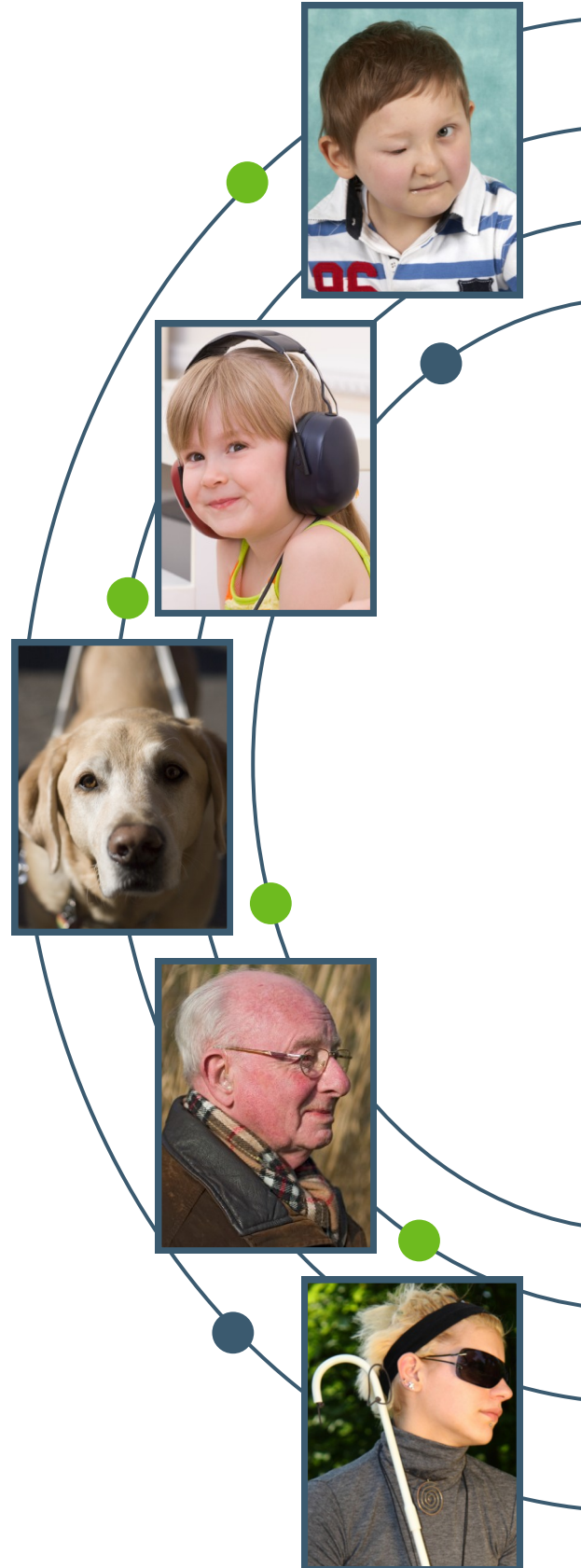




National Disability Services

# Connecting disability support with sensory need





**POLICY  
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### **About National Disability Services**

National Disability Services is the peak industry body for non-government disability services. Its purpose is to promote and advance services for people with disability. Its Australia-wide membership includes over 780 non-government organisations, which support people with all forms of disability. Its members collectively provide the full range of disability services—from accommodation support, respite and therapy to community access and employment. NDS provides information and networking opportunities to its members and policy advice to State, Territory and Federal governments.

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# **Connecting disability support with sensory need:**

NDIS, aged care reforms and people with vision and/or hearing loss

**National Disability Services**

## What's different about the sensory disability sector?

While the prospect of the National Disability Insurance Scheme (NDIS) is embraced by most of the disability sector, some people with sensory disability and the organisations that support them are sceptical that the needs of this group will be adequately met. There are features of the sensory disability sector which distinguish it from other parts of the disability sector and help explain the concerns.

