAFE for personal care workers.

We look forward to working with interested parties in ensuring that people in remote areas are fully involved and properly considered as the NDIS unfolds.

Attachment E

NATIONAL RURAL HEALTH ALLIANCE INC.

ABN: 68 480 848 412

National Rural Health Conference
Australian Journal of Rural Health

PO Box 280 Deakin West ACT 2600
Phone: (02) 6285 4660 • **Fax:** (02) 6285 4670
Web: www.ruralhealth.org.au • **Email:** nrha@ruralhealth.org.au

Submission to Department of Families, Housing, Community Services and Indigenous Affairs
on the proposed rules for the
National Disability Insurance Scheme

26 March 2013

This Submission is based on the views of the National Rural Health Alliance but may not reflect the full or particular views of all of its Member Bodies.

Submission on the Proposed NDIS Rules

1. Rules for Protection and Disclosure of Information

One of the most important issues identified by people living in rural and remote communities about effective implementation of the NDIS is that participants should not be shuffled between the health, disability and aged care sectors. Nor should participants be required to continually retell their stories and repeat their personal and medical information to each agency or service provider to which they are referred.

These are particular issues for people who live in rural and remote communities who more often have to travel to regional centres or cities and may have to be away from home for longer periods of time to get specialised health and disability care. Then they have to go back to areas where services and health care may be stretched, so it's really important that the pathway is as seamless as possible and that their local service and healthcare providers are fully informed about issues, treatments and developments that took place while they were in the city.

Recommendation
The NDIS Rules for Protection and Disclosure of Information should include provisions which state that, if it is agreed in the Participant's Support Plan, the appropriate sharing of personal and medical information between agencies and support providers should be enabled, in the interests of ensuring that seamless support is provided. These provisions would need to be limited to the sharing of information between service providers and agencies that are actually engaged in providing services or support to the participant.

2. Rules for Registered Providers ofSupport

In relation to managing the funding for support provision, section 1.2 of the Rules for Registered Providers of Support states:

For each participant, someone (or more than one person) will be identified as managing the funding for supports under the participant's plan. Funding can be managed by the participant, the Agency, a plan nominee, or a registered plan management provider.

Section 1.3 makes it clear that there is no restriction on who may provide support, provided funding for the plan is not managed by the Agency. If, however, funding is managed by the Agency, the supports provided must be provided by a registered provider of supports: see section 1.3 below.

Unless a participant's plan is managed by the Agency, there is no restriction on who may provide supports under the plan. Participants are able to exercise choice about the selection of their providers. It is only when funding for a participant's supports is managed by the Agency that the supports must be provided by a registered provider of supports: see subsection 33(6) of the Act.

This rule (1.3) creates a fundamental problem for people living with disability in rural and remote areas. Some States already allow people living with disability who are funded under State schemes to manage their own funds; but a majority of these people find it convenient to allow the State agency to manage their funds. In rural and remote communities there is a wealth of experience and resources available that are capable of providing support, but due to the small size of these communities there is no incentive for these people to register as support providers, because disability support is not their principle source of income. Rule 1.3 effectively makes it impossible for these informal sources of support to be utilised by people with disability who, for various reasons, prefer to have their funds managed by the Agency. This rule may be less of a problem for people with disability living in urban areas where there may be a large choice of registered providers of support, but in rural and remote areas, it is clearly inappropriate.

The NRHA is currently consulting with a range of people with lived experience of disability and carers from rural and remote areas. Here is an excerpt of what the mother of a young girl with multiple disabilities wrote about this issue:

> "In the past we have accessed emergency respite through Commonwealth Respite and Carelink Centre. They fund respite, but don't provide it. We were able to use people we knew (family or friends) who were also familiar with our daughter and didn't need to be taught anything for respite, and they were paid directly for it.
>
> As I understand it, if you manage your own NDIS funds you can use non-registered service providers, but if the NDIA manages your fund they have to use registered service providers. I think there is significant potential in this area to ensure that the NDIS rolls out successfully across rural and remote areas. It is completely reasonable in metropolitan areas for the NDIA to use registered service providers; after all there are many more services available. In small communities there is a wealth of experience and resources available that don't belong to (and probably never will) a "registered agency". My particular situation gives me a wealth of understanding of the needs of families with a child with a disability, so that's where my focus is. In terms of what we need in order to provide the best care possible for [our daughter], it's things like domestic assistance, respite, assistance with meals, appropriate child care (i.e. not at a centre). These are all things that can be done by just about anybody in our community; they don't require special skills or training for the most part. Even things like therapy programs could be undertaken by just about anybody if provided with a detailed therapy plan by a registered professional. Another of our needs is picking our daughter up after school and bringing her home and staying with her until we get home from work (about an hour); it's such a simple thing, but we have to use a respite service and their workers can't work for any less than a 2 hour block which means that we use twice as many of our respite hours as we need to.
>
> If the NDIA has the flexibility in rural and remote areas to waive the requirement to use registered service providers there is a much greater chance of success."

Recommendation

Rule 1.3 should include flexibility for people living with disability in rural and remote areas who choose to have their funding managed by the Agency, so that they can receive care from local people or services that are able to provide timely, appropriate and good quality care although they may not be accredited disability services.

3. Rules for Support for Participants

The cost of providing supports to people living with a disability is almost certain to be greater in rural and remote areas than in an urban area. The costs of providing disability supports are proportionally greater with the degree of remoteness of locality of the person with disability. These costs are greater for reasons such as increased transport costs and travel times between clients, coupled with the scarcity of service providers and higher costs of staff and other resources in rural and remote areas. The cost of short term staff to ensure continuity of care to cover leave arrangements, continuing professional development or staff vacancies can be a particular challenge for services that provide care in rural and remote areas, where costs may include the need for local accommodation as well as substantial travel costs on top of agency rates. The cost of infrastructure, maintenance and communications to support the provision of services is also likely to be substantially higher in many locations outside the cities.

Section 1.3 of the Rules for Support of Participants states:

In giving effect to these objects, regard is to be had to the need to ensure the financial sustainability of the NDIS.

Section 2.3 sets out the factors that the CEO is obliged to consider when deciding whether to approve the participant's support statement.

Section 2.3 (c) states:
the support represents value for money in that the costs of the support are reasonable, relative to both the benefits achieved and the cost of alternative support.

Section 2.3 (e) states:
the funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community to provide.

