

Wobbly Hub & Double Spokes Rural Research Team Faculty of Health Sciences

Submission to the consultation on the *Proposed NDIS Quality* and Safeguarding framework – 29 April 2015

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About the Wobbly Hub Rural Research Team

We welcome the opportunity to comment on the current proposal. This submission will focus on the implications of the proposed Quality and Safeguarding framework for the implementation of the NDIS in rural and remote Australia, and will draw on the research of the Wobbly Hub Rural Research Team (WHRRT) at the Faculty of Health Sciences, the University of Sydney. Our research has focused on the Western New South Wales region (Veitch et al., 2012). This region accounts for 72% of New South Wales by land area and 9% of the state's total population; approximately 43,000 people with disabilities live in this region (Data supplied by NSW Government Family and Community Services- Ageing, Disability and Home Care, derived from Australian Bureau of Statistics 2006 Census data). The aim of the WHRRT projects is to develop, implement and evaluate evidence-based policies that promote timely and effective therapy service delivery, to people with disability living in rural and remote communities. More information about our research can be found at: http://sydney.edu.au/health-sciences/research/wobbly-hub

Summary of Key Points of Feedback:

There is a need for **leadership and an oversight function that proactively monitors the rural NDIS service sector**, unmet demand, and recruitment and retention patterns in the rural allied health disability workforce.

Rural proofing strategies that appear to have much potential includes (a) creative local solutions such as the use of community-based therapy support workers who implement therapist-designed programs, and community capacity-building in mainstream rural settings, and (b) the innovative use of technology in the delivery of therapy supports (Dew, Bulkeley, Veitch, Bundy, Gallego, et al., 2013).

Due to the disadvantage experienced in rural communities, individuals may require **additional communication and decision making supports** before they are in a position to make informed decisions and real choices.

Strategies to train, recruit, and support **locally connected Aboriginal people into LAC roles** should be prioritized.

Delivery of high quality supports in rural or remote Aboriginal and Torres Strait Islander communities will require a **culturally competent and safe workforce**.

Capacity development within Aboriginal Community-Controlled organizations is a priority in order to ensure Aboriginal people with a disability have access to quality, accessible supports.

Whilst we found the **mainstream private allied health workforce** is experienced, they do not necessarily have the skills and knowledge to work successfully with people with disability.

Capacity development within the rural disability workforce will require ongoing investment. Development of accessible learning and teaching resources in disability are needed immediately.

There is a need for **university learning**, **teaching and curricula** to reinforce or embed aspects of practice that will be essential for the future disability workforce (Shakespeare & Kleine, 2013).

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Towards Safeguarding and Quality: Rural Proofing the NDIS

We agree that there is a need for a quality and safeguarding framework that ensures that all people with disability have access to high quality supports. This is of particular concern in rural and remote areas where the disability service sector is often less developed than those in metropolitan areas. People with disabilities in rural and remote areas of Australia have historically faced considerable challenges to accessing quality disability supports and services. They report travelling long distances, extensive waiting times and workforce shortages resulting in difficulties accessing therapy resulting in high levels of unmet need (Dew, Bulkeley, Veitch, Bundy, Gallego, et al., 2013). A lack of local therapy options (n.b., occupational therapy, speech pathology, physiotherapy, and psychology) often means that people with disability in rural and remote communities have not received the quantity or quality of services and supports they require to live a good life.

Rural proofing of the NDIS, with attention to continuous quality improvement mechanisms will mean greater equity in access to supports for people with disability living in rural and remote communities (Dew et al., 2014). Rural proofing involves strategies aimed at mitigating rural inequities. First coined in the UK, rural proofing denotes the need for policy makers to consider the impact policies will have in rural communities during design and implementation (Swindlehurst, Deaville, Wynn-Jones, & Mitchinson, 2005). There is a need for leadership and an oversight function that proactively monitors the rural NDIS service sector, waiting lists and unmet participant demand, and patterns in the recruitment and retention of the rural allied health disability workforce. Monitoring of these factors will allow identification of strategies for supporting or stimulating rural disability service sector growth in rural and remote communities, and disseminate and translate this knowledge across the Scheme. Attention to mechanisms that ensure provision of high quality therapy supports in rural and remote communities may also prevent challenging behaviours in people with cognitive, intellectual and/or communication difficulties or autism, and may eliminate the need for restrictive practices (Durand & Moskowitz, February 12, 2015, advance online publication; Webber, McVilly, Fester, & Chan, 2011).

