



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 of DisabilityCare Australia should be a seamless service for clients wherever they live – one without barriers between 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 broker coordination 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 Holiday Visa 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 important for 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 remote health, 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

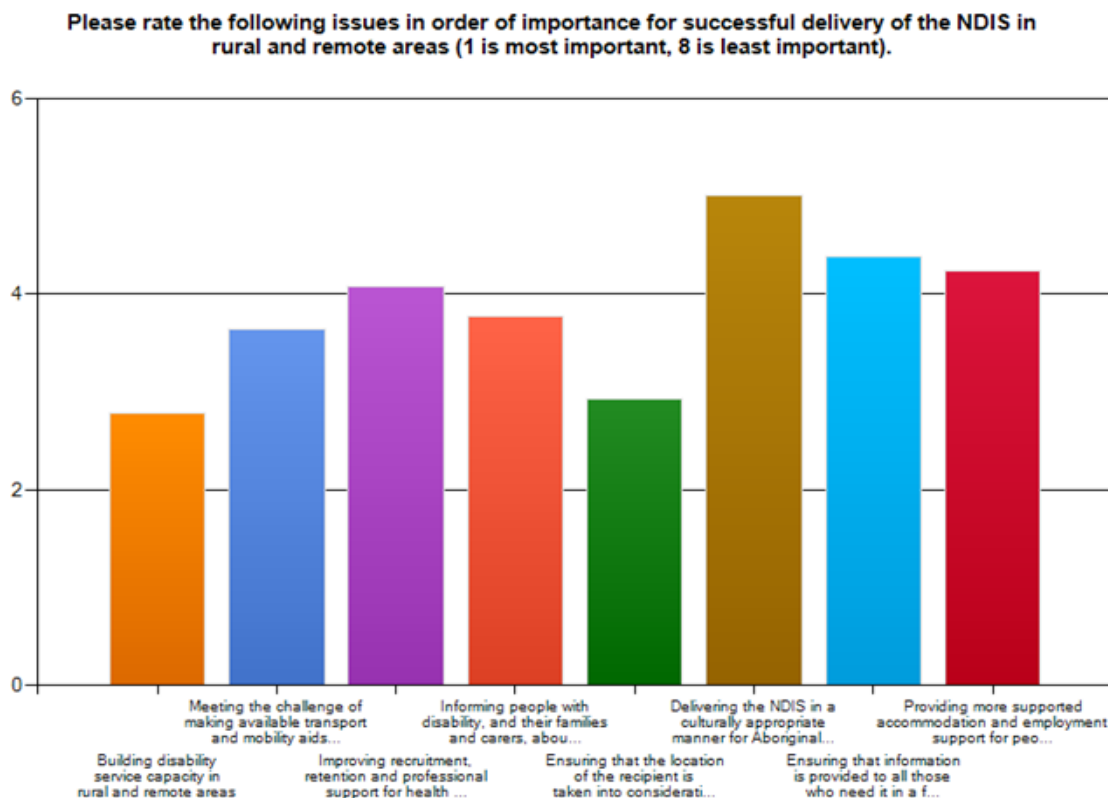
A survey was designed and placed on the Internet (see Appendix B).

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 with metropolitan 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 topics with a small group of people from both organisations.

The Roundtable was then held at Parliament House in Canberra on 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. This contribution 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 understanding of 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 identified key issues which will shape this:

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 areas identified 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.

A delegate 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 to discern 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 example post-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 achieve by fly-in, fly-out or drive-in, drive-out means, because the 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 disability said:

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	

APPENDIX B
QUESTIONS FOR DELPHI SURVEY ON DISABILITY ISSUES IN RURAL AND REMOTE AREAS

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?