Section 3.1 (**Value for Money**) sets out a number of matters that the CEO is obliged to consider when deciding whether the supports listed in a participant's support plan represent value for money.

Section 3.1 (e) states:
whether the cost of the support is comparable to the cost of supports of the same kind that are provided in the area in which the participant resides.

As they currently existthese rules do not give any confidence that the disparity in disability support costs between urban and rural and remote areas will be recognised. At this stage the principles for the NDIS do not make any distinctions between participants based on their locality or any other factors.

Recommendation
To ensure that people living with disability in rural and remote areas receive equitable support under the NDIS, these Rules should explicitly acknowledge the greater costs associated with providing disability support in rural and remote areas. The Rules should state that there will be sufficient flexibility to allow the level of support provided to participants to be determined, in part, by where the participant lives.

The costs of travel and accommodation for access to specialised health and disability services for country people and their families and carers also need to be considered.

Commentary on these Rules in relation to Indigenous and culturally and linguistically diverse participants

Section 3.2 of these Rules sets out factors that the CEO should consider when deciding whether the support will be effective and beneficial for a participant.

Effective and beneficial and current good practice

3.2 In deciding whether the support will be, or is likely to be, effective and beneficial for a participant, having regard to current good practice, the CEO is to consider the available evidence of the effectiveness of the support for others in like circumstances. That evidence may include:

(a) published and refereed literature and any consensus of expert opinion; or

(b) anything the Agency has learnt through delivery of the NDIS.

There is nothing here that recognises the necessity to deliver disability support in a manner sensitive to the race, beliefs and cultural practices of the participant. This recognition is essential if the support delivered is to be effective and beneficial to the Indigenous or culturally and linguistically diverse participant.

Recommendation

Section 3.2 should be expanded to include the need to deliver support in a culturally sensitive manner as a factor to consider when deciding whether the support will be effective and beneficial for a participant.

Attachment F

Shaping the National Disability Insurance Scheme for Rural and Remote Areas

Denis Ginnivan
Policy Consultant, National Rural Health Alliance

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 focussed 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 lesson 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; and
- 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.
- E-mail 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 focussing 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:

1. 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.

2. 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.

3. 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.

4. 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.

5. 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.

6. 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.

7. 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 it 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 cognizant 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 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 valued and recognized 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.

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.

Attachment G

Members of the Project Reference Group

Name	Category
Jennifer Cullen	CEO Synapse The Brain Injury Association of Queensland Inc, Indigenous representative
Craig Dukes	CEO Indigenous Allied Health Australia, Indigenous representative
Trish Eerden	Mother of a child with multiple profound disabilities; health worker in rural South Australia
John Franze	Project Officer, National Rural Health Alliance
Denis Ginnivan	Policy Officer, National Rural Health Alliance
Tony McIntyre	Person with lived experience of disability from rural area
Gordon Gregory	Executive Director, National Rural Health Alliance
Gayle Rankine	Chair First Peoples Disability Network, Person with lived experience of disability, carer, Indigenous representative
Daniela Stehlik	Chair Rural Industries R & D Corporation
Lynne Strathie	National Rural Health Alliance Council member, mother and carer of a person with disability, Indigenous representative
Belinda Wallin	Project Manager Industry Development Victoria -National Disability Services
Helen Wright	Mother and carer of a child with multiple disabilities

Attachment H

QUESTIONS FOR DELPHI SURVEY

NRHA 6 March 2013

1. Rate the following issues in order of importance for successful delivery of the NDIS in rural and remote areas (1 is most important, 8 is least important).
   - Building disability service capacity in rural and remote areas
   - Meeting the challenge of making available transport and mobility aids for people with disability in rural and remote areas
   - Improving recruitment, retention and professional support for health professionals in rural and remote areas
   - Informing people with disability, and their families and carers, about their rights under the NDIS and basing the Scheme on a human rights approach
   - Ensuring that the location of the recipient is taken into consideration when allocating plans, to take account of increased costs to access services
   - Delivering the NDIS in a culturally appropriate manner for Aboriginal people and Torres Strait Islanders, people from a culturally-diverse background and people in remote areas
   - Ensuring that information is provided to all those who need it in a form (mode, language, style) that suits their needs
   - Providing more supported accommodation and employment support for people with disabilities in rural and remote areas.
2. List any other issues that you regard as equal in importance or of higher importance for successful delivery of the NDIS to people in rural and remote areas.
3. What are some ways that community and social inclusion for people living with disability in rural and remote areas could be improved?
4. What are the best rural and remote disability programs/services/approaches we should be highlighting and which could be copied or adapted for wider use across rural and remote areas?
5. Who are the other key people and organisations we should be talking to about this issue? Can you help us with their contact details?
6. Is there something that we're missing or anything else you'd like to add?

Attachment I

NATIONAL RURAL HEALTH ALLIANCE INC.

National Disability and Carer Alliance

Implementation of DisabilityCare Australia in rural and remote areas

Roundtable Report

Summary

In February 2013 the National Disability and Carer Alliance (NDCA) and the National Rural Health Alliance came together to investigate some of the practical strategies that will make the NDIS work well in rural and remote areas.

The work of the two organisations included a Roundtable held in Parliament House, Canberra, on 29 April 2013. The Roundtable brought together about 40 people with a strong interest in the issues affecting those who live with disability in rural and remote areas. People at the event included some with lived experience of disability, rural health professionals with a particular interest in disability, carers of people with disability, and Aboriginal and Torres Strait Islander people from remote communities. The delegates came from rural and remote areas, regional centres and a few from major cities. A list of delegates is included in Appendix 1.

Introduction

To be effective in rural and remote Australia, DisabilityCare Australia will need to be designed, funded and operated in such a way as suits the circumstances of people living with a disability in those areas. While there is a wide variation in the demographics and needs in different rural communities there are some common challenges, including lack of services,distance and isolation, which will need to be met, including through a general flexibility of service models.

Within the DisabilityCare Australia program the person with a disability will be funded to secure the supports they need throughout their life to facilitate their participation in community life. In rural communities there may well be no local services and there will be barriers to accessing more distant services. Even with the best will in the world, some services will not be able to be delivered within the community and people with a disability and their families will require extra support to travel to metropolitan or regional centres to access those services.

Seeking and listening to the views of people with disability and their families living in rural communities is absolutely essential if the scheme is going to meet needs in those areas. The essential and aspirational needs of people with disability and their families in various rural communities need to be identified as a basis of facilitating, developing and supporting services to meet those needs.

