

# Response to draft recommendations

Deaf Children Australia and the West Australian Deaf Society generally support the finding of the Commission that the current system in Australia is underfunded, unsustainable and in desperate need of reform. We welcome the directions of the Commission in the draft report and recommendations and offer further comment in regards to the following recommendations:

DRAFT RECOMMENDATION 3.2

***Individuals receiving individually tailored, funded supports should be Australian residents, have a permanent disability, (or if not a permanent disability, be expected to require very costly disability supports) and would meet one of the following conditions:***

- ***have significant difficulties with mobility, self-care and/or communication***
- ***have an intellectual disability***
- ***be in an early intervention group, comprising:***
  - ***those for whom there was a reasonable potential for cost-effective early therapeutic interventions (as in autism and acquired brain injury)***
  - ***those with newly diagnosed degenerative diseases for whom early preparation would enhance their lives (as in multiple sclerosis)***
- ***have large identifiable benefits from support that would otherwise not be realised, and that are not covered by the groups above. Guidelines should be developed to inform the scope of this criterion.***

Deaf Children Australia does not agree with the inclusion of Intellectual Disability as to do so will likely result in applications being made under the ID category when other more specific categories would be more appropriate. We believe this distortion has occurred with the recent Autism Early Intervention packages. A broader category of brain function impairment or simply using the remaining categories – perhaps specifically the “large identifiable benefit ....” would suffice.

For the reasons mentioned above we accept the “communication difficulty” will sufficiently identify eligibility for deaf people and also relates to the “experience of” rather than simply the “fact of” impairment.

DRAFT RECOMMENDATION 3.7

***The supports to which an individual would be entitled should be determined by an independent, forward-looking assessment process, rather than people's current service use.***

These assessment processes need capacity to embrace difference in disability type, language and culture. Assessors will need to receive training in the use of interpreters (including sign language interpreters). Assessors themselves should be representative of disability groups and be appropriately trained.

DRAFT RECOMMENDATION 4.4

***People should pay the full costs of services (primarily therapies) for which clinical evidence of benefits are insufficient or inconclusive if they wish to consume those services.***

Is there a danger here? For example, will individuals be “required” to undertake certain interventions and if they choose otherwise may be not supported and have to meet those costs? A specific example could be a requirement to undergo a cochlear implant procedure rather than utilising a more cultural view of deafness and using sign language as a means of communication which would require financial support for interpreters?

A rights-based model must embrace a generous view in regards to an assessment of “clinical benefit”.

DRAFT RECOMMENDATION 4.5

***Services that meet the needs of much wider populations, including people with disabilities not covered by the NDIS, should lie outside the scheme:***

- ***health, public housing, public transport and mainstream education and employment services, should remain outside the NDIS, with the NDIS providing referrals to them***
  - ***but specialised employment services, disability-specific school to work programs, taxi subsidies, and specialised accommodation services should be funded and overseen by the NDIS.***

We are particularly concerned that there will be a difficult line to draw in the area of deafness and health, education and employment.

In the health arena we ask why the services of Australia Hearing should be allowed to stand outside an NDIS when its work is entirely concerned with assisting people to maintain communication in their daily lives through the provision of hearing aids. This is a unique disability specific service, not a mainstream health service. There is also a major gap in this program at present with eligibility being restricted to children up to the age of 21 after which “you are on your own” unless a pensioner or arrive at Age pension age. This represents a major quality of life and financial burden for many deaf people.

As we mentioned in our appearance at the Melbourne Hearings, this is a major problem as the provision of hearing aids for working age deaf people in the workforce is not supported and a recent decision closed a small door that had opened in the Employment Assistance Program operated by DEWR. Access to communication technology and interpreting services definitely need to be eligible services for deaf people.

In this regard we fear that there may be a serious under estimation of the number of individuals who have “long term” support needs.

DRAFT RECOMMENDATION 8.1

***The NDIA should support consumer decision-making by providing:***

- ***a centralised internet database of service providers that indicates the ranges of products and services, price, availability and links to measures of performance and quality***
- ***well resourced and effective provision of advice and information to clients, as well as monitoring of their wellbeing. These services should be graduated in terms of the needs of the client and concentrated at key points, such as when entering the disability system or important transition periods.***

There seems to be opportunity here for specific DSOs to be providers of information and advice with regard to monitoring outcomes although this needs to be made clearer in order to comment further.

