



**Carers NSW and Carers Victoria joint submission to the
Joint Standing Committee on the NDIS inquiry into the
provision of hearing services under the NDIS**

30 January 2017

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

Introduction

Carers NSW and Carers Victoria wish to thank the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) for the opportunity to make a joint submission on the provision of hearing services under the NDIS. Our submission will focus on the experiences of people living with a hearing impairment in a care relationship.

Carers NSW and Carers Victoria are the peak non-government organisations for carers in their respective states, and are members of the National Network of Carers Associations. Our vision is an Australia that values and supports all carers, and our goals are to work with carers to improve their health, wellbeing, resilience and financial security; and to have caring recognised as a shared responsibility of family, community, and government.

For further information, please contact, either:

- Sarah Judd-Lam, Senior Policy & Development Officer, Carers NSW, on (02) 9280 4744 or at sarahj@carersnsw.org.au
- Rachel Vanstone, Policy Advisor (Disability and Housing), Carers Victoria, on (03) 9396 9528 or at Rachel.Vanstone@carersvictoria.org.au

Background

A carer is anyone who provides informal care and support to a family member or friend who has a disability, mental illness, drug or alcohol dependency, chronic condition, terminal illness or who is frail aged. The care recipient may be a parent, child, spouse/partner, grandparent, other relative or friend.

Care relationships are multifaceted and dynamic. Carers advocate for the health, safety, wellbeing, dignity and inclusion of the person living with a disability to ensure they meet their potential and lead a life of purpose and meaning. However, this often comes at a personal cost to the carer.

Caring can have negative effects on carers' own financial situation, retirement security, physical and emotional health, housing arrangements, social networks and career trajectory. The impact is particularly pronounced for carers of people who have complex chronic health conditions and both functional and cognitive impairment.

In a report prepared for Carers Australia by Deloitte Access Economics, it was estimated that informal carers in the Australian community provided 1.9 billion hours of care in 2015. Deloitte Access Economics conservatively estimates it would cost \$60.3 billion per year if all informal community care was delivered through formal care systems.¹

Carers provide communication assistance to 250,300 people in Australia,² undoubtedly including a large number of people with a hearing impairment. Furthermore, 870,600 carers – more than one in three – have a disability themselves.³

Eligibility

An estimated 760,700 people use communication aids for hearing loss in Australia.⁴ Permanent hearing loss is known to increase in prevalence with age,⁵ meaning large numbers of Australians with a hearing impairment are aged over 65 years and therefore not eligible for the NDIS.

However, in the first quarter of the national NDIS rollout alone, between 1 July 2016 and 30 September 2016, the National Disability Insurance Agency (NDIA) received 665 requests for access to the NDIS on the basis of a hearing impairment. Of this number 593 were deemed eligible.⁶ During the same quarter 139 plans were approved for participants with a hearing impairment.⁷

Our first concern is for the ineligible applicants. No further demographic information about these individuals is available, so we cannot be sure why they were denied access. However, this shows a substantial number of people with a hearing impairment may be excluded from the individualised, self-directed support offered by the NDIS. This is particularly concerning in states and territories rolling their entire disability support system into the NDIS, such as NSW.

Information, linkages and capacity building (ILC), a part of the NDIS, has a stream for individual capacity building which is prioritised for people with disability who do not have an NDIS plan.⁸ “The supports under this stream are often one-off, low intensity or episodic”.⁹ With the low level supports theoretically available to these individuals and/or their families, Carers NSW and Carers Victoria have a number of concerns:

- the ILC is presently being piloted in the ACT – the rollout for NSW starts mid-2018 and Victoria starts mid-2019¹⁰ – what, if any, are the interim arrangements?
- there is a lot of uncertainty about the program guidelines, which are not due to be released until November 2017;¹¹
- ILC support is very limited in scope, especially for carers;
- some states have appropriated specialist disability funding to the NDIS – few have quarantined reserves to support individuals ineligible for the NDIS. This could result in service delivery gaps for these individuals, their families and carers.

We urge the Joint Standing Committee on the NDIS (the Committee) to pay special attention to individuals ineligible for the NDIS and their families and carers to ensure there are no service delivery gaps. The consequences of not addressing potential service delivery gaps could include: individuals not receiving necessary supports; cost and obligation shifting to carers to meet necessary support needs; and inappropriate systems use, such as hospitals.

One group at risk of losing support is children with a hearing impairment who have been accessing the federally-funded Better Start Initiative for Children with Disability (Better Start). Better Start is an early intervention program for children with a range of disabilities, including

hearing impairment, up to the age of seven years. A key component of the program is a set amount of individualised funding for families to spend on therapies to assist with their child's development.