Service Level Safeguards: Increasing Access to High Quality Supports

Our research has informed the development of a **Rural and Remote Family-Centred Approach** that is based around four pathways to delivering therapy to people with disability in rural and remote areas: Creative Local Solutions; Responsive Outreach; Responsive Centre-based Care; Innovative Technology (see Figure 1). This approach **provides a framework for the extension of therapy services** to increase service coverage and access to quality supports (Dew, Bulkeley, Veitch, Bundy, Gallego, et al., 2013).



Figure 1. Rural and Remote Family-Centred Approach

Rural proofing strategies that appear to have much potential includes (a) creative local solutions such as the use of community-based therapy support workers who implement therapist-designed programs, and community capacity-building in mainstream rural settings, and (b) the innovative use of technology in the delivery of therapy supports (Dew, Bulkeley, Veitch, Bundy, Gallego, et al., 2013). Access to any individual therapy support (i.e., travelling to a specialist services, or receiving therapy from a generalist local private therapist) may not adequately meet a person's needs or preferences, but in combination, may provide them with real choice and access to high quality therapy services. Supports may need to be combined and configured so as to develop a full range of rural proofed strategies. For example, the family of a child with cerebral palsy living in a rural community may choose to (a) travel to a **responsive centre-based** specialist service once every six months for a multidisciplinary "check up". This visit is then coupled with (b) building **creative local solutions** by accessing regular physiotherapy and speech pathology with local private therapists who refine and implement the therapy program recommended by the specialist service, followed by (c) monthly input from the specialist service who connect to the therapy sessions via **innovative technology**, including web-based real time videoconferencing.

The Local Area Coordinator (LAC) role also appears to have much promise in "rural proofing" the NDIS by ensuring participants have access to quality supports, and by building inclusive rural communities. LACs will need to utilise place-based approaches in developing relationships between individuals, their families, their communities, and the service sector. In particular, it will be **imperative that LACs have strong local connections**. It is unlikely that local area coordination conducted at a distance will mobilize the local knowledge and relationships required to ensure the NDIS remains responsive. For instance, it may be more effective and feasible to employ LACs in part time roles for a circumscribed number of geographically linked, small rural communities, rather than employing one coordinator full time across a larger jurisdiction. Indeed, LAC roles and initiatives should be tailored to, and reflect the communities in which they work. **Strategies to train, recruit, and support locally connected Aboriginal people into LAC roles should be prioritized**.

An important element of the proposed framework is building natural safeguards through access to high quality information. This is of particular importance to those living in rural and remote communities. Our research has shown that people with disability, their families/carers, and their wider communities, lack information about the types of support that they need and that would help them live a good life (Dew, Bulkeley, Veitch, Bundy, Lincoln, et al., 2013). Due to a history of a lack of available therapy services, and a lack of peers who can share their experiences in mobilizing the full range of support options, people with disability in rural communities may not have a clear understanding of what is possible. This may also be also true for those who choose to manage their own plans, who may find it difficult to understand the options available to them, imagine alternatives, and communicate their decisions. Due to the disadvantage experienced by people living in rural communities, individuals may therefore require additional communication and decision making supports before they are in a position to make informed decisions and real choices.

