# Deaf Children Australia
# Submission into Inquiry of Disability Care and Support

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Prepared by Kyle Miers

**Deaf Children Australia**
PO Box 6466, St Kilda Road Central
Melbourne  Victoria  8008
Ph: 03 9539 5300
Fax: 03 9525 2595
Email: helpline@deafchildren.org.au

Web: deafchildren.org.au

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# 1 Introduction

Deaf Children Australia welcomes this opportunity to provide feedback to the Productivity Commission Inquiry into Disability Care and Support.

Deaf Children Australia has been empowering deaf and hard of hearing children and their families for 148 years. We provide information, advocacy, support services, skills training, educational resources and opportunities for social networking. Current funding does not adequately cover the needs of all children and their families. Outside of Victoria very little direct service is offered apart from educational support services which vary greatly from state to state and typically do not meet the level of expressed demand.

Our vision is for "a life to be lived – deaf people empowered, connected and achieving."

Our point of difference as a provider is our commitment and willingness to respond to the needs of all deaf and hard of hearing children regardless of their background, educational environment, communication method, severity of hearing loss and additional disabilities. Historically our service has been based in Victoria and has survived for almost 150 years. Outside of Victoria a comprehensive service provider for all children and their families does not exist. Deaf Children Australia has established and has self funded services in Queensland and NSW to begin to address these gaps.

Current services provided by Deaf Children Australia include: national telephone helpline, advocacy support at a local/state/national level, case management, Auslan tuition, community education, family support, recreational activities, parenting skills training, employment services, accommodation support and mentoring programs.

We also undertake systemic advocacy as well as individual advocacy with parents. This has taken us into a variety of legal environments including the Federal Court of Australia. Supporting Parent groups is a key strategy through local, state and national networks. This calls on us to pick up costs including travel and accommodation.

Policy development and support of Research and Development is also a key function. Parents make decisions all the time for their children. We are committed to ensuring parents have access to the best information in order to make informed choices.

# 2 Eligibility for the Scheme

Deaf Children Australia believes that any child or youth who is diagnosed with a permanent hearing loss, together with their families should be eligible for the scheme. Eligibility should remain for life. The degree of hearing loss will impact on the type and cost of support required but should not impact on eligibility. The lifelong impact of lost educational opportunity associated with even a mild unilateral hearing loss is well documented. Hearing loss in the early years can fluctuate and be unstable making it essential that early intervention is provided to reduce lifetime costs.

Australia has a well established and internationally acclaimed hearing service *Australian Hearing* which is responsible for the diagnosis of hearing loss and is funded to provide free of charge hearing assistance devices up to the age of 21 years. This service has been greatly enhanced with the commitment of COAG to 100% universal newborn hearing screening from January 2011. We should aim to build on and compliment this system. National data is available for these programs and should be taken into account as part of this inquiry.

An NDIS should provide support to the individual child and their family in regards to daily communication support requirements. This support should incorporate those services provided by Australia Hearing as well as speech therapy, sign language instruction for the child and family members, note taking and captioning services.

## 3 Empowerment and Decision Making

Critical to the success of an NDIS would be the individual and their family having the right to choose their provider and the type of intervention they believe is best for them. Decision making must be supported by a case management / information service which is specific to the disability in question. Generalised Case Management services are not able to effectively meet the needs of families for specialist advice and support. Following extensive consultation with families, Deaf Children Australia has pioneered a parent to parent mentoring service which has recently received State Government funding in Queensland and Victoria. This "lived experience" support is an essential part of the mix of family support and information services that can reduce the economic and emotional impact on families and results in better life outcomes for the children.

Deaf Children Australia believes that all families should be able to access multiple programs simultaneously to ensure that their deaf/ hard of hearing child receive maximum benefits. It is difficult to foresee a child's future outcomes when the child is at a tender age and sometimes the services they are receiving are not appropriate, particularly where language acquisition is critical in the development of child's future capacity. A "this and that" approach must be provided in contrast to the present system that forces families to choose one approach and which can lead to "wrong doors". An NDIS must address this current system shortcoming.

## 4 Coverage and Entitlements

Presently the disability service system in Australia is characterized by inequity, fragmentation, inadequate levels of funding, as well as major disparity between States and systems. This is particularly so in the area of deafness and hearing loss. As a result it is not surprising that families report to us not only dissatisfaction with early intervention, health, and education services but also services provided by our organization.

