

Response to the Disability Care and Support: Productivity Commission Draft Report

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Deaf Australia is pleased to have the opportunity to make this second submission to the Productivity Commission's inquiry into a long-term disability care and support system.

Acknowledgement

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About Deaf Australia

Deaf Australia is the only Australian peak body, managed by deaf people, representing deaf people and their communities. We work with Australian Governments and collaborate with key stakeholders to ensure that Australia complies with the United Nations Conventions on the Rights of Persons with Disabilities.

Our Vision:

Deaf people are respected and fully included in the Australian Community and the right to use Auslan is legally recognised.

Deaf Australia commends the Productivity Commission on their Draft Report on Disability Care and Support in Australia.

Generally, Deaf Australia supports the Draft Report's proposals for the establishment of a National Disability Insurance Scheme, and believe that if done well, and with some further adjustments, it will lead to significant and positive change for deaf people.

However, we do have a number of concerns and would like to make the following comments:

1. Who is included

- People with severe and profound disability are eligible for tier 3 services. This will include many deaf people who use Auslan.
- Tier 3a covers people with significant communication limitations. We assume this will include deaf people.
- Tier 3c covers the early intervention group that would benefit from early therapeutic interventions that would improve levels of functioning. We assume this would include people who would benefit from hearing aids, cochlear implants, learning Auslan and lipreading.
- It seems that people with mild/moderate disability may not be eligible for tier 3 services. This is a problem because degree of deafness alone is not necessarily a reliable indicator of functional ability and support needs. For people with mild and moderate hearing loss the impact is lifelong and significant. These people need support and many people in the Deaf community who use Auslan are actually only mildly or moderately deaf.
- The proposed Tier 2 referral to available mainstream services as the only support available for people with mild or moderate deafness will be unlikely to meet the needs of these people. It has already been shown that referral to mainstream services does not always work for deaf people, including those with mild/moderate deafness. Many need (1) access provisions e.g. interpreting or real time captioning support to enable them to use mainstream services; and (2) help to understand mainstream services because of poor access to education which

leads to poor English literacy and poor general knowledge. These people need to have access to tier 3 type support so that the referral to mainstream services can be effective.

• We wish to reiterate the position stated in our first submission that any person with a disability (including any person who is Deaf or has a hearing loss, regardless of the degree of hearing loss, or who is deaf/blind) should be eligible for the new scheme – including tier 3. Deaf Australia believes the new scheme should be for everyone who needs it regardless of who they are, when or how they got the disability, or the degree of disability/impairment, with support from the community they are involved in. This is outlined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) Article 4 (c), To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes. This includes all people from birth to seniors over age 65 and should include groups such as migrants and persons in the correctional services system and other institutional settings.

2. What services can be received

• The Draft Report Overview (page 21) seems to identify several supports under the scheme, and seems to limit what supports will be available. There are other supports that deaf people need, and Deaf Australia re-asserts the needs of all deaf people to have access to the following supports in addition to those mentioned in the Draft Report to enable them to actively participate in the community and lead active and productive lives:

Aids & Appliances and home & vehicle modifications.

It is now compulsory in all states and territories for buildings including private homes to have fire alarms. Deaf and hard of hearing people need visual alert (flashing light) or vibrating unit fire alarm systems, which come at a cost of over \$400. Non deaf people can purchase an audible fire alarm from K-Mart for \$20. Some states and territories have funding to subsidise the purchase of suitable fire alarms, however, not all deaf people are eligible and even those who are still sometimes have to pay \$50 towards the cost of the unit – it still costs them much more than a fire alarm costs a non-deaf person.

Personal Care

Deaf seniors now in aged care centres are unable to actively participate in the general activities of the centre because the programs or services are largely inaccessible to them due to their deafness and the fact that staff and other residents do not have the skills to communicate with them, resulting in their being lonely and isolated within the aged care system. Anecdotal evidence indicates that deaf seniors dread having to move into aged care centres for this reason.

Community Access Support

This would be a most significant aspect of deaf people's needs. As stated in our first submission, significant numbers of deaf people are born to hearing parents who have little or no knowledge of deafness. Communication and access to the community are often difficult because no one seems to know how to communicate effectively or is able to accommodate deaf people's needs (and their family's needs).

In addition, most deaf people who are interested in learning skills or taking short community courses are faced with barriers as community centres do not have funding to provide interpreters or other supports.