People who receive support from sensory organisations are typically older than disability service users in general. This reflects the strong correlation between sensory loss and ageing. For instance, 79% of the service users of a large organisation assisting people with vision impairment are aged over 65 years. These organisations receive little or no government aged-care funding to support their work.

The services provided by sensory organisations differ in many respects from those provided by other parts of the disability sector. For example, assistive technology, orientation and mobility training and independent living training form a significant part of the work of organisations that support people with vision disability. This assistance is generally episodic or periodic and is often initiated by a change in a person's circumstances (their abode, educational setting or workplace), or by a need to replace or update assistive technology. Special note should be made of people who are deafblind; their need for assistance is often intensive and ongoing.

Organisations that support people with hearing disability are likely to provide interpreting services, sign language courses, independent living skills, counselling and social activities. Their provision of assistive technology is growing. Once again, most support tends to be episodic in nature (with the significant exception of interpreting services).

A further distinguishing feature is that sensory disability organisations typically rely less on government funding and more on public fundraising and volunteering than other parts of the disability sector. Guide dog associations attract funding for most of their activities through the appeal of their dogs. The NDIS is likely to fund guide dogs, but there are concerns that it may not fund the other activities that donations fund. If the capacity of such organisations to attract donations and volunteers diminishes as a consequence of the NDIS, it will result in either a reduction of much-needed services or an increased demand for government funding.

This paper seeks to identify the key concerns of the sensory sector and proposes responses.

## Early intervention is important

Children who are born with or acquire hearing and/or vision disability are an important exception to the age profile of the sensory disability sector described above. Services to these children in their early years are intensive and of significant duration. These children will often have extensive interaction with the health system for items such as cochlear implants or hearing aids, or ongoing vision assessment.

The sensory disability sector rightly underlines the importance of early intervention for many people with disability. Children with sensory disability need to receive timely, appropriate and sufficient interventions to support their development across a range of domains—communication, social, emotional, physical and educational. These intervention services are likely to be needed at different times and with varying intensity throughout their childhood. Similarly, adults who acquire sensory loss often require early intervention and skill development.

Some concern has been expressed that people with significant sensory disability will be excluded from Tier 3 support under the NDIS. Given the projected expansion of the service user population and the NDIS's strong focus on early intervention, there seems no reason to suppose that this will be the case. However, the NDIS will require good interfaces with allied sectors, particularly health and education. The introduction of the NDIS should entail practical protocols being put in place for how these sectors will work together to best assist children and adults with a recent onset of sensory disability.

The assessment of children should combine the 'technical' definitions of sensory loss (such as those used in the Better Start initiative) with consideration of how a child is functioning within their environments. Taken together, these factors would determine how a child may benefit from early intervention. This approach would also enable consideration of a family's capacity to support their child's development and whether additional services to support the family (such as respite) are required. The assessment of adults should also combine diagnosis and functional need but should also include consideration of the goals the person has for their future.

It is important to stress the complexities that can arise for children with sensory disability and respond to them appropriately. For example, it is not uncommon for a measure of visual acuity to be deferred until a child is about 3 years of age. For many children, early intervention should not be delayed until this formal assessment has been made; other factors should be used to determine eligibility. And for a deaf child with a cochlear implant, sign language should also be taught to enable the child to communicate while participating in activities such as swimming or when the cochlear implant is not functioning.

## How the NDIS can respond to the sector's concerns

Broadly, the concerns of the sensory disability sector about the NDIS are:-

- Because of age eligibility, the NDIS will not assist the many people who experience sensory loss over the age of 65, and the aged care system is ill-equipped to assist these people as well;
- People with vision or hearing loss often require relatively low-frequency episodic or periodic support and therefore won't qualify for Tier 3 funded support (it is important to note that this episodic support may be of high intensity);
- Although specialist aids and equipment programs are part of the NDIS, historically these programs have excluded the assistive technology used by people with sensory loss—and this may continue;
- If the public sees the NDIS as an entitlement scheme that provides government-funded disability services to all who require such services, public fundraising and volunteering will diminish, thus, reducing the capacity of sensory disability organisations to assist people who do not meet NDIS Tier 3 eligibility criteria.