A range of approaches to disability services will be needed for rural and remote areas of different type. In some, a 'hub and spoke' approach would enable specialist staff based in a regional city to provide outreach support to surrounding areas. Such a model requires a higher staff-to-client ratio in more remote areas than in city and closely-settled areas due to the time and other resources necessary for travel.

Depending on the type of service required and the characteristics of particular places, there may be a place for some 'fly-in, fly-out' (FIFO) services. However the common view is that such an approach is not suitable for the delivery of day-to-day services where a high degree of trust must be established between the client and the support provider. FIFO and drive-in, drive-out services may therefore be best directed to provide secondary and tertiary support to local health and community service providers.

With FIFO, experience has shown that the longer the stay, the better the outcomes. In Meekatharra, the Royal Flying Doctor Service is using FIFO nurses who work one month on and one month off. Having people around for a month at a time gives them a chance to participate in community life, with both nurses and communities benefiting as a result.

Whatever models of service are adopted, there is a continuing call from rural and remote communities for services to be provided as locally as possible and for people with disability and their families in rural and remote communities to be consulted throughout the course of their development.

This report is premised on the belief that close and ongoing consultation with interested individuals and organisations can help ensure that DisabilityCare Australia becomes genuinely universal, so that a person's eligibility for and access to services will be unaffected by where they live.

Key recommendations from the Roundtable

1. **Compounding of disadvantage by level of remoteness**
   DisabilityCare Australia should recognise that the disadvantages experienced by people living with disability and their families and carers are compounded by living in rural or remote areas. The more remote the location, the more pronounced is the disadvantage; and the more isolated the situation, the higher the cost of service provision.

2. **Flexibility is key**
   When developing support packages for people with disability, DisabilityCare Australia must recognise the key role of families, carers and informal support networks. Support packages must be flexible enough to provide assistance to improve the resilience of families in the face of the unrelenting pressures of caring for a person with disability.

This flexibility is particularly important in rural and remote areas, where support such as home help, meals, counselling, transport and respite build family resilience and therefore increase the health and wellbeing outcomes for the person with a disability, the carer and the community. Recognition of this crucial range of informal support mechanisms does not diminish the parallel need for professional services. There are many and varied opportunities for some of the supports required by people with disabilities, and their families, to be provided through informal networks – including in rural and remote areas.

Flexibility of support packages is particularly important in rural and remote areas. Because there are likely to be fewer 'registered' or mainstream support providers in these areas, local capacity must be fully utilised in innovative or impromptu ways. For example, a family may need to take their child with a disability to a major city for a medical consultation; minding the child's siblings becomes an issue that can be solved by a flexible package that enables a local person to be paid to perform this role.

3. **Training for professionals**
   Particularly for those who practise in rural and remote areas, appropriate training should be provided for a broad range of health, health-related and community professionals and service providers who support and work with people living with a disability. In rural and remote areas professionals are often 'specialist generalists' and therefore are not always able to be specialists in disability. In cities, specialist providers would more usually be available. A better understanding of disability by those who provide support can mean generic healthcare and community services can be tailored and prioritised to improve outcomes for clients and their families. Professional areas where improved training related to disability is needed include:

   - medical, nursing and allied health professionals;
   - social workers; and
   - teachers.

4. **Training for disability support workers**
   Disability support workers have a central role in healthcare, as their responsibility includes being vigilant for the signs of illness, facilitating access to appropriate health professionals and following through on management recommendations. They too need training in the ways health issues may present, particularly in people with cognitive and communication impairments, and ways to engage and work with health services.

5. **Training for locals**
   Training and support should be developed and made available to local people in rural and remote areas to enable them to provide non-professional services to those with a disability. This will enhance the local capacity for communities to provide optimal lifestyles for those with a disability and also be an added means of providing paid work in rural areas.

6. **Some needs will not be met by individualised funding**
   DisabilityCare Australia must acknowledge that the needs of some people with severe disabilities will not be met by individualised funding. Infrastructure such as appropriate supported accommodation for young people with disabilities is not currently in place in most parts of Australia, and for the implementation of DisabilityCare Australia to be fully effective, adequate infrastructure, and the people to staff it, must be integral to the scheme.

   DisabilityCare Australia should recognise that the human rights of both the person with a disability and of his or her parents are violated by the unspoken assumption that the parents will provide care and accommodation for the whole of their lives. Just as people without disabilities move to adulthood and wish to become independent of their parents, the same holds for people with disability, and this human right should be accepted and facilitated by policy and program delivery.

7. **Benefits of employment for people with disability**
   DisabilityCare Australia should develop programs through which people with a disability can be supported to engage in paid work, including help with identifying appropriate jobs and applying for them. This would help to enhance their social engagement and their financial means of support, particularly in rural and remote areas where local jobs may be scarce. DisabilityCare Australia should investigate the feasibility of training people with relatively low levels of disability to develop mutual support networks and, where appropriate, to provide support for people living with more severe disabilities, provided the level of support delivery is not compromised in any way.

8. **Coordination of supports**
   The goal ofDisabilityCare Australia shouldbea seamless service for clients wherever they live – one without barriersbetween various agencies and services - and one that comprehends the needs of families and carers as well as clients. In rural areas, where there are less clear boundaries between disability, health and aged care, and more visible community networks, it ought to be relatively easy to build such a seamless system.

   In the case of children with disabilities who require support to attend school,DisabilityCare Australia should brokercoordination between schools, health professionals, teachers and support providers.

9. **Role of First Peoples Disability Network**
   The First Peoples Disability Network has a pre-eminent role in developing recommendations for remote Indigenous communities where people are living with disability. The National Rural Health Alliance and the National Disability and Carer Alliance support that Network in its recommendations for the rural and remote roll out of DisabilityCare Australia.

10. **Extending Second Year Australian Working HolidayVisa Scheme**
    DisabilityCare Australia should investigate the feasibility of extending the Scheme under which second 12-month Australian working visas are made available to people on working visas who are prepared to undertake specific

types of employment in rural and remote areas. At present the types of work that are eligible include farm work and some in the mining sector. This should be extended to include work supporting people living with a disability and their families and carers, particularly in rural and remote areas.