Respite

Parents of deaf children are often the sole provider of everything the deaf child needs. However, Deaf Australia believes that these parents are often driven to frustration with

lack of appropriate support and services and need time out to recharge. Deaf children also need a place where they can be actively involved in activities without their parents watching and being involved in their every activity; this would be a key contributor to the development of self-esteem and confidence, which is severely lacking in many deaf people.

Domestic Assistance

Due to communication barriers within the family and at school, a number of deaf people need to learn basic living skills and personal safety and grooming skills when leaving school.

Specialist employment services

Most mainstream employment agencies do not have the basic skills required to work with people who have a hearing loss and have difficulty finding work placements for them. Anecdotal evidence indicates that it takes longer for deaf people to find employment than it does for non-deaf people and they are working at a job that they dislike and is not a good match for them.

Therapies

Deaf people often need access to suitably qualified service providers who understand the needs of deaf people. They often face a long wait for a specific person to become available, and often the person charges a very high rate which deaf people are unable to afford given their current status in the employment sector (as outlined in our first submission).

Crisis/ Emergency support

In crisis or emergency situations, and even in such 'everyday' events as a death in the family, what is a traumatic situation for anyone is made much more so for deaf people because they have to struggle harder to find what support/services are available to them and then when they do find them the communication issues and barriers add an additional layer of trauma.

- Deaf Australia recognises that some elements of existing provisions such as the
 Disability Discrimination Act (DDA) play a vital role in promoting deaf people's right to
 access the community and services. However the DDA does not provide clear guidelines
 on what is 'reasonable accommodation' and it is left to service providers to interpret the
 term irrespective of information and requests from deaf people. Deaf Australia believes
 that greater education and awareness of human rights is needed in the mainstream
 community.
- Deaf Australia believes there are three approaches to supports that deaf people need:
 - Direct support for deaf children and their families to develop communication support/skills enabling them to effectively communicate within the family, and providing deaf individuals access to services that are appropriate for deaf people.
 - Information support for service providers to know and understand what specific support is needed for deaf people to access their services, i.e., information about deafness, communication needs and interpreting needs.
 - General information appropriate referral system that provides guidance and support for people seeking information about deafness.

3. Individualised support packages

- The concept of individualised support packages is excellent, but only if design of the packages is based on significant self-assessment and is not decided solely or even largely by an independent assessor.
 - Deaf Australia also has an ongoing concern that deaf people will be coerced or required to accept 'supports' that they do not want e.g., hearing aids and cochlear implants: not all deaf people want them or find them useful.
- Support delivered through the individual via vouchers or cashing out supports and buying own supports. This is fantastic for many deaf people they know what they need and are capable of arranging their own supports, making their own choices.

4. Disability Support Organisations

- Disability Support Organisations to advise and help people and families to manage their
 resources and provide service brokering is an excellent proposal for deaf people. Because
 many deaf people do not get a good education and service provision has been paternalistic for
 so long, many are not accustomed to making their own decisions. This aspect of the NDIS
 would be especially valuable as a transition from dependence to independence.
- However, Deaf Australia has some concerns about the suggested functions of Disability Support Organisations, as outlined in points 7 and 11 below.

5. Workforce

 One of the challenges with the expected increase in demand for workers in an expanded disability support system is to provide suitably skilled people and this will be a big issue for the deaf sector because of the need for Auslan skills. It could offer more employment opportunities for deaf people themselves.

6. NDIS and aged care

- For people who are deaf before age 65, the ability to keep NDIS supports after age 65 is important for deaf people – their needs do not stop at age 65 – and we appreciate that the proposal allows this.
- For people who lose their hearing after age 65 the divide between NDIS and aged care is a problem. These people need supports as much as people younger than age 65 and they should not be excluded from NDIS supports.

7. Service models

- Deaf Australia strongly supports the concept of consumer choice models of service provision that allow for support packages where the person chooses their service providers either themselves or through a Disability Support Organisation.
- For deaf people, currently there is mostly only 1 major service provider a Deaf Society in
 each state. There are a few other service providers such as the National Auslan Interpreter
 Booking and Payment Service for private health appointments (NABS) and some independent
 interpreting agencies but deaf people themselves generally go mostly to their state Deaf
 Society for all their support needs.
 - The proposed new model could encourage the rise of more service providers and more choice and we believe this would have a positive impact.
- However, there are some questions about the proposals. Would Deaf Societies continue to be service providers? Or would they be Disability Support Organisations? Or both?