The following proposals provide further explanation and seek to address these concerns.

### 1. Ensure that a person with an episodic need for assistance has access to support

As noted above, some people who require occasional support—such as updating assistive technology or time-limited independent living or orientation and mobility training—are concerned they will not be eligible for Tier 3 support. This concern is complicated by the fact that some of the services people receive are currently provided through the education or health systems (for example, hearing aids for people under 25 years).

Principle 1 of the *High-level Principles for a National Disability Insurance Scheme* states:

A National Disability Insurance Scheme should be needs based and provide people with disability access to individualised care and support...

- a. Provide certainty for people with disability in accessing high quality and effective services and support when they need them...

This appears to encompass episodic support being available when it is needed.

Assure people with sensory disability that an occasional need for assistance will not in itself mean they are ineligible for funding under the NDIS.

Negotiate protocols between the NDIS and allied sectors—such as health and education—which ensure that people with disability receive the support they require.

## 2. Improve the availability of assistive technology

Important to many people with disability is access to affordable assistive technology, which includes consumer information; support to select the most appropriate item/s of aids and equipment; installation and training; and maintenance and repairs. Importantly, it must be available to people regardless of age.

The delivery of appropriate and timely assistive technology to those who need it has benefits including: improving the quality of life for those with disability and their families; reducing reliance on expensive personal support; lessening the need for accommodation support or residential care admissions; reducing family carer injuries and stress; increasing participation in employment and education; reducing hospital admissions; and shortening hospital stays<sup>1</sup>.

Unfortunately, much of the assistive technology used by people with sensory disability is not currently available through the existing aids and equipment schemes operated by state and territory governments. Under the NDIS this must change.

Ensure that the equipment used by people with sensory disability—often to support communication, mobility and independence—is available under the NDIS; and regularly update notions of ‘eligible equipment’ to reflect technological advances.

## 3. Block fund some assistive technology

The provision of most assistive technology requires careful assessment and even training (significant for items such as canes for people with low vision and electronic communication devices); these items would form part of an individual’s package of funding or support. However, there are other items that should be easy to obtain. These items include replacement tips on canes or walkers, some magnifiers and lamps, large button or captioned telephones and daily living aids such as liquid level indicators and visual alarms.

The NDIS should block fund specialist equipment banks for low-cost, low-risk, low-training assistive technology (and associated replacement parts). This type of equipment is currently provided by many sensory organisations and should continue—without unnecessary red tape—under the NDIS. In addition, services such as an audio book library and a technology helpdesk should also be blocked funded.

Investigate the optimal way to provide different classes of assistive technology during the design of the NDIS (this investigation should include not just sensory disability equipment but also the equipment some organisations lend to people with progressive conditions such as motor neurone disease).

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<sup>1</sup> For examples, see ‘The Equipping Inclusion Studies: Assistive Technology Use and Outcomes in Victoria’ at <http://www.aeaa.org.au/documents/Equipping-Inclusion-Full-Reports-FINAL01Oct-2010.pdf> and Connell J, Grealley C, Olver, K and Power J, (2008), Comprehensive scoping study on the use of assistive technology by frail older people living in the community, Urbis for the Department of Health and Ageing.

#### 4. Block fund guide dogs

The provision of guide dogs is time-consuming and costly—the breeding of puppies, overseeing their wellbeing and early education, the intensive training of the young dogs, and the training of the dog with the person who is visually impaired. An additional cost arises from the fact that a significant proportion of puppies do not ultimately meet the stringent assessment criteria.

Unlike much assistive technology, guide dogs are not sitting on a shelf waiting to be purchased and customised; a breeding and education program must be in place to respond to future demand. Much of the investment is required before the end user is even identified. The breeding and training of guide dogs is a highly-skilled undertaking and should be governed by adherence to appropriate quality standards. The absence of standards would impose significant risk on the guide dog user.

