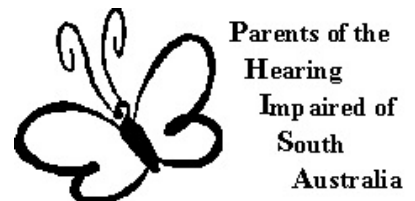


Submission to the  
Senate Standing Committees on Community Affairs  
Inquiry into the National Disability Insurance Scheme  
Bill 2012

January 2013

A joint submission from  
Aussie Deaf Kids  
Parents of Deaf Children  
Parents of the Hearing Impaired of South Australia



Our submission to the Senate Inquiry into the National Disability Insurance Scheme Bill 2012 represents the views of three organisations representing parents of deaf and hearing impaired children:

**Parents of Deaf Children** is the peak body for parents of deaf or hearing impaired children in New South Wales. 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 South Australia. PHISA has been actively advocating for and supporting families since 1977.

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.

In this document we seek to highlight the needs of children with hearing loss and their families in relation to the National Disability Insurance Scheme Bill 2012.

We thank the Senate Standing Committee on Community Affairs for the opportunity to make a submission to the Inquiry into the National Disability Insurance Scheme Bill 2012.

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Section of Bill	Comments	Recommendation
Chapter 1 Part 2	Our organisations support the Objects and Principles laid out in the Bill. However, the legislation would be strengthened by explicit reference to promoting and protecting the rights of people with disability within the Bill.	A reference to promoting and protecting the rights of people with disability is included in the Principles of the Bill.
Chapter 3 Part 1 Section 22	Paragraph (2)(b) states the National Disability Insurance Scheme rules “may prescribe different ages and different dates in relation to different areas of Australia.” While understanding this is required for the NDIS launch sites, we would like confirmation that this will rule will be superseded with the introduction of the full scheme. We need the NDIS to provide equitable access to service and support to children with disability and their families, irrespective of where they live.	
Chapter 3 Part 1 Section 23	From time to time, families with deaf children move temporarily to Australia on work contracts. We believe there should be access to the NDIS for children here on temporary residence visas so the child’s needs are not compromised while the family is temporarily resident in Australia. We are concerned that if this is not the case, it will be difficult or cost prohibitive for families to find appropriate services and support for their child once the NDIS is launched.	There is a safety net for children with disability whose parents come to Australia on temporary residence visas to ensure their progress and outcomes are not compromised whilst in Australia.
Chapter 3 Part 1 Section 24 Paragraph (1)(c)	<p>Paragraph (1)(c) states “the impairment or impairments result in substantially reduced functional capacity to undertake, or psychosocial functioning in undertaking, one or more of the following activities”...</p> <p>Families have expressed concern about the term “functional capacity” in relation to children with hearing loss and it would seem that the legislation has sought to address this concern by adding, “psychosocial functioning” into the disability requirements. We would like to see clear definitions of</p>	<p>Clear definitions of “functional capacity” and “psychosocial functioning” be included in the Bill.</p> <p>The capacity of people with hearing loss to communicate, socialise, learn and work be assessed using their <i>unaided</i> hearing thresholds.</p>

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	<p>what these terms mean in relation to the Bill.</p> <p>Many children whose only disability is hearing loss, who receive appropriate services and support, demonstrate developmentally appropriate communication and activities of daily living skills. We therefore feel the term “functional capacity” is problematic in the context of hearing impairment. Communication access is the issue and this should be reflected in the eligibility statement.</p>	
<p>Chapter 3 Part 1 Section 25</p>	<p>We welcome the inclusion of this section within the Bill and hope that this will mean that a large number of children who are currently diagnosed with a hearing loss but are unable to receive Better Start funding, will be able to receive early intervention services under the NDIS. This includes children with mild or unilateral hearing loss identified through the newborn hearing screening process but not currently eligible for funding or services in some states.</p> <p>Newborn hearing screening was intended to identify babies with a permanent bilateral hearing loss of 40db or greater. However, children with mild and unilateral hearing loss are also identified in the newborn hearing screening process.</p> <p>Families of children with mild and unilateral loss, despite being told their child has a disability through a newborn hearing screening program, have no clear pathways to ensure their child is able to achieve appropriate outcomes.</p> <p>Children with a mild or unilateral hearing loss are at risk of achieving poor educational outcomes. These children need to be ‘failing’ before access to</p>	<p>Our reading of this section of the Bill implies that children with a mild or unilateral hearing loss will meet the early intervention requirements. If this were not the case, we would encourage the CEO to request the evidence for their need for early intervention, so they will be included.</p>