Service Level Safeguards: Supporting Development of a High Quality Rural Workforce

The need for rural workforce development

Service level safeguards aimed at ensuring safe and high quality supports will be of paramount importance in rural and remote communities. Quality workforce development is a critical aspect of being safe to work with participants. Yet, lack of a strong allied health disability workforce in rural and remote areas presents a real threat to the realization of the National Disability Insurance Scheme (NDIS) vision to improve the lives and promote community inclusion of people with disability. The rural allied health workforce is smaller than that in metropolitan areas, resulting in even less access to allied health professionals for people in rural and remote locations (Keane, Smith, Lincoln, Wagner, & Lowe, 2008). Where these are available, services are often provided in a spasmodic and ad-hoc manner (Dew, Bulkeley, Veitch, Bundy, Gallego, et al., 2013). Thus, capacity building of the rural disability workforce has the potential, not only to improve the quality of supports, but also to facilitate development of a more robust disability sector in rural communities. Workforce development in rural areas is a priority in order to achieve quality, safe services and to ensure coverage.

The proposed framework points out that under the NDIS, it is expected that "a different mix of providers will enter the market, requiring a new approach to quality and safeguarding" (p.3). This is also true for rural and remote regions of Australia. Our recent research (Dew, Barton, & Ragen, 2013; Gallego et al., accepted November 2014) indicated that the **rural private allied health sector** may be well positioned to offer the services and supports that will be required by people with disability in the future. Whilst we found the mainstream private allied health workforce is experienced, **they do not necessarily have the skills and knowledge to work successfully with people with disability** (Dew, Barton, et al., 2013). In particular, allied health practitioners in rural areas have been trained to, and have experience in, delivering services in the way that the health and disability Sectors have always demanded, where hands-on services delivered by therapists acting on their own are the norm. These therapists will need to shift existing skills, knowledge and attitudes to delivery supports within more contemporary approaches to disability service provision that emphasise individual choice and control, participation and social inclusion.

Similarly, Aboriginal community-controlled organizations and services have strong links to the local Aboriginal people and may be well placed to support families to navigate the NDIS. Research undertaken by Gilroy (J Gilroy, 2008; J. Gilroy, 2012) shows that many disability workers utilise Aboriginal community controlled organisations and Aboriginal community workers to support Aboriginal clients and their families. Currently, many Aboriginal community organizations do not have the requisite experience in disability service provision. The NDIA or FACS could provide support and training for Aboriginal community controlled organisations and services to deliver disability supports in line with the NDIS. Capacity development within these organizations is a priority to ensure Aboriginal people with a disability have access to quality, accessible supports.

What skills, knowledge, and attitudes need to be developed?

Provision of training and education is required to support all clinicians to develop required **foundational skills**, **knowledge and attitudes**. Achieving a shift in professional practice and conduct will take time and resources. Although contemporary disability policy has shifted to emphasise concepts of self-determination, participation and inclusion, these have not necessarily been reflected in the work of allied health practitioners (Breen, Green, Roarty, & Saggers, 2008). This may in part be due to the fact that current allied health accreditation standards do not consistently reflect a biopsychosocial model of health care (McAllister & Nagarajan, 2015) which underpins principles of the NDIS Act. Further, there is a need for **university learning, teaching and curricula to reinforce or embed aspects of practice that will be essential** for the future disability workforce (Shakespeare & Kleine, 2013).

Aside from core skills for disability practice, rural therapists require additional skills in order to meet the needs of people with disabilities in their communities and provide quality supports. It will be critically important that rural therapists adopt **roles as consultants or indirect service providers rather than as direct service providers**. Service delivery models that appear to have much potential in rural areas may require therapists to (a) work with families and rural community service providers to support the inclusion of people with disability in local community activities, (b) delegate therapy roles and activities to remotely-based therapy support workers, (c) work as a member of a transdisciplinary team, necessitating strong communication amongst team members who may not be co-located, and the ability to oversee therapy implemented by other team members. These service delivery models will therefore mean that rural therapists must learn to think differently about their primary clinical roles, and practice accordingly.

Rural areas are unlikely to have ready access to specialist allied health clinicians, such as augmentative and alternative communication (AAC) and seating specialists. Allied health therapists will require access to professional support in order to build their capacity to meet specialist needs and delivery quality services (Dew, Barton, et al., 2013). This applies even more so in the reduction of restrictive practices for people who display challenging behaviours. Therapists may need access to specific learning and teaching resources in disability and support from specialist therapists. For example, rural therapists may need to consult with allied health specialists or disability-specific organizations based in a major city via phone or videoconferencing between therapy sessions or during therapy appointments to support follow up and provision of advice. In addition, rural private practitioners will require support to develop business development skills and build business models that will facilitate this type of quality improvement, which ultimately may help to grow the rural disability service sector and provide better service coverage.

