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

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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 reality for 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.[1]

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

[1] 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/

- 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 staff are 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.[2]

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 the Australian College of Rural and Remote Medicine (ACRRM), Rural Doctors Association of Australia (RDAA) and Medical 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 for providing 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 higher costs 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 may not 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

[2] 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 to connect 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 carers and 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 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. 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 hospital system, 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

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 Health Professions 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