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	the intervention becomes available. This is 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.	
Chapter 3 Part 2 Section 3 Paragraph (d)	<p>Paragraph (d) states “where possible, strengthen and build capacity of families and carers to support participants who are children.” We would endorse this statement if the phrase “where possible” is removed. We believe that strengthening and building the capacity of the family or carers is pivotal to the success of the child’s outcomes and should not be seen as a possibility but a necessity.</p> <p>The model of person-centred funding has clouded the importance of family-centred service delivery for children. Family-centred services are recognised as best practice in the delivery of programs for children with disabilities and should not be compromised within a person-centred funding model.</p> <p>There are, therefore, a number of aspects of paragraph (d) that we feel need highlighting in the context of families of deaf and hearing impaired children.</p> <ul style="list-style-type: none"> <li>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. Congenital hearing loss is a relatively uncommon disability – one in a thousand babies is born with hearing</li> </ul>	<ol style="list-style-type: none"> <li>1. We see Section 31 Paragraph(d) as pivotal to the success of the NDIS for children.</li> <li>2. Section 31 Paragraph (d) should state, “strengthen and build capacity of families and carers to support participants who are children.”</li> <li>3. Peer support programs for parents and carers are recognized as a necessary support within the NDIS for building resilience within families and enabling them to provide a home environment that will assist them to raise and support their child.</li> <li>4. Communication involves the whole family. When a family chooses a bilingual approach to communication for their deaf child, the whole family needs access to learning Auslan, not only the child.</li> </ol>

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	<p>loss - and most parents of deaf children are hearing themselves. There is much to learn and to understand in order to provide an optimal environment for the child to learn and communicate effectively.</p> <p>Since the introduction of Better Start funding, we have seen the focus of early intervention move to the child, compromising the principles underpinning 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 sidelined to the detriment of the family unit.</p> <ul style="list-style-type: none"> <li>• Families learn and are enriched and empowered by contact with other parents of children who are deaf or hearing impaired. Contact with other parents helps parents to negotiate the ups and downs more effectively and provides an improved sense of well-being. Parent support groups and parent-to-parent mentoring programs play a crucial role in building the capacity of the family to effectively support the child. Peer support for parents and carers promotes their well-being and is in the best interest of the child.</li> <li>• Better Start funding has demonstrated the drawback of person-centred funding when families choose a bilingual communication approach for their deaf child. It is pointless teaching a child to communicate using Auslan if the family is not able to communicate in Auslan. Families need access to funding for Auslan courses so they can optimise communication within their family. Research shows us that when parents are unable to effectively communicate with their deaf signing child, there are serious mental health consequences for the</li> </ul>	
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	child.	
Chapter 3 Part 2 Section 31 Paragraph (i)	<p>Paragraph (i) –“maximise the choice and independence of the participant.”</p> <p>For many years, parents of deaf and hearing impaired children have championed the need for choice for their children. We have, however, stipulated that this choice needs to be informed. This means that parents need unbiased information about all possible options, in a format that is meaningful to them, and assistance to understand the information and its implications for their child and family.</p> <p>Choice has also tended to be very limited in regional and rural areas and we hope that the NDIS will build the capacity of the workforce so that families in regional and rural areas have equal access to choices for services and support as their metropolitan counterparts.</p> <p>Bilingual early intervention programs for deaf and hearing impaired children are limited wherever a child lives and we would encourage service providers to recognise the emphasis on choice in the NDIS and develop programs that provide a broader range of options for families than currently exists.</p> <p>There is no mention in the draft legislation about advocacy and it is advocacy that plays a key role in ensuring parents understand their choices and are able to negotiate pathways that meet the needs of their child and family. Advocacy and information services play a key role in providing unbiased services to the family as they make decisions and must be funded under the NDIS to ensure optimal outcomes for both child and family.</p>	<ol style="list-style-type: none"> <li>1. Appropriate information and guidance is provided to parents to assist them to make informed choices.</li> <li>2. The role of assisting families to make informed choices is independent of service providers. This is particularly important in when a child has a hearing loss where service providers may have strong opinions on communication methodologies and technology.</li> <li>3. Funding for information, advocacy and support services for the family should be independent of funding for services for the child. Parents will not seek assistance and support for themselves at the expense of services for their child.</li> </ol>