Block fund organisations that supply guide dogs and ensure appropriate standards.

#### 5. Provide for people with hearing impairment

Some members of the deaf community are not convinced the NDIS will adequately provide for their needs. They question whether people will have sufficient access to AUSLAN/English interpreters or deafblind interpreters—relatively expensive services—and whether AUSLAN or deafblind interpreter training will be provided to the parents and siblings of deaf children. There is also concern about whether the NDIS will keep abreast of rapidly-changing technology to ensure access to the best supports and assistance available. In addition, hearing aids are currently provided through schemes which, even when taken together, fail to give consistent and equitable coverage for all who need them.

Provide appropriate assistive technology and a reasonable allowance for AUSLAN/English or deafblind interpreters to help allay the concerns of the deaf community; provide the parents and siblings of deaf children with funded access to AUSLAN or deafblind interpreter training.

Invest in the infrastructure required to improve the availability of cost-effective services that utilise digital technology, such as videoconferencing for interpreting and for services such as captioning.

Negotiate with the health system to address inequities in the current provision of hearing aids.



## 6. Promote public support for the not-for-profit sector

If the general public come to believe that the NDIS adequately supports all people with disability who require support, they may stop contributing through donations, bequests or volunteering—which service organisations currently rely on to support many people with sensory disability.

The COAG-agreed high-level design principles acknowledge that the NDIS should “not create any disincentives for carers and family members to provide support”. The principle should be extended to public support through fundraising, bequests and volunteering.

The COAG principles also indicate that the National Disability Strategy should inform the NDIS design, recognising that social and economic opportunities for people with disability require more than government-funded services.

The message of the NDIS should be consistent with the National Disability Strategy: support and opportunities for people with disability require a strong and active partnership with the broader community.

## Improving the ageing-disability interface

A key concern identified above is that the NDIS will not assist the many people who experience sensory loss over the age of 65, and the aged care system won't assist these people either. Responding to this concern requires considering not just the design of the NDIS but also the reforms proposed for the aged care system.

Two major inquiries completed last year by the Productivity Commission (PC)—*Caring for Older Australians* and *Disability Care and Support*—identified difficulties some older adults experience when seeking support. These difficulties arise from issues including:

- tightly rationed systems that manage high demand by limiting access and/or restricting the level of support provided; and
- service responses are determined by age and prescriptive program boundaries rather than need.

The PC noted that “there are significant variations in the philosophies and goals in each sector [aged care and disability], the services that people use and their aspirations”<sup>2</sup> and that “there are compelling arguments that the systems should be differentiated in terms of objectives, the role of co-contributions, the appropriate elements of funded support packages, and in funding sources.”<sup>3</sup> However, in each of its reports it noted that people should receive the support they need:

Irrespective of the funding source or assessment arrangements, all people with a disability and all older people needing care and support should receive services appropriate to their needs, on a fair and equitable basis.<sup>4</sup>

There should be no artificial barriers to people accessing eligible services, even if those services are notionally identified as primarily serving the demands of the aged care or disability system. Rather, the critical concern is to ensure that people would be able to use the support system that best met their needs, regardless of the funding source.<sup>5</sup>

The PC's recommendations on reforming the disability and aged care systems reflect the age delineation established under the National Health and Hospital Network Agreement. Accordingly, the PC found the NDIS should provide support for people who acquire a significant disability before the age of 65 years (other than those who would be eligible for support under the National Injury Insurance Scheme). These people could elect to have their support funded by the NDIS for the remainder of their life, or on reaching 65 years (or any time thereafter) they could elect to move to the aged care system (and be governed by all the processes of that system). People who become eligible for support when aged over 65 years would have their support needs met by the aged care sector.

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<sup>2</sup> Productivity Commission 2011, *Caring for Older Australians*, Report No.53, Final Inquiry Report, Canberra, p. 182.