The Draft Report does say that service providers could possibly also be Disability Support Organisations (but in that case they could not also take on the function of brokering support services for people with disabilities).

- Deaf Australia believes that allowing service providers to also be Disability Support
 Organisations would mean that for deaf people the current system of paternalistic service
 provision and dependence on one organistion would simply continue in a slightly different form
 and there would be little if any improvement in deaf people's independence and selfdetermination.
- Service provision and Disability Support Organisations need to be clearly separate functions.

8. National standards for service provision

 The proposal for nationally consistent standards for service provision based on consumer outcomes, and some performance information about service providers being made available to consumers is excellent and will help empower deaf people.

9. Access to mainstream education, employment and mental health services

- Deaf Australia understands the logic of not including mainstream education, employment and health services in the NDIS. However, this is a big problem for deaf people. The current mainstream service system for education, employment and mental health does not meet the needs of deaf people and will continue to not meet them under the NDIS as proposed in the Draft Report.
 - Education. The current system for interpreting support is atrocious, particularly in schools where unqualified and poorly skilled 'educational interpreters' are frequently used.
 Teachers with appropriate skills, particularly Auslan, and training in specific teaching methodology, particularly Auslan/English bilingual methods, are thin on the ground and schools generally are unable to provide the type of educational access and support that deaf people need.
 - Specialist education supports such as Auslan interpreting and bilingual programs should be included in the NDIS.
 - Employment. The problems with mainstream employment services could perhaps be resolved with interpreters and deafness awareness training provided through the Employment Assistance Fund or specialist support from the NDIS to enable access to mainstream employment services, but the availability of these supports for this purpose needs to be clear.
 - Mental health. Access to mainstream mental health services is not enough. Mainstream clinical mental health service providers do not generally understand or know how to respond to deaf people's experiences that lead to mental health issues. Deaf people need specialist mental health services, but these services are not widely available, only Queensland has one. The NDIS needs to include specialist mental health services.

10. Access to mainstream general health services

 Currently deaf people are able to have free interpreting for private and public health appointments, funded by government, and we would assume this will continue either in its current form or be included in the NDIS.

However, hard of hearing people who do not use Auslan do not have the same level of access to mainstream general health services. There are currently suggestions that real time captioning access should be provided, and something along these lines should be included either under the National Disability Strategy or in the NDIS.

11. Advocacy

- The Draft Report does not adequately deal with the issue of advocacy. This is an area that is absolutely vital. Without a clear and adequately resourced advocacy system, real change is unlikely.
- The Draft Report does say that one of the functions of Disability Support Organisations (DSO) would be advocacy, which in this context appears to mean individual advocacy.
 - But if a DSO is providing management services i.e., managing the individual's support package for them and is also providing advocacy support, this is a conflict of interest. Where would the disabled person be able to go for advocacy support if they were not happy with the DSO's management of their support package? A complaints system does not solve this problem many deaf people need advocacy support to help them make complaints; deaf people are notoriously shy of/afraid to make formal complaints about their specialist service providers.
- The Draft Report also suggests that it is acceptable for a service provider to also be a
 Disability Support Organisation. We strongly disagree with this. If service providers are also
 Disability Support Organisations then service providers can also be advocates, under the
 proposed model. The provision of both services and advocacy about services by the same
 organisation is a conflict of interest and not in the best interests of people with disabilities.
- The Draft Report does not appear to address the issue of adequately resourcing systemic advocacy.
- Advocacy needs to be separate from other disability services provision, and from the Disability Support Organisation function. Without this separation between services and advocacy, there will be little real change at the fundamental human rights level and the current system of paternalistic and controlling service provision will continue largely unchanged. Deaf Australia believes this very strongly and urges the Productivity Commission to address this issue in the final report with recommendations for adequately resourced and clearly separate advocacy support (both individual and systemic).

Overall, although Deaf Australia supports the general proposals outlined in the Draft Report we believe that it does not sufficiently address the issues and needs of people who are Deaf or hard of hearing and their families and that the scheme also need to take into consideration cultural and linguistic needs of this minority group to enable them to engage actively in the Australian community. We would like to refer to the UN Convention on the Rights of People with Disability which states:

'Recognising the importance of accessibility to the physical, social, economic and cultural environment, to health and education and to information and communication, in enabling persons with disabilities to fully enjoy all human rights and fundamental freedoms' (preamble v).

References:

- United Nations Convention on the Rights of Persons with Disabilities
- Disability Care and Support: Productivity Commission Draft Report, February 2011