DRAFT RECOMMENDATION 11.1

***Early intervention approaches used by the NDIA should draw on evidence of their impacts and be based on an assessment of the likelihood of cost-effectiveness. NDIS funding for early intervention should be additional to that allocated to clients for their ongoing care and support and should not be able to be cashed out under self-directed care packages.***

Within the Deaf sector there is currently a major focus on the use of cochlear implant technology including bi-lateral implants for deaf children. While initially implantation was considered only for profoundly deaf children increasingly infants with mild and unilateral loss are being implanted. There is also a trend to double implants as evidence appears to support the benefits in this regard.

Similarly, recognised “therapies” are too often medical in nature as in speech therapy, audiology, and psychology; when interventions such as role models, mentors, and language tutors can provide equal or better value. If the proposed NDIS is to achieve its expectations then an open and client centred view of appropriate interventions will be required.

DRAFT RECOMMENDATION 11.2

***The NDIA should build an evidence base on early intervention. It should commence this task by identifying, in consultation with stakeholders, existing or potentially promising approaches for further research.***

It will be essential that these consultations be specific to the particular intervention as for example in the deafness area there are considerable differences in stakeholder views about appropriate approaches and the cost benefit of each approach. Wide stakeholder involvement will be required as well as a non-medical approach being core to the task.

DRAFT RECOMMENDATION 13.1

***The Australian Government should attract further support workers into the disability sector:***

- ***by marketing the role and value of disability workers as part of the media campaign launching the creation of the NDIS***
- ***by providing subsidies to training of disability workers***
- ***through immigration of support workers, but only in the event that acute and persistent shortages occur, and drawing on the lessons from the Canadian Live-In Caregiver program and other similar programs.***

We would support the development of national training and development plans for specific sectors for example in the deaf sector the availability of interpreters is a recurring challenge to access.

Wage levels are currently a problem and to effectively embrace the opportunity of an NDIS there must be a corresponding focus on attractive wage outcomes to ensure retention of skilled workers in a more competitive environment as well as to attract new people to the field.

DRAFT RECOMMENDATION 13.2

***Australian governments should ensure that, across all jurisdictions, police check arrangements for paid workers providing services to people with a disability:***

- ***apply only in cases where both the person with a disability is vulnerable AND the risks associated with delivery of services are sufficiently high***
- ***not include disclosure of crimes covered by spent convictions legislation***
- ***cover people for a given period, rather than for a particular job.***

This is a complex area. As a service provider the current requirement is costly and onerous and it could be said provides minimal assurance of protection being effected. At the same time we consider that particular jobs do represent higher risk, and that it is imperative that standards are maintained to ensure the professionalism and credentials of workers.

A related matter is that of standards and qualifications of staff. In the deaf sector we face the challenge of standards being eroded by unqualified personnel in the interpreting arena. When there are ongoing supply side issues several operators are lowering standards which impact the quality of service provided. Short cuts are taken on the basis of “consumer agreement” and “best available fit”. While we accept that in a rights-based system the consumer is the final arbiter, the NDIS must be proactive in ensuring standards are appropriate and that consumer training, information and advice are available.

DRAFT RECOMMENDATION 13.3

***In order to promote training and counselling for carers, the NDIS should:***

- ***assess carer needs as well as those of people with disabilities (draft recommendation 5.6) and, where needed, use the assessment results to:***

- *refer people to the ‘Carer Support Centres’ recommended in the Commission’s parallel inquiry into aged care and to the National Carers Counselling Program*
- *include the capacity for accessing counselling and support services for carers as part of the individual support packages provided to people with a disability*
- *assess the best training and counselling options for carers of people with disabilities as part of the NDIS research and data collection function.*

This is an area of particular interest to Deaf Children Australia. We have been piloting in the provision of Parent-to-Parent mentoring programs in Queensland and Victoria post diagnosis of hearing loss. We also work with families to develop support networks across Australia as well as supporting on-line opportunities for carers to network informally and on immediate needs.

All too often these opportunities rely on volunteers and there is an urgent need to finance activities that reduce the burden of the carer. Along with international comparators, we have found that specific networks and support for the deaf and hearing impaired are needed. Parents of deaf children have consistently demonstrated a lack of interest in broader disability carer networks for their own supports and answers to question in relation to their child. Examples in Australia are the system of informal POD (Parents of Deaf) groups operating, as well as on-line supports like Aussie Deaf Kids.

While general information centres have a place, the social capital involved in specific groups for parent information and support in our domain as well as associations such as Fragile X, and Downs Syndrome Australia testify to the importance of this approach.

### **Additional Information**

*The Commission seeks feedback about whether Carer Payment, Carer Supplement, Carer Allowance, Mobility Allowance, and the Child Disability Assistance Payment should fall within the scope of the NDIS.*

We believe these payments should be included as they all relate to a rights-based, non-welfare approach to disability.