Delivery of high quality supports in rural or remote Aboriginal and Torres Strait Islander communities will require a culturally competent and safe workforce and will ensure that staff are safe to work with participants. The primary access barrier facing Aboriginal and Torres Strait Islander peoples to quality care is that our care system does not reflect the cultural values of health and wellbeing at a local community level. Investment in the disability support system must be driven by contemporary approaches to building a culturally responsive community services system. Cultural competence refers to the relationship between the service provider and the person with a disability in a cross-cultural context. Cultural competence focuses on the capacity of the service provider to improve individual service outcomes by integrating Aboriginal cultures and values into the clinical or service environment. Cultural safety, in contrast, focuses on the experiences of the person with a disability in a care setting. Cultural safety aims to enhance the delivery of services by identifying and balancing the power relationship between the service provider and the consumer, hence empowering the person with a disability in the organisation and management of their individual and family care experience (Downing, Kowal, & Paradies, 2011). Unsafe cultural practice is any action that diminishes, demeans or disempowers and undervalues the cultural identity and wellbeing of an individual. These two approaches to building upon a culturally responsive disability support system will help close the inequality gap by ensuring that Aboriginal and Torres Strait Islander peoples have a positive experience when they interact with disability service providers.

Implications for continuing professional development and practitioner registration

Rural allied health practitioners' ability to develop specific competencies and shift existing skills, knowledge and attitudes which allows them to practice in new ways is compromised by their professional isolation, and lack of access to quality continuing professional development (CPD) (Dew, Barton, et al., 2013). There is a critical need for flexible and accessible strategies that assist this workforce to realise their potential to provide services to people with disabilities in their communities. Development of accessible learning and teaching resources in disability are needed immediately. Such resources have the potential to benefit new graduates working rurally who want to extend their learning in disability, practicing rural practitioners entering the disability field for the first time, or practicing rural practitioners encountering people with disabilities in the context of generalist services. Orientation to disability work practice needs to be accessible so that clinicians are able to access this information when they are considering, or starting to work in disability. Online platforms, such as Massive Open Online Courses (MOOCs) could be used to ensure equity in access for allied health professionals working in disability in rural communities. UNSW's Intellectual disability and mental health (IDMH) e-learning site is an example of how this type of information could be presented in an accessible way. UNSW (lead by Leanne Dowse, Kelley Johnson, Karen Soldatic and Louisa Smith) is also developing the first MOOC in disability studies in Australia. Similarly, ADHC developed the Core Standards for Practitioners who Support People with a Disability which is designed to focus on the key areas in which practitioners require skills in order to effectively support people with a disability, including information on interdisciplinary and transdisciplinary practice. The standards, along with a range of e-learning resources are accessible at http://adhc.mediahouseplus.com/. Awareness of these resources and the development of social media to gather together communities of practice is an essential adjunct to these tools to support quality practice.

Linking registration to strategies that build the capacity of service providers may help to ensure that delivery of high quality supports does not come at the expense of an available workforce. In addition, a well supported allied health disability workforce would help to minimize risk across other domains, including helping to ensure that staff are safe to work with NDIS participants, and would reduce the risk of the inappropriate use of restrictive practices. For instance, mandated independent quality evaluation requirements for registration could include evidence of completion of modules focused on foundational skills, knowledge and attitudes required of disability practitioners. This ensures that registration reflects a quality of care perspective, rather than purely from a workforce availability and resource allocation perspective. Alternatively, practitioners could be required to complete core skills modules in their first year of practice to remain registered as a transition requirement. The need to respond to changes in practice, based on emerging evidence, is an essential feature of the framework, which will require practitioners to continue to update their knowledge and skills. Therefore, capacity development within the rural disability workforce is likely to be cyclical in nature and will require ongoing investment, which would be further enabled by mechanisms in Option 4.

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