

Children with Hearing Loss, Their Families and the National Disability Insurance Scheme

Discussion Paper September 2012

Introduction

Parents of Deaf Children is the peak body for parents of deaf or hearing impaired children in NSW. The role of the organisation is to support families in NSW with information, referral and advocacy services.

Aussie Deaf Kids is the national information and support website and portal for parents of deaf children in Australia. The organisation provides online information and support to families throughout Australia.

Parents of the Hearing Impaired of South Australia (PHISA) is the parent group for families of deaf children in SA. PHISA has been actively advocating for and supporting families since 1977.

There has been ongoing discussion within the parent community about the upcoming NDIS and what it may mean for deaf and hearing impaired children and their families. As the NDIS moves to make decisions about assessment tools, eligibility and what is reasonable and necessary support for people accessing the NDIS, it is essential that they gain insights from the parents of children with a disability, in this case, hearing loss.

In this document we seek to highlight the needs of children with hearing loss and their families and to respond to the NDIS Select Council's draft document that lays out a proposal for eligibility and reasonable and necessary support criteria within the NDIS.

As parents of children with hearing loss, we want our children to grow up to be able to participate fully in society. In order to do this, they need:

- A family with the capacity to provide them with the language environment and support they will need to become independent adults.
- Communication skills that allow them to learn, make friends, engage with their community and work.
- Access to technology, which allows them to communicate with their family, their friends, their teachers, their employers and to participate fully within their community.
- Education and socio-emotional support to assist them to successfully achieve the goals they envisage for themselves.

Response to the NDIS Draft Document on Eligibility and Support Criteria

According to the Select Council's draft statement on eligibility and reasonable and necessary support:

"The individual has a disability that is attributable to an intellectual, psychiatric, cognitive, neurological, sensory or physical impairment, or a combination of impairments; or is a child with a global developmental delay".

While sensory impairment is included in this list, it is unclear whether children with auditory processing disorders would be included. Children with Auditory Neuropathy Spectrum Disorder do have a hearing loss component but the level of hearing loss does not indicate the ability to acquire spoken language. The child may have a mild hearing loss but marked auditory dys-synchrony. Children with central auditory processing disorders have considerable difficulty communicating but there is generally no hearing loss involved.

"The impairment/s:

- results in a substantially reduced functional capacity of the individual to undertake activities of daily living; and*
- impacts on the individual's participation in the community or employment"*

These two components of the proposed eligibility criteria do not reflect how an infant or child should be assessed for eligibility. Children cannot be assessed on activities of daily living or participation as these are skills children learn over time. There is no reason why children whose only disability is hearing loss should not demonstrate developmentally appropriate activities of daily living skills and we feel this term should not be used in the context of hearing impairment. Communication access is the issue and this should be reflected in the eligibility statement.

Parents are also concerned about the term "functional capacity" in the statement above. If the NDIS is to support our children throughout their lives, then a functional audiological assessment that measures their unaided hearing threshold is required.

"The support needs will persist for the foreseeable future and are not more appropriately met by other systems including education, health and/or palliative care."

Children with a hearing loss receive all audiological services through the Australian Government Hearing Services Program. Many children also receive early intervention services through their state education departments. This statement appears to indicate that the provision of these services would preclude them from the NDIS and this is a considerable concern to our organisations.

"Reasonable and necessary supports are designed to support the individual to achieve their goals and maximise their independence"

Our organisations support this statement that the supports are about individual needs and goals. Each child and their family is unique.

“Reasonable and necessary supports are effective, and evidence informed.”

We certainly advocate that support is evidence based. However, technology is changing so rapidly and new technologies have changed the way children with hearing loss can learn, participate and communicate. We recommend some flexibility in the NDIS funding for new and innovative approaches and technologies so our children can benefit from them while evidence for their efficacy is being gathered.

“Reasonable and necessary supports reflect community expectations”

The general public believe that hearing aids and cochlear implants transform a deaf child into a hearing child. Families know this is not the case. We would not recommend that community expectations are a means of evaluating reasonable and necessary support. A more informed opinion from people in the community with the lived experience would better reflect the support needs of the child.

Additionally, we note that the NDIS scope and design is focused on people with a disability. Whilst this person centred approach works well for young people and adults, we believe that the eligibility and support criteria for children needs to reflect the needs of the family unit, not solely the child with the disability.

Family Centred Support within the NDIS

Families are the constant in the child’s life. For children with a hearing loss, the potential impact of that loss can be mitigated by the capacity of the family or primary carer to adapt to the increased needs of the child. In order to best support their child, the primary carer must be empowered and informed to make the best decisions for their child. Congenital hearing loss is a relatively uncommon disability – one in a thousand babies are born with hearing loss - and most parents of deaf children are hearing themselves. There is much to learn and to understand in order to make the best decisions for the child. It is our belief that ensuring families have access to unbiased information and support must be a critical component of a successful NDIS. Determinations around eligibility need to consider the provision of funding for the support of parents/families, not just direct intervention to the child.