11. **Promoting awareness of DisabilityCare Australia**
    DisabilityCare Australia should implement a committed and complete program to promote awareness by people in rural and remote areas about DisabilityCare Australia. Many people eligible for disability care, particularly in rural and remote areas, have never registered with the current system and so will be unknown to existing service providers and other bodies.

12. **Increased availability of allied health therapy and counselling services**
    There need to be major efforts to increase the availability of allied health therapy and counselling service capacity in rural and remote areas, including at the intersections of the health and disability sectors. This is importantfor better treatment and management of a wide range of conditions, such as for injured children after they complete their hospitalisation and require on-going therapy in the community, possibly for years.

13. **Consolidation of part-time health positions to full-time**
    There should be joint work by interested parties in the rural and remotehealth, disability and aged care sectors to collaboratively consolidate part-time positions to full-time ones, for instance in allied health. Such developments should be supported by the additional funding available for disability and aged care services. This should lead to greater access to allied health professionals, for example.

14. **Eligibility to DisabilityCare Australia from age 65**
    Further consideration will have to be given to issues that arise at age 65 for the relationship between DisabilityCare Australia and the aged care sector. If the entitlements and arrangements differ between the two sectors, there will be equity issues between someone who experiences traumatic injury and consequent disability at age 64 and someone similarly affected at age 66.

15. **Collaborative partnerships**
    DisabilityCare Australia should take steps to establish collaborative partnerships with agencies dealing with health, children's services, disability services and aged care so that integrated service responses can be developed for people of all ages with profound disability and complex other needs.

The Process

The process for developing the discussion topics at the Roundtable was as follows.

Interactive survey

A survey was designed and placed on the Internet (see Appendix B).

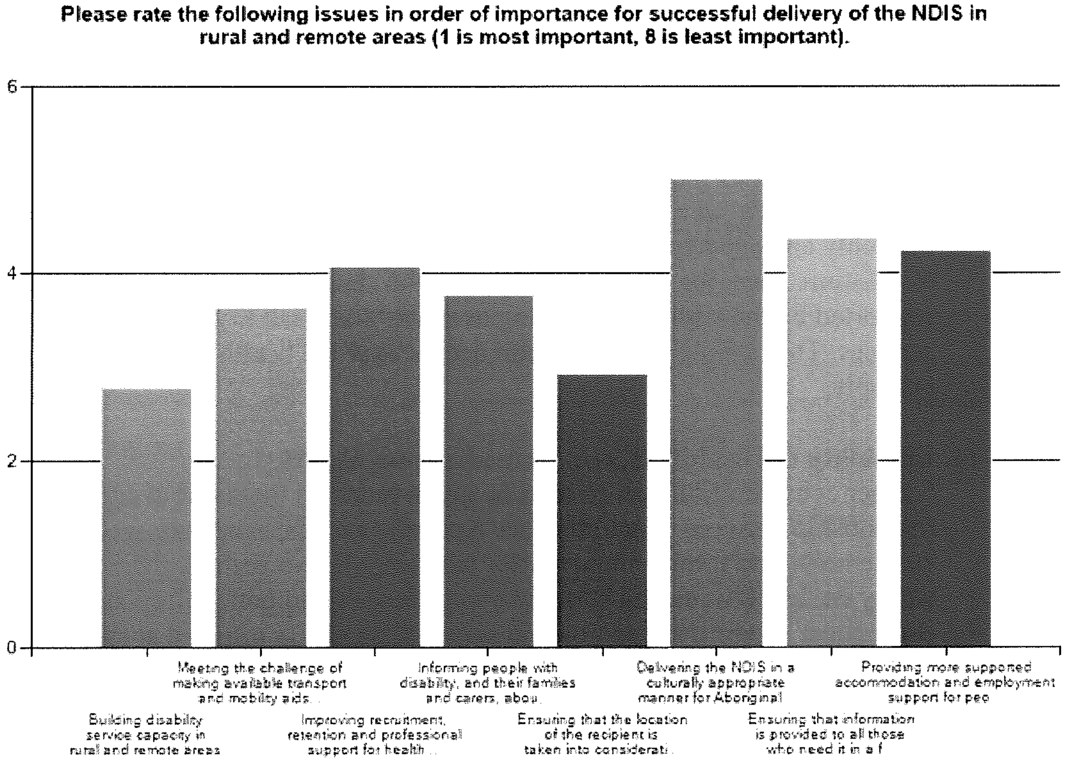
A group of people with a strong interest in rural health and disability issues were sent links and invited to respond. This group included members of the NRHA Council, Friends of the

Alliance and a range of people associated with the National Disability and Carer Alliance. The group included people with lived experience of disability, carers, health and allied health professionals, and service providers.

The purpose of the survey was to identify the issues that people with an interest in disability considered most important for successfully delivering DisabilityCare Australia in rural and remote areas.

There were 133 responses to the survey. The first question asked respondents to rate the relative importance of a number of disability related issues for rural and remote areas. The issue that achieved the highest rating was "Delivering the NDIS in a culturally appropriate manner for Aboriginal and Torres Strait Island communities".

The following Figure shows the overall results.



The remaining questions were designed to elicit the issues that respondents were most concerned about. Two issues that were mentioned by many respondents were:

- Transport, including:
  - lack of availability of public transport in some rural and remote areas;
  - greater costs incurred by people with disability in travelling to consultations; and
  - increased time expended by health professionals in delivering services in rural and remote areas compared withmetropolitan areas.
- Age issues including:
  - the non-eligibility of people who acquire a disability when aged 65 or over, for DisabilityCare Australia; and

- the importance of age-appropriate facilities, so that people with disability do not end up in aged care facilities due to lack of more suitable accommodation.

Feedback session at the National Rural Health Conference

From the 133 responses to the survey a list of the most commonly mentioned issues was drawn up and presented for feedback in a session at the National Rural Health Conference which was held in Adelaide in April 2013. The feedback received from attendees at this session was used to refine the issues for discussion at the Roundtable.

Planning workshop

A working meeting was later held to further refine the discussion topicswith a small group of people from both organisations.

The Roundtable was then held at Parliament House in Canberraon 29 April 2013.

The Roundtable proceedings

The recommendations in this paper arose directly from the discussions held at the Roundtable.

Everyone present was asked to briefly introduce themselves and explain what they brought to the table.A keynote address provided a personal experience of what it's like to live with and support a child with disability in a remote community. Thiscontribution provided valuable insights into the lifestyle and challenges of a family living in a remote area with a child with a disability, and placed the client and their family at the centre of the day's proceedings. An open discussion session followed in which all delegates were able to contribute.

