

14 July, 2014

Mr Mark Fitt
Secretary, Parliamentary Joint Standing Committee on
the National Disability Insurance Scheme
PO Box 6100
CANBERRA ACT 2600

Dear Mark

I am writing in relation to the Committee's current enquiry and hearings on the implementation of the National Disability Insurance Scheme. National Respite would like to put some issues before the Committee for its consideration.

1 Challenges for change

Our challenge is to support the **interconnected well-being** of people with disability and their chosen carers, family and informal supports.

Supporting growth in interconnected well-being is a significant challenge, especially while simultaneously managing growth and transition.

But getting it right is critical – resilience of informal care provided by carers and families to people with disability is central to well-being; and to the financial sustainability of the scheme.

2 Respite services

At the last MDS, there were 1497 service outlets offering respite in Australia (497 NSW, 294 Victoria, 287 Queensland, 212 Western Australia). 4% of outlets are in remote or very remote areas, and 42% are in regional or outer regional locations.¹

Respite services are often relatively small, but because they mobilise volunteers, especially in rural communities, also contribute significant social capital to those communities.

In 2012 they delivered services to about 11% of service system users, or 37,000 people.

Respite service outlets are also relatively productive, with the median weekly hours of service higher than for accommodation support (394 hours compared to 313 hours) but using more volunteer labour (mean 0.3 FTE compared to 0.2 for accommodation support).²

This is a significant service infrastructure to transition, and it must be done at a time of rising demand.

Between 2009 and 2012, the **unmet demand** for respite went up almost 1/3 to 15.8% or 121,660 carers.³

¹ Australian Institute of Health and Welfare 2013. Disability support services: Appendix 2011–12. Disability series. Cat. no. AUS 173 p 14,16

² AIHW 2013 p20

The strong regional and remote distribution of respite outlets, use of volunteers, and more recently, innovation in flexible service, should all be built on as we navigate change.

The experience of members and services in the NDIS Trial Sites suggests is that there are some difficulties in meeting this challenge.

3 NDIS Trial Sites

We acknowledge the very significant efforts made by staff of the NDIS in the trial sites; and by participants, carers, families and service providers.

Unless some of the challenges they face are managed successfully, there is some risk to the stability of informal care arrangements and to valuable features of service delivery (flexibility, use of volunteers). The size, cost and impact of this risk is not yet accurately understood (see research below); but its importance is recognised.

Services, participants and families report that widely differing experiences of and outcomes of the planning process in relation to the support that participants and families once knew as respite. This unevenness, though expected as part of the Trial, also suggests that the Scheme is still having difficulty in finding the right way to support the interconnected well-being of participants and their chosen supports.

Some issues that services have raised with us include:

- uneven and poorly understood outcomes of the planning process;
- concerns about loss of 'flexibility' in service supports;
- no clear funding our policy for carer support that is not 'substitute care'
- lack of co-ordination arrangements for emergency respite

Two key issues need to be managed successfully:

- the tension in the NDIS Act requiring the NDIA to both
 - 'build capacity of families and carers to support participants' (s 31(da)); and
 - for the CEO to have regard to ' what is reasonable for family, carers and the community to provide' (s34 (e))
- ensure that respite (care substitute) carer support, and non-respite carer support are appropriately funded.

National Respite supports the efforts of the NDIA to find solutions, which lie strategic policy, operational policy (the guidelines), research and structural adjustment or sector development and transition.

³ ABS 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2012, 2009

4 Recommendations

4.1 Outcomes data – survey

National Respite's knowledge of outcomes is based on regular phone hook-ups of services in 5 trial sites. It would clearly be better to have hard survey data rather than rely on anecdote, but we have been unable to secure funding for a regular 6 monthly survey that would measure participant, carer and service experience of outcomes from the planning process in relation to respite.

- We recommend that the NDIA provide funding for a regular pulse survey of respite outcomes of participants, carers and services in the trial sites.

4.2 Clarity for planners

The Guideline *Supports for Sustaining Informal Supports* was a major step forward in articulating the intention of the Agency to support chosen carers, family and informal support. But the Guideline remains too complex, and still lacks a fully coherent approach. The very complex operational policy demand of managing the tension inherent in the Act is could still be given clearer simple guidance in the Guideline.