<sup>3</sup> Productivity Commission 2011, *Disability Care and Support*, Report No.54, Appendix C: Disability and aged care interface, Canberra, p. C.7.

<sup>4</sup> Productivity Commission 2011, *Caring for Older Australians*, p. 182.

<sup>5</sup> Productivity Commission 2011, *Disability Care and Support*, p. C.7.

The Australian Government has since announced reforms to the aged care sector. Key elements of the reforms that interface with disability are:

- developing a 'My Aged Care' website and a new gateway for access;
- integrating the Home and Community Care Program (HACC) with the National Carers and Respite Program and the Day Therapy Program to create a new Commonwealth Home Support program;
- introducing a nationally consistent approach to user contributions for community-based and residential aged care services (comprising an annual and a lifetime cap); and
- increasing the number of Home Care packages (and adding two new levels).

The reforms include an important commitment to maximise the independence of older people, promising to review

... the service types delivered through the new Commonwealth Home Support program to ensure that they target best value, evidence based services optimising prevention and restoration. This will ensure older people avoid unnecessary progression to high care, high cost services.<sup>6</sup>

If the aged care system is to become more responsive to the needs of people who acquire sensory disability with age, it is essential that this review broadens the scope of Home Support services to include specialist disability services that provide a cost-effective intervention to support older people. The aged care reform agenda provides scope to improve services to people with sensory loss.

## 1. Consider sensory loss during assessment

Receiving good support hinges, in part, on careful and appropriate assessment. Currently, Aged Care Assessment Teams are the gateway to aged care services but extensive anecdotal evidence indicates that they frequently refuse to assess older people with long-term disability or, when they do, that they have difficulty in determining what level and types of support the individual needs. Under current aged care assessment processes consideration of whether a person would benefit from a specialist disability service (such as orientation and mobility training for someone losing their vision) rarely occurs.

Negotiate clear assessment processes and protocols for the interface between the NDIS and the aged care system; encourage interaction between assessment staff at the 'gateways' to the two systems to improve their knowledge.

## 2. Improve the availability of assistive technology for older people

A current shortcoming of aged care has been the extremely limited recognition of the important role assistive technology has in maintaining the independence and wellbeing of older people. Many older people are denied access to state-administered aids and equipment programs.

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<sup>6</sup> Department of Health and Ageing 2012, *Living Longer. Living Better. Aged Care Reform Package April 2012*, Canberra, p. 27.

Good access to assistive technology should be a feature of reforms to the aged care system; it is a false economy to deny older people affordable access to this assistance.

Negotiate with aged care to jointly fund and establish a single assistive technology provision service that can be accessed by people with disability and people in the aged care system.

### **3. Increase the service options available through the Home Support program and Home Care packages**

The Australian Government's aged care reforms refer to the need to improve the interface between basic Home Support and other aged care programs "so that care recipients can move smoothly through an end-to-end aged care system as their needs change". It advocates national consistency of care that is equitable, regardless of where people live. Sensory disability services (such as orientation and mobility training and rehabilitation) should be available through the Home Support program and Home Care packages.

Negotiate improved access to specialist disability services such as therapy, orientation and mobility training, independent living training, assistive technology and rehabilitation for older people experiencing sensory loss.

Consumer-Directed Home Care packages are a welcome development in assisting older people to remain living at home. In design, they reflect aspects of the trend in disability services to increase choice and control for people with disability.

Fast-track the proposal to make consumer-directed care an option in all community care packages, thereby reducing the differences between the NDIS and the options available for people who acquire disability over the age of 65 years.

Minimise differences between the NDIS and the aged care system by allowing self-managed options in Home Care packages.

As well as providing more control, this option would allow the purchase of a greater level of services, as the package would not have an administration fee applied (the average administration fee applied in the Consumer Directed Home Care package is approximately 20 per cent). In reality (based on UK experience), only a relatively small number of older people would choose this option; but, for that group, having control over their support arrangements would be valuable.