The introductions and discussions provided a forum for delegates to learn more about DisabilityCare Australia and to share their own unique perspectives.Value was added for all participants by the fact that the people present included:

- people from the launch sites who were starting to get a feel for how the changes will be introduced and who shared their experiences;
- the Parliamentary Secretary, Hon Amanda Rishworth MP, who provided some important information and responded to a number of questions; and
- officers from both the Department(FaHCSIA) and the DisabilityCare Australia Launch Transition Agency,who were able to answer questions and give clarifications as the need arose during the discussions.

In the afternoon session delegates broke into smaller groups to discuss issues of particular interest that had arisen from the interactive survey and were reinforced during the morning session. Each subgroup reported their findings to the whole group during the final session.

Introductions and keynote address

The personal introductions revealed a great depth of experience and insight into disability issues within the room. The delegates included health professionals with many years' experience working in rural and remote communities. Some of these professionals also had personal experience as carers for a family member living with disability. There were delegates with lived experience of disability, and carers with personal understandingof the additional pressures of caring for a person with disability while living in rural and remote regions. There were also representatives from various organisations which advocate for and support people living with disability, together with delegates who combine providing professional disability support with working in related areas of academia.

The keynote address was given by Helen Wright, carer for her 12 year old daughter who has multiple physical disabilities. The family was located in the remote Kimberley region of Western Australia and decided to remain in that area as they made the decision "not to be defined by illness or disability". At first the support provided for their daughter in this community appeared to be working well, but in recent years "either as a consequence of getting older, or more disabled - or both - it became clear to us that the deficits [of living in a remote area] had begun to outweigh the benefits, and in January 2013 we moved back to Perth to access better educational and social opportunities".

The following excerpt from Helen's speech epitomises the problems faced by families from rural and remote areas who have a child with a disability.

> *In the first year, our baby required specialist visits and early intervention. Each specialist visit entailed me packing 2 small babies on to a plane, and spending a week 3500 km away from home. Thankfully PATS covered the cost of this, but it was still a gruelling and disruptive trip. I was lucky in that I had family who could accommodate and assist me in Perth, but I know of many others – who have had the same experience, and found themselves alone, vulnerable and without financial and social resources. For single parents this situation was far worse as the PATS didn't cover the cost of another child, and in some cases there was no one to look after an older sibling.*

Helen's address highlighted issues particular to living with disability in remote areas which were reiterated by other delegates during the discussions. These include:

- lack of understanding of the eligibility criteria for becoming a participant in DisabilityCare Australia;
- the burdensome effects of disability are amplified by degree of remoteness;
- the contrast in quality and availability of disability support services between the major cities and rural and remote areas;
- the lack of capacity in over-stretched towns to deal with disability;
- the transience of non-Indigenous people in very remote areas makes it very difficult for them to form the support networks that are needed to assist with the raising of a child with disability;
- the transience of service staff impacts on the quality of care and relationships with therapy teams;
- the lack of choice of schools in remote areas, coupled with the additional pressures faced by schools in these areas, makes it particularly difficult for a child with disability to receive adequate support at school;
- lack of GP services - many small towns don't have a GP;
- the massive gap in level of service delivery between the acute medical care and allied health, rehabilitation and chronic care services ("Your outcomes will be far better if you are sick than disabled");
- lack of and overstretched counselling services;

- lack of and prescriptive nature of respite services; and
- lack of suitable alternative activities for people with disability.

Themes which emerged from the Roundtable

Needs assessments

Fundamental to the success of DisabilityCare Australia is the necessity to identify the particular needs of people in rural and remote Australia. The Parliamentary Secretary for Disabilities, Hon Amanda Rishworth MP, clearly identifiedkey issues which willshapethis:

> *Disability Care Australia, is to cover anyone with a significant/profound disability. But we need to identify those people in particular. .... not having identified someone that may not have engaged with services previously is a challenge in rural/remote areas.*
>
> *Early intervention ...will be a critical part of the Disability Care Australia, as people will be able to get the support when they need it..to live a better life.*
>
> *Extra funding or loading will be allocated for Disability Care to attract and support professionals to work in rural and remote areas*

A physiotherapist based in rural Australia commented as follows:

> *I think needs assessment is critical here. There's knowledge about need but an inability to address it. The great time to do needs assessment is when you have resources...and I would have thought NDIS is a good time to get that information together, not through just the local area coordinators. I think we need a beefed up approach to assessing disability need in rural/remote areas.*

Capacity building

One of the broad areasidentified for discussion leading up to the Roundtable was building capacity and ensuring equity.

A delegate from the Australian Federation of Disability Organisations, who has a lived experience of disability, commented:

> *If you are in an established rural/remote community, you might have better connectedness, more informal support; disability might be more visible in your community. So we want to make sure that we think about how we capture that, how we maintain it and how we strengthen it.*

A health worker from rural Australia, mother of a young girl with multiple profound disabilities, commented:

> *.... we were talking about building capacity. Our experience is, our capacity is already overloaded. When you are talking about building capacity in families/communities, I am really concerned, because my capacity is already exceeded. In the 12 years that my daughter has been with us, 12 and a half years, I have personally ... negotiated with case managers ... [from] 15 different organisations*

> *at any one time. The nature of my daughter's disability is that we became less connected with our community, her disability was so extreme in her behaviours, that we were more and more excluded. And the community just wasn't able to cope with her. So I am concerned that we are talking about "building capacity". That is great, but I don't want that capacity to be up to parents/families, because we are already overloaded and exceeded.*
>
> *.... we have had access to allied health services and we have had access to health but that is not actually what we need. When my daughter wakes at 2 a.m. and screams for five hours and then spends many hours screaming during the day, I have no capacity to do my housework, no capacity to do what my son needs; so sometimes what I need is housework. Maybe somebody will cook a meal for me. Respite, God help us, yes, absolutely, we need that. So I would hate to see people locked into the idea that "all we need in rural/remote areas is allied health services". There's no question that we need that, but that's not all we need. Sometimes we need really simple stuff. Child-care, for example, we were accessing, three different child-care services for my daughter because the child-care services weren't able to cope with her area of disability. It wasn't a good place for her but that's all we had. Across a whole range of services, there's a whole lot more we need than just health.*