Services for children with hearing loss around the world are acknowledging that a family-centred approach to service delivery is a best practice model. The First International Congress on Family-Centred Early Intervention for Children who are Deaf or Hard of Hearing was held in Bad Ischl, Austria from May 30th to June 1st 2012 and a consensus document is currently being formulated to provide principles of standards around delivering family-centred services to children with hearing loss.

Family centred services empower parents to make informed choices and has systems in place to provide parents with the information, support, role models and mentors they need to feel confident in their ability to raise a deaf child.

Parents with children who are deaf or hearing impaired have had some exposure to a person centred model of funding and service delivery in the form of Better Start funding for children with a disability. It is essential that the NDIS advisors learn from this model, which has created more complexity for families, rather than less.

Since the introduction of Better Start funding, we are seeing a disturbing increase in mental health problems amongst mothers of children with hearing loss. We feel this warrants some rigorous investigation particularly as we move towards an NDIS. Anecdotally we see a number of causes for these increases in stress and depression we are witnessing.

- Newborn hearing screening has provided the hope of age-appropriate spoken language by the time the child starts school. When this doesn't eventuate, mothers feel guilty and responsible that they have somehow failed their child.
- Better Start funding has moved the focus of early intervention back on the child compromising the principles behind family-centred practice. Under Better Start, services can only receive funding when the service is for the child and so the needs of families and particularly mothers, are being sidelined to the detriment of the family unit.

Recommendation: That the scope of the NDIS acknowledges the crucial role that families play in the lives of children with a disability and provide funding, that is not linked to services provided to the child, for parent support and mentoring. Services may include counselling, service planning and evaluation and parent-to-parent mentoring.

Our organisations would also like to draw attention to a number of hearing loss profiles and diagnoses that are not currently reflected in the draft eligibility and reasonable and necessary support document and we strongly believe need to be considered within the scope and design of the NDIS:

Children with mild and unilateral hearing loss

Newborn hearing screening was intended to identify babies with a permanent bilateral hearing loss of 40db or greater. But children with mild and unilateral hearing loss are also being identified in the newborn hearing screening process.

According to the Population Based Screening Framework endorsed by the Australian Health Ministers' Council at its 9 October 2008 meeting, "There should be evidence that the treatment intervention is effective, will lead to reduction in the burden of the disease or condition and is more effective than treatment at a later stage that would occur without screening. Evidence based best practice guidelines and policies for treatment should exist."

Families of children with mild and unilateral loss have been left in a management and funding vacuum. Despite being told their child has a disability, there are no clear pathways for families to ensure their child is able to achieve appropriate outcomes. There remains a "wait-and-see" philosophy. It would appear that although we know these children are at greater risk of achieving poorer educational outcomes, they need to be 'failing' before access to the intervention they need becomes available. This would appear to be contrary to the intent of a screening program and the acknowledgment that early intervention reduces the burden of the condition and is more cost effective way of achieving improved outcomes.

It must be acknowledged that evidence for the effectiveness of hearing aid use in this population has yet to be established. Families are given the choice of using hearing aids or not but in the face of inconclusive evidence it is a difficult decision.

Some States and some early intervention services offer early intervention to children with mild and unilateral hearing loss but this is highly variable so it depends on where the child lives as to what additional support they receive.

Families whose children have a unilateral hearing loss need to be particularly strong advocates for their children as the services provided are so patchy. So children with unilateral hearing loss whose families do not have the physical or emotional capacity to advocate on behalf of their child are further disadvantaged. Parents do not receive the Carer Allowance for children with mild or unilateral hearing loss

Under the NDIS, it is proposed that “the system will have enough resources and will be smart enough to invest in remedial and preventative early intervention instead of just providing support when a family is in crisis.” <http://www.ndis.gov.au/about-an-ndis/frequently-asked-questions/> The proposed eligibility criteria would appear to preclude this group from the NDIS but we would argue that these children do need some consideration, particularly in the early years.

Recommendation: Children with mild and unilateral hearing loss are included within the scope of the NDIS in order to access appropriate early intervention services and ensure they start school with age-appropriate language and development.

Children with Complex Needs

As many as 40% of children diagnosed with a permanent hearing loss have additional needs. Many of these children have considerable support needs and will be eligible for the NDIS. However, the NDIS needs to ensure that families with children with complex needs can access a funding package that meets all the diagnosed needs of the child. For example, currently under Better Start, a child who is deaf with autism (a growing demographic) cannot access funding for both disabilities, only one. Parents feel they need to choose intervention for one disability over another. This must change with the NDIS.

Children with Mild Hearing Loss and Additional Needs

Families whose children have a variety of mild impairments, which have a cumulative effect on the child, are another demographic that we see regularly. The family is required to source multiple service providers to meet the needs of the child and generally do not receive Better Start funding or the Carer Allowance.

Early intervention is important in this population of children but currently difficult to receive without a financial burden on the family and the flow on effect of this on the wellbeing of the family and child. While noting that global developmental delay is one of the conditions in the eligibility criteria, we want to ensure that the needs of these children will be met with changes in service provision under the NDIS.

Thank you for this opportunity to comment on the draft eligibility statement.

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