Better Start, like all federally-funded disability programs, is in scope for the NDIS and is currently transitioning in the national rollout sites. Better Start eligibility is based on diagnosis, whilst the NDIS is based on impacts on functional capacity. Perhaps as a result of this difference in focus, the two programs define and measure an eligible hearing impairment differently.

A child is eligible for Better Start if they have hearing loss in both ears that is either:

- average hearing loss of 40dBHL or greater in the better-hearing ear (the four frequency average hearing loss represents the average of hearing thresholds at 500 Hz, 1000 Hz, 2000 Hz and 4000 Hz); or
- Auditory Neuropathy Spectrum Disorder diagnosed in both ears.¹²

Access to the NDIS is not contingent on diagnosis or clinical assessment, however a list of diagnosed conditions are identified on the NDIS website as requiring no further assessment for children under six years of age. For a hearing impairment, this applies to a 45 decibels or greater hearing impairment in the better ear, based on a four frequency pure tone average (using 500, 1000, 2000 and 4000Hz).

The difference in criteria suggests some children may not be automatically accepted when applying for the NDIS for clinical reasons. We strongly recommend the Committee explores whether this is the case and if any children are adversely affected. However, the emphasis of the NDIS on impairment rather than diagnosis should theoretically imply likely eligibility for children with a significant and permanent hearing impairment.

Carers NSW is aware of one child with a hearing impairment who was deemed ineligible for the NDIS despite previously receiving Better Start. We are concerned this may apply to others. If a child cannot transition to the NDIS they will not receive any additional Better Start funding and may only access future intervention services that have Medicare item numbers, once their current package is expended.¹³ Furthermore, families living in outer regional or remote areas will no longer be able to claim the transport allowance of \$2,000 to provide assistance with travel and accommodation for attending appointments, or other expenses associated with accessing services.¹⁴

Recommendations:

- The Department of Social Services (DSS) report to the Committee on:
 - the number of Better Start recipients who have successfully transitioned to the NDIS;
 - the number of Better Start recipients so far deemed ineligible; and
 - the reasons for which Better Start recipients were denied access, including those with a hearing impairment.

- Once the above information is made available, DSS and the NDIA ensure Better Start families and providers are given accurate information regarding eligibility criteria for children.
- The NDIS participant transport allowance (support item number 02_051_0108_1_1) for the participant be offered by NDIA planners to the families who received the Better Start payment because they live in outer regional or remote areas, to ensure they can continue to attend necessary appointments.¹⁵

Funded supports

Carers NSW is aware of children successfully transitioning from Better Start to the NDIS but, in some cases, receiving a reduction in funded support as a result. While representatives of the NDIA in NSW have repeatedly stated Better Start recipients should only receive an equivalent or higher level of funding for early intervention therapies, this has not always been the case for NSW families. There is potential for this to become an ongoing problem as participant numbers rapidly expand throughout the full rollout across the country; this is inconsistent with the NDIS no disadvantage principle.¹⁶

Furthermore, the NDIS criteria for funding some assistive technology, notably iPads, are more restrictive than under Better Start. Carers NSW has heard that iPads, when requested, are often not included in plans because they are not deemed reasonable and necessary for the individual participant's needs and goals. For the most part, this is consistent with NDIS operational guidelines and appropriate for the long term financial sustainability of the Scheme.

However, Carers NSW has heard of cases where iPads have not been included in a plan, or have been inadequately funded for participants who, according to their carers, actually need them to communicate and participate in everyday life. In one case, a participant had a certain amount of money allocated in his NDIS plan to the repair and maintenance of assistive technology, but this did not cover the costs required to maintain his iPad. Another carer with two sons who are non-verbal had heard that a family in a similar situation to his own had been refused an iPad, even though the iPad was a critical tool for the participant to communicate with their family and the community.

Recommendations:

- The Committee review, in consultation with people with a hearing impairment and their families and carers, any reference packages developed for NDIS participants with hearing impairments to ensure assistive technology is adequately covered.
- Guidelines are developed for people with a hearing impairment and their families and carers on what types of assistive technology are available and what criteria and evidence are required in order for these to be funded.

Accessibility

The NDIS website is somewhat accessible to the Deaf community as it provides key information in Auslan.¹⁷ However, in Victoria and NSW to meet enrolment targets, the NDIA now relies on a telephone-based process to determine eligibility and develop participants' plans. A face-to-face meeting with an NDIA representative is available for people with complex communication needs,¹⁸ and should also be available upon request.

Carers have repeatedly told Carers Victoria that participants are not generally offered face-to-face planning meetings, and even if they request one, it can be difficult to convince the planner this is appropriate. Carers and participants in both Victoria and NSW, including those with communication difficulties and cognitive impairments, have in some cases been caught off-guard by an initial phone call, reducing their preparedness to ask for a face-to-face meeting. This phone-based system may also prevent participants or carers with a hearing impairment from fully understanding or participating in the planning process, and may result in inadequate information or poorly informed decision making.