Adelegate with lived experience of disability from remote Australia:

> *.... about building capacity: obviously there's a broad spectrum of disability and I haven't really been able todiscern just what level of disability will be covered by DisabilityCare Australia. Also, I was interested in the comments about the difficulty getting people to provide the service. I was just wondering about the feasibility of using some of the less 'disabled' to provide the service, thereby building capacity from both sides.*

A delegate from an organisation which represents children with disability across Australia and who is also the mother of a young man with a disability commented as follows:

> *.... when you get respite or you get support from a disability service, it is for that one child. So if you have got two kids at school, the kid with disability can be picked up and the other one can't, so that doesn't support a family at all.*

A rural GP and academic in the disability field:

> *Families with a person with a disability have a need for health professionals but there are many other needs, particularly day-to-day support needs such as home help or meal support or transport.*
>
> *To me that speaks to the need of NDIS, the training of local people...building local capacity. I would call it an independent living service, not a disability service. It's called something else. Local people employed, trained to do the day to day stuff that's required of families and within that, though, your doctor/health professionals are important support people and training providers as well, but I think the NDIS really needs to focus on that local capacity building.*

A delegate who is a carer illustrated the dilemma in remote areas where services that most of us take for granted, do not exist:

> *..what we need is a health professional, someone who is quite smart, quite able and who can case manage, someone who can, in Plain English, say "This is your problem, these are the issues, and these are the things that we can put you in touch with." .... that person can also tap into the GP. But if we are looking at something that is possible to roll out, not perfect, that kind of intermediate step might be quite good. We have had local area coordinators in ....and I think they are fabulous advocates, but oftentimes they have got nothing to coordinate. They don't have funding, so unless they have got a resource, it's a bit of a mystery what they are doing after a while.*

The stories from people with lived experience of disability and of caring for family members with disability gave rise to our strong recommendation for flexibility in the support packages offered to participants, particularly those living in rural and remote areas.

The suggestion by a delegate with lived experience of disability of employing 'less disabled' people to provide services for the more disabled, supports the twin objectives of building capacity and of providing employment and social inclusion for people with disabilities.

There was concern expressed that there is a risk that existing service provider and infrastructure capacity in rural and remote areas could be lost in the transition to new service models. It was felt that some State-based support services are very good, and that there may be a risk to capacity if future funding is directed solely to non government organisations. It was felt that there is already an existing dearth of 'bricks and mortar' physical capacity in rural and remote areas, and this is reflected in situations where non government organisations in areas of 'thin markets' had not developed sufficient infrastructure in order to deliver their service contracts. Delegates also reported that in some rural and remote areas, there is already some 'cost shifting' by states in anticipation of the new model.

Information and education

Delegates emphasised that most people in rural and remote Australia are not aware of the details relating to DisabilityCare Australia – including its intended philosophy and approach.

There is a strong need to communicate the move from block service funding to individualised funding; and from 'no choice, to choice'. There were regular references to situations where people with disabilities have not engaged in the service system at all, as they have no confidence that they would be eligible for anything or would actually get access to any services provided.

One delegate emphasised the need for community education when saying, "There has been no discussion with anyone in the Torres Strait Islands about the coming changes to disability care".

Coordinating support services in rural and remote areas

In rural and remote areas, something that we normally take for granted, such as a visit to the bank, can be an obstacle to mount when factors such as child minding, transport, and even access to the premises have to be taken into account.

The mother and carer of a 20-year-old daughter with multiple disabilities, from rural Australia:

> *I also work as a social worker and for Local Government. I have helped pull together partnerships to provide services for disabled people in our local/rural community. I would like to see the most disabled/disadvantaged people are not disadvantaged in a new marketplace.*
>
> *I think a whole of community approach is required. Perhaps starting with bigger businesses/organisations, which would assign you that you have a 'disability concierge'. I have a daughter with quite extreme behaviour, autism and intellectual disabilities – often it's very difficult to access services in a way that gives dignity and respect to me and her ....but to have somebody that you could contact before you approached the service and I mean banks and hotels, I mean big places, where you say, "We are coming in today and we need some things to happen, so that we can make it an enjoyable experience for all of us." And if we started in a community, to make things accessible for people with disabilities, I think that would be a huge step forward.*

A general paediatrician based in a rural area:

> *In most regions there are a range of established services available that may be very successful even if they may appear somewhat disjointed. A key goal should be to assist communication between existing organisations rather than reinventing them. The further out you get from major urban centres, the more difficult it becomes as attracting service providers is a challenge. Support schemes for recruitment would be vital but enhancing the interrelationship between all the various existing services and augmenting them is the key. With additional services, we have to be really careful that people don't stand on each other's toes and duplicate already functioning services. Strengthening and supporting services is a huge potential benefit of the scheme. One of the biggest problems is that everyone is really busy so regional coordinators are needed to facilitate the opportunities for the players to talk to each other. This coordination role is going to be vital.*

Other delegates also spoke of the vital need to provide seamless support services for people living with disability in rural and remote areas, so that they can avoid the dispiriting process of continually having to negotiate across a disjointed range of providers.

Need for systemic reform

An area which generated substantial discussion is how disability care will function and develop in rural and remote areas in the context of the three keys service sectors – disability, health, and aged care. In rural areas these sectors tend not to be perceived as separate, partly because the smaller number of clinicians in the area work with people in all three categories. Opportunities exist for trialling alternative approaches for flexibly working across sector boundaries, more so than in metropolitan settings. These include opportunities for aged and disability services to jointly utilise community-based support services, particularly those which have a focus on escalating quality of life and increased participation for people living in the community.

Discussion focused on the need for system reform to ensure smooth transitions between sectors. For example, health is a key system through which people with disabilities emerge after injury and return to more community-based service systems. However there are aspects of the health system which are undeveloped, for examplepost-hospital brain injury rehabilitation in rural and remote areas. As a result people 'leave' the health system and return to the community with a higher level of disability implications and life challenges. This can also involve an overlap with the aged care system with young people with high personal and care needs sometimes ending up in aged persons' nursing homes for want of better options. An integrated approach to reform is required, and DisabilityCare Australia has a key role in leading it.