For example, the Guideline does not suggest how planners should resolve the competing tensions of paragraph 13 d ('consider what reasonable supports may be required to sustain or build the carer's ongoing provision of support...') and paragraph 23 ('It is reasonable to expect that families would work together to support carers of people with disability').

A resilient family can be one of the most important supports for a person with disability; family resilience is a useful policy framework for use in the guideline.

- The Guideline should give simpler, clearer Guidance to planners in supporting the resilience of chosen carers, families and informal supports

4.3 Carer support

Non-respite (non-care substitution) carer support remains a confusing grey area for families, participants, advocates and services. There is no clear strategic policy position on how and where such support (including counselling, peer support, education for carers, resources) should be funded, with some stand-off between Commonwealth and State and Territory governments. This is closely related to the 'tier 2' issue. The Commonwealth Government needs to have a clear policy position, including a transparent policy review process that invites participation by stakeholders.

- The Commonwealth Government should provide a transparent policy review process for Carer Support, and commit to adequate funding of carer support inside and outside the NDIS.

4.4 Flexibility

A welcome development in recent years has been the innovation in flexible respite, which allows a range of personally tailored supports that provide respite outcomes for carers and families, and meet meaningful goals of people with disability. Flexibility can include drawing peers, friends and informal supports into care substitution, paying for out of pocket expenses; as well as paying for small out of pockets for short breaks for carers such as a visit to the cinema. In respite services, the drawing in of peers and informal supports often takes the form of specially recruiting these as

'volunteers' to support the person with disability and carer. These arrangements are obviously very cost-effective and substitute for much more expensive paid supports, as well as making carer support more resilient.

National Respite is undertaking a cost/benefit and impact study of Volunteer, flexible and family based services to make recommendations about how and why these supports should be funded within the Scheme.

Some of this flexibility may be lost if it cannot be included in a plan (and so far there is little evidence of plans including these); or funded outside under so called Tier 2 arrangements.

- We recommend that Guidelines for plans make clear that out of pockets to support 'care substitution' by volunteers and informal supports can be funded in plans
- Tier 2 funding arrangements should extend to supporting volunteer and informal support arrangements.

4.5 Structural adjustment

Respite outputs are already a significant part of the service infrastructure, and in rural and remote areas, by mobilising volunteers, contribute significant social capital. As smaller not for profits they face particular challenges in transition. Yet if they are not transitioned successfully, it is not clear that larger for-profit or for purpose providers will immediately fill the gap; or that if they do so, they will be able to reproduce the same social capital in the communities. This would have significant implications for the requisite diversity required to support choice.

National Respite is about to undertake significant research with SPRC at the University of New South Wales to:

- do a map of respite outputs currently delivered in the disability and aged care systems
- do cost/benefit and social impact analyses of different transition scenarios, where some or many current service outputs do not significantly transition
- analyse the impact on participants, carers, community and government.

We recommend:

- NDIA plans for sector development and transition take account of the research, and make provision for small and medium respite services, especially those in rural or remote communities.

4.6 Further research

As noted above, research and good evidence is required to support these transition challenges. This includes:

- A regular pulse survey of respite outcomes of planning of participants, carers and services in the Trial Sites
- How a 'family resilience' model could underpin the approach to building the capacity of chosen carers and families
- Analysis of the social impact, and cost/benefits of volunteer flexible and family based services in and outside the Trial sites
- The potential costs of any undermining of carer resilience and informal support due to loss of respite outputs in transition



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Support of the Agency, including funding support, would be very welcome!

5 National Respite

National Respite is a small peak for small-medium not for profits that provide respite outcomes in the disability, aged and mental health care systems. Most of our members are in NSW, ACT and QLD, though we also have members in Western Australia and Tasmania, and work with respite Interchanges in South Australia and Victoria.

Our focus is the

interconnected well-being of people with disability, frailty from age or mental illness; and their chosen carers, family or informal support.

Our vision is to support strong relationships that support the lives people choose.

We thank you for the opportunity to make this submission. I can be contacted on 02 9789 1348 or 0408 863 590 if further details are required.

Yours sincerely

CHRIS GRATION
Executive Officer