The current system is highly rationed, inconsistent, and overly reliant on an outdated "welfare / charitable" model. Parents must be highly motivated and empowered to get a fair go for their children. This is not just. All children should be able to access services and support based on their needs alone.

An NDIS should include all aspects of daily communication support required by an individual and their family. This would require a major restructuring of the system. A few examples would be:

- The additional costs of therapy and communication support should not be the responsibility of an education department – funding for this support should be linked to the individual child and family and be transportable at the family's choice.
- Accreditation / recognition of service providers where families can "spend" their entitlements (a model much in the same vein as the Employment Services offered under the Disability Employment and general labour market programs).
- The cost of assistive listening devices including:
    - Cochlear implants – the current mix of State Health grants / private health insurance etc is not adequate and significantly disadvantages the most marginal in our society.
    - Hearing aids (current funding provision stops at the age of 21 unless the individual is entitled to a pension).
    - Sound field amplification for classrooms and induction loop systems

  - Communication access including interpreting, note taking and captioning services for educational, recreational and community participation.

In summary, for example an Education Department should provide education while an NDIS should provide the means to access that education. To give an example – a state education department would provide a teacher of the deaf to support the child's learning while the provision of a note taker, interpreter, hearing aid or sound-field amplification system would be provided by the NDIS.

The level of funding available to families should be determined through a self-assessment approach considering a range of "approved" services with the support of an independent adviser/ case worker who possesses an understanding of living with deafness. Families should be able to make decisions to enable their child to be fully active and independent as stipulated in CRPD Article 3(a).

Consideration needs to be given to families living in rural and remote areas of Australia and those from low socio-economic backgrounds. Service delivery must be flexible and take advantage of developments in communications technologies as they arise. The definition of what is a service or delivery platform must be constantly reviewed.

If a family disagrees with an eligibility decision, they should be provided with detailed information on how the decision was reached, and with the opportunity to appeal to an independently managed authority comprised of people with different disabilities, and professionals who have a good understanding of specific needs and the ability to assess the merits of the appeal.

## 5 Funding

A National Disability Insurance Scheme should be funded by all taxpayers through general revenue or through a Medicare type levy.

## 6 Organising and Implementing

COAG arrangements including the CSTDA should be used to introduce change over an agreed period. Existing providers / services could be recognized initially while also opening up the market to other commercial and non-commercial providers.

Based on strong family feedback, our experience is that while some services can be delivered in a generic way, others are best provided by specific disability organizations. An example of this in our experience is note taking,

An NDIS would challenge the existing service industry and should introduce greater flexibility in the choice and use of different types of intervention and support. Alignment between needs and services can transition once initial packages / panels of offerings are agreed.

As an organization Deaf Children Australia entered the employment services field at the beginning of the outsourcing of the old CES. Initially we were able to offer a limited tender to provide only to our target client group. Some of these initial pathways have now relaxed and we no longer work exclusively with deaf people.

While we have remained a viable and high quality employment service provider with a specific focus on deaf and hard of hearing people, we now cater for those with mental health issues as well as the population of general job seekers. We have faced no outstanding difficulties in meeting needs and, via a niche marketing approach; we have been able to retain our focus while running a viable business.

We would expect a greater level of competition under an NDIS but believe this would be healthy for all providers and provide maximum choice for the individual with a disability, who would exert greater control over their service experience. An example of the opportunity we see is that while we receive funding in Victoria to provide a range of children's and family services including case management, recreation, information services and independent skills training, apart from a small grant in NSW there is not specific funding provided for similar services in other state. This is not acceptable. Funding equity must be address by a National Scheme. We need to move forward from the current lottery situation which determines if you receive services or not.

A further implementation difficulty could be in the area of Education. As we stated earlier, deaf individuals should be assisted in regards to communication disadvantage. This means that an Education Department should provide education while an NDIS should provide the means to access that education. To give an example – a state education department would provide a teacher of the deaf to support the child's learning while the provision of a note taker, interpreter, hearing aid or sound-field amplification system would be provided by the NDIS.

## 7 Conclusion

We welcome the type of initiatives proposed by the major parties prior to the election. Labor offered early education support packages to a wider number of disability groups while the Liberals offer $20,000 to support additional educational access. Both proposed the entitlements be attached to the individual rather than a service provider. We agree.

What needs to improve is that the whole approach needs to be based on needs rather than clever ideas and political persuasions.

We fully support the direction of this inquiry.