Local Area Coordinators and Planners

Delegates expressed strong support for the concept of Local Area Coordinators(LACs) in rural and remote communities, defined as follows on the NDIS website at http://www.ndis.gov.au/ndis-recruitment/expression-of-interest/

> "LACs (only applicable in some sites) will work to increase community inclusion and support people with disabilities. They will connect participants with mainstream services and local, community based supports and help participants to realise their plan by building individual and informal support capacity. LACs may be required to support those that need assistance to complete online assessments and provide information to those people who are not eligible about other appropriate services."

(Note that the above definition is not necessarily the same role as LACs under some current state arrangements.)

The role of 'Planner' was also defined on this site as follows.

> "Planners will be required to have qualifications in and/or experience in the allied health professions, including social work area, will work with participants to identify support needs including access to mainstream supports and community life to enable a good life and enable progress with the participant's goals and aspirations."

These roles will be critical for people in under-served rural and remote communities, and delegates identified some key characteristics which will be important. Essentially the person will need to be able to develop a good collaborative, trusting working relationship with the person with a disability, and their family and carer. This will be difficult to achieveby fly-in, fly-out or drive-in, drive-out means, becausethe person will not be'on the ground'. The person will need to be knowledgeable about the community and the real local options which may exist for implementing and maintaining a plan. The person could engage the local disability community in identifying the important issues and developing local solutions.

Some of the groups discussed the importance of a local plan manager or coordinator who would continue to be involved in case management, well beyond the establishment of the support and other services included in the individual's plan. This role would be a'go to' person to help with continuity of care if services were not working out or failed to be delivered, or if circumstances changed.

Ultimately, however, local area coordination can only be as effective as permitted by the local people, services and resources available to be coordinated.

Training of Medical, Nursing and Allied Health Professionals

Various speakers pointed out that the introduction of DisabilityCare Australia, together with the general need for better outcomes for people with disability, will increase the demand for training in disability across the board.

A delegate from one of the launch site areas reported:

> *.... one of the things that's been very difficult in recruiting staff is the lack of training in Certificate 3 for disability in rural areas. As we move into a new place, where we have more money to support carers or to get carers and staff, training is going to be really important.*

A delegate with many years' experience in primary healthcare - a remote practitioner working in Indigenous communities- said:

> *.... because I am a medical educator, I am very passionate about developing a workforce that actually can deliver some of these services. Sometimes the services are funded but we don't actually have any providers. So I think the placement/support of trainees of all professions in these contexts is important for the future, because we are talking about a long term plan.*

A disability advocate and carer volunteered the following:

> *....my concern with the NDIS, we are going to throw the baby out with the bathwater. There are some really good systems that are in place and we need to utilise them as well. One of them is doctors. I think doctors are the first port of call, they are the gatekeepers to anything with disability. Without doctors knowing what a disability is and being able to diagnose in a timely manner, then people don't get services in a timely manner. I would also like to see doctors skilled up, to be able to pass on information. Doctors often - I'm not picking on doctors here - I'm not - the system is such that doctors don't get a lot of information that is necessary to pass on to families. So it would be good if our doctors were treated with a lot more respect, that they were given a lot more information and they were given a lot more training about disability and identifying disability.*

It was considered that service delivery workforce requirements must be assessed on a regional basis. There was concern that some services may be funded but that there are situations where there is no one to actually deliver them. It is necessary to increase opportunities and support of trainees in various professions and occupations as a strategy for securing an available and reliable workforce.

Advocacy and empowerment

A number of delegates expressed the need for strong advocacy for people living with disability. The empowerment of people to provide self-advocacy was seen as essential.

A delegate from an organisation that advocates for people with disabilitysaid:

> *We have some very large disability organisations that are quite well off, ..., one of them runs employment services , where people work for less than $20 a day. These organisations have huge resources which we think they should invest back for people*

> *with disabilities. Although they own lots of buildings, it is these kind of services that we probably like people to be able to - we would like to advocate for and with individuals, through the NDIS, to improve for people to assert themselves and have a new way of thinking. And that's for people with disabilities to start to do that themselves, so we would really like to support that.*
>
> *A Board member of one of these organisations often refers to it as "cradle to grave services", some of these huge organisations that are set up. While we value what they do, we think that individuals need a voice through the NDIS and need to strongly put that voice to gain back some control.*

Another participant stated:

> *What continues to be missing from this whole process is the individual's voice and what we are starting to see now are - the NGOs are starting to, in preparation of the NDIS, they are starting to create other parts of their services, so they are starting to become 'whole of life', which really alarms me, particularly given that individuals with intellectual disability's voices [are] minimised anyway. So if they are in a service that provides service to their home, day support, that whole of life service, it yet reduces their voice.*
>
> *.... that's one of the issues that has been asked of me to bring to this table of a number of people who, when they visit a GP - one's own healthcare is a fundamental basic human right. So going through the service of the gateway service, a woman that I deal with, her issue is that she is very independent in her life and yet the one thing that she needs support with, and that is to go to the GP and interpret that information, she can't get through the gateway service. They can give her ten hours of support for lots of things in her life that she doesn't need - she lives independently, she's married, drives - someone to go maybe two hours every six months to interpret information from the specialist. She can't get that. So her answer to that is: "Give me $2,000 under the NDIS and I can keep that in my bank. I can use that when I need to. I can be accountable for that and I can have a real and meaningful say into my healthcare and it will be the person that I choose/trust, not the person that's allocated to me to support me through that healthcare."*

Another delegate:

> *One of the issues that I think is very important to recognise: while there are carers here who are very eloquent, ... there must be far more people out there, families where there's disability, families who are not eloquent and those people would love to have a voice but even given the opportunity, they wouldn't be able to effectively get their message across. So there is a crying need for advocacy services for families who need it, and it's been mentioned here several times.*

Delegates heard clearly that there is a strong need to prepare for the new approach of individualised funding and consumer choice, and to support people with disabilities to have their voice in this new paradigm of service provision. An important observation made about rural and remote people is that, in general, they are 'undemanding' and as a result will have lower expectations of this new scheme. This reinforces the need for advocacy and education about what services and supports are going to be available, and about how to access them.

Cost shifting by State and Local Government

A rural clinician from one of the DisabilityCare launch site areas stated that there are already signs of withdrawal of State Government services:

> *I am also seeing on a weekly basis the State Government local hard-pressed managers withdrawing services and I keep writing to their bosses - withdrawing services in anticipation of the NDIS and it's a consequence that you don't need. I know it's managed jointly but the left hand doesn't know what the right hand is doing either Federally or in the State system.*

Loss of existing services

A high risk pointed out by a number of speakers was that the introduction of DisabilityCare Australia may lead to the loss of some existing services that are working well.