Recommendations:

- Information about a participant or carer's communication needs are routinely identified early in the assessment process, such as from existing government data or via written correspondence (letter or email).
- Face-to-face meetings are routinely offered to participants or carers with identified communication needs.
- Participants and/or carers approved for a face-to-face meeting are routinely asked in advance and in a meaningful way, whether Auslan interpreting or a meeting room with hearing loop are required.

General comments

Carers NSW and Carers Victoria wish to reiterate our ongoing concerns about the recognition, inclusion and support of carers of NDIS participants.

Section 3(3)(c)(ii) of the *NDIS Act 2013* states that regard is to be had to the *Carer Recognition Act 2010* (the Act). The Act includes a Statement for Australia's Carers (section 6) which recognises and respects the critical role carers have in the lives of person they share a care relationship with. It emphasises partnerships in decision making with service providers, taking into account carers' own needs within and beyond the caring role, and providing them with timely support. As such, we stress the importance of upholding the Statement for Australia's Carers and ensuring DSS and the NDIA meet their statutory obligations.

The *NDIS Act 2013* further enshrines the importance of recognising care relationships:

- Section 4(12) states 'the role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected';

- Section 5(e) states ‘the supportive relationships, friendships and connections with others of people with disability should be recognised’;
- Section 31(c) states ‘the preparation, review and replacement of a participant’s plan, and the management of the funding for supports under a participant’s plan, should, so far as reasonably practicable:...consider and respect the role of family, carers and other persons who are significant in the life of the participant’.

In reporting on their compliance with the *Carer Recognition Act 2010* the NDIA stated “Carers can include a carer statement as part of the participant’s plan development, and this statement is recorded in the plan”.¹⁹ Now planning and review meetings have shifted to a shorter, generally phone based arrangement, usually conducted by a Local Area Coordinator, it is unclear whether or not carers are being given the opportunity to provide the Carer Statement to which they are entitled. This opportunity is not systematically provided nor communicated when NDIA planners are conducting planning sessions, despite continual advocacy by the National Network of Carers Associations to formalise and promote it.

Recommendations:

- The Committee review the recognition, inclusion and support of carers within the NDIS, especially the promotion and implementation of the Carer Statement.
- The NDIA be required to systematically promote and implement the Carer Statement whenever a carer is involved in the planning process.

¹ Deloitte Access Economics, (2015), *The economic value of informal care in Australia*, 2015, p iii

² ABS, (2017), *Disability, Ageing and Carers, Australia: Summary of Findings*, catalogue number 4430.0, Table 15.1

³ ABS, (2017), *Disability, Ageing and Carers, Australia: Summary of Findings*, catalogue number 4430.0, Table 33.1

⁴ ABS, (2017), *Disability, Ageing and Carers, Australia: Summary of Findings*, catalogue number 4430.0, Table 13.1

⁵ Access Economics (2006) *The economic impact and cost of hearing loss in Australia*. Access Economics.

⁶ NDIA, (2016), *COAG Disability Reform Council Quarterly Actuarial Report*, p 45.

⁷ NDIA, (2016), *COAG Disability Reform Council Quarterly Actuarial Report*, p 49.

⁸ NDIA, (2016), *Information, linkages and capacity building commissioning framework*, p,20

⁹ NDIA, (2016), *Information, linkages and capacity building policy*, p 12.

¹⁰ <https://www.ndis.gov.au/ILC-FAQ-Organisations> accessed on 24/1/2017

¹¹ <https://www.ndis.gov.au/community/ILCCommissioningFramework.html> accessed on 24/1/2017

¹² <http://betterstart.net.au/> accessed on 20/1/2017

¹³ <https://www.ndis.gov.au/document/factsheet-helping-children-autism.html> accessed on 20/1/2017

¹⁴ <http://betterstart.net.au/what-is-better-start/> accessed on 20/1/2017

¹⁵ NDIA, (2016) *NDIS price guide: Vic/NSW/QLD/Tas*, p 33

¹⁶ <https://www.ndis.gov.au/document/what-principle-no-disadvantag> accessed on 24/1/2017.

¹⁷ <https://www.ndis.gov.au/auslan> accessed on 20/1/2017

¹⁸ NDIA, (2016), *The NDIS in the North East Melbourne Area: Information for services providers regarding participant access*, p 2

¹⁹ NDIA, (2015), *Annual Report 2014-2015: Appendix 2: Compliance with the Carer Recognition Act 2010*. Available from <https://ndis.gov.au/appendices.html> assessed on 27/1/2017.