A delegate here provides examples of services that have already been lost:

> *.... there have been really great programs that don't exist anymore, both State-based and Commonwealth-based, that have gone out of - I don't know, just defunded in the last ten years, and I would love to see some of those come back because they answer the problems that most parents have had. In Queensland we had what was called the flexible family support until the government took the "flexible" out of it and it became "family support". It provided just a basic amount of money for families to spend as they chose to support their family; not just the child with a disability, but siblings as well, so you could spend on house cleaning, whatever it kept to keep the families together. And Queensland has defunded that now.*
>
> *And then there was a Federal program that supported nannies to come out to people's homes, where the kids with disability were, and they would support the whole family; that was Federal. And the key thing about that is: when you get respite or you get support from a disability service, it is for that one child. So if you have got two kids at school, the kid with disability can be picked up and the other one can't, so that doesn't support a family at all. So I would like to see some of those programs come back, so families do have choices.*

Models of service for Aboriginal and Torres Strait Islander people

The Roundtable delegates agreed that the First Peoples Disability Network is the primary point of reference for policy development of disability care for Aboriginal and Torres Strait Islander people living in rural and remote communities.

There were a number of Aboriginal and Torres Strait Islander delegates, and a larger number of delegates who work with Aboriginal people in rural and remote communities, and some of the issues raised are recorded below.

For many Indigenous communities 'disability' is not a concept used to describe someone's situation. One delegate reported on a project in a remote desert community which is just beginning to understand the implications of disability. Members of the community had discussed what their needs were. Bringing relevant support to this community could involve improving basic access to buildings and installation of footpaths; securing water quality and food supply; and the development of understanding attitudes towards a person with a disability.

DisabilityCare Australia procedures will need to be culturally respectful, and decision making regarding eligibility and allocation of resources needs to occur as locally as possible. Where there are insufficient numbers (or any) appropriate Aboriginal and Torres Strait service providers 'on the ground' in Indigenous communities there are unlikely to be culturally appropriate and clinically effective services provided.

...A Final Thought

A mother of a young girl with multiple profound disabilities:

> *"Nothing about me, without me: so if you are making policy decisions, if you are making service decisions, then include me, because it's about me."*

APPENDIX A

DELEGATES TO ROUNDTABLE CONFERENCE ON IMPLEMENTATION OF DISABILITYCARE AUSTRALIA IN RURAL AND REMOTE AREAS

	Attendees National Rural Health Alliance invitees	**Organisation**	**Group**
1.	**Rob Curry**	Council for Physiotherapy also AMSANT	Allied Health Professional
2.	**John Franze**	National Rural Health Alliance	
3.	**Denis Ginnivan**	National Rural Health Alliance	
4.	**Gordon Gregory**	National Rural Health Alliance	
5.	**Hugh Heggie**	Senior Rural Medical Administrator Remote Health Services NT	Medical Professional
6.	**Helen Hopkins**	National Rural Health Alliance	
7.	**Dr William Liley**	Cooktown QLD doctor with an interest in disability	Medical Professional
8.	**Karen Lock**	Social worker for health services	Carer, support provider
9.	**Dr Neil McCarthy**	Medical Professional in rural area, carer for daughter with disability	Medical Professional - carer
10.	**Melinda McIntyre**	Manager District Community Nursing Service, Burnett District South East QLD	
11.	**Tony McIntyre**	Project Reference Group	Lived experience of disability
12.	**Dr Ewan McPhee**	Deputy Chair, Central Qld Medicare Local	Medical Professional
13.	**Dr Damien J Mergard**	Senior rural medical practitioner – operations for Central Australia remote health	Medical Professional
14.	**Dr Bronwyn Morkham**	Young People in Nursing Homes National Alliance	Advocate
15.	**Dr Michael Nowotny FRACP**	Rural Paediatrician	Medical Professional
16.	**Nicole O'Rielly**	Chair, Allied Health Professions Australia Rural and Remote	Allied Health Professional
17.	**Priscilla Robinson**	Living with a disability– hearing impairment	Indigenous – living with disability.
18.	**Bettina Robinson**	Carer, signer & Translator for her sister Priscilla Robinson	Carer
19.	**Russell Roberts**	Director, Mental Health & Drug & Alcohol rehabilitation, Western NSW and Convenor of National Alliance for Rural and Remote Mental Health	Allied Health Professional
20.	**Helen Soerink**	Disability Services Commission	Carer, Local Area coordinator

21.	**Dr Nigel Stewart**	Paediatrician on Council	Medical Professional
22.	**Lynne Strathie**	Project Reference Group and NRHA Council Member	Carer
23.	**Bethia Sullivan**	Occupational Therapist Ngaanyatjarra Health	Allied Health Professional
24.	**Joanne Symons**	Physiotherapist	Allied Health Professional
25.	**Wendy Thiele**	Early Childhood Coordinator, CHSA, LHN, Executive Director – Ambulatory, Community & Aged Care Country Health SA Local Health Network	Allied Health Professional
26.	**Dr Peter Vine**	Doctor with special interest in child disability	Medical Professional
27.	**Helen Wright**	Project Reference Group	Carer
28.	**Dr Lucie Walters**	Lucie received the Louis Ariotti award at the National Rural Health Conference	Medical Professional
29.	**A/Professor Robert Davis**	Head of The Centre for Developmental Disability Health in School of Primary Health Care, Monash University.	Medical Professional
	National Disability and Carer Alliance Invitees		
30.	**Trish Eerden**	Carer	SA Health
31.	**Sue Elderton**	Policy Manager, Carers Australia	
32.	**Melinda Ewin**	Chair, Children with Disability Australia, carer	Chair
33.	**Leah Hobson**	AFDO	
34.	**Judy Huett**		
35.	**Elizabeth Madden**	Team Leader Remote services, Carers, NT	
36.	**Roland Naufal**	National Disability and Carer Alliance	Conference convenor
37.	**Carol Okai**		
38.	**Jody Saxton-Barney**		
	NDIS Taskforce and Agency		
39.	**Ray Jeffery**	Branch Manager, Stakeholder Engagement NDIS Taskforce	
40.	**Douglas Herd**	Branch Manager DisabilityCare Australia	
41.	**Hon Amanda Rishworth MP**	Parliamentary Secretary for Disabilities and Carers	