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Chapter 3 Part 2 Section 31 Paragraph (j)	<p>Paragraph (j) – “facilitate tailored and flexible responses to the individual goals and needs of participants.”</p> <p>Families know that one size does not fit all and we welcome this paragraph in relation to participants’ plans. Better Start has demonstrated that service providers do not necessarily appreciate how important flexibility and the goals of the family are when providing their services.</p>	
Chapter 3 Part 2 Section 31 Paragraph (k)	<p>Paragraph (k) – provide the context for the provision of disability services to the participant and, where appropriate, coordinate the delivery of disability services where there is more than one disability service provider.</p> <p>Coordination of services without a case manager has been a problem for families over many years which we have attempted to address both in the introduction of newborn hearing screening as well as Better Start funding but without success. We hope this will be a positive step forward for families as they negotiate the complexities of the system when their child is diagnosed with a hearing loss.</p>	
Chapter 3 Part 2 Section 33	<p>Paragraph 2 (a) and (b) make mention of “general supports” and “reasonable and necessary supports”.</p> <p>It is unclear to us what this means for deaf and hearing impaired children. We believe there needs to be robust descriptions of what “general supports” and “reasonable and necessary supports” comprise.</p>	



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Chapter 3 Part 2 Section 33 Paragraph 4	<p>There appears to be no timeframe for the CEO's decision on whether or not to approve the statement of participants' supports.</p> <p>We are concerned the current system where families can wait months to find out what services they are eligible to receive should not be a feature of the NDIS.</p>	A timeframe be included within the Bill for the CEO to make a decision regarding the statement of participants' supports.
Chapter 3 Part 2 Section 34 Paragraph (c)	<p>Paragraph (c) – “ the support represents value for money in that the costs of the support are reasonable, relative to both the benefits achieved and the cost of alternative support.</p> <p>We understand that the NDIS needs to provide cost effective supports in order for it to be fiscally responsible and sustainable. We do not, however, believe that cost effectiveness should over-ride possible outcomes.</p> <p>Deaf and hearing impaired children currently receive hearing aids through the governments community service obligation. Children are provided with fully funded hearing aids that meet their audiological and communication needs. Parents can choose to “top up” but every parent knows that the fully funded hearing aids will meet the communication and learning needs of the child. We recommend that this approach be maintained with the NDIS – cost-effectiveness should not compromise outcomes.</p>	
Chapter 3 Part 2 Section 34 Paragraph (e)	<p>We are concerned that what is reasonable to expect from families, carers, informal networks and the community to provide in regards to funding and support is too subjective.</p> <p>Expectations for people with a disability are often low. In addition, the community tends to view hearing aids and cochlear implants as ‘fixing’ the</p>	We recommend that any judgement made regarding reasonable expectations for support from family, carers, informal networks and the community be an informed view of people with the lived experience of hearing loss and their families.

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	problem of hearing impairment which is not the case.	
Chapter 3 Part 2 Section 34 Paragraph (f)(i)	<p>Paragraph (f)(i) – The support is most appropriately funded or provided through the National Disability Insurance Scheme, and is not more appropriately funded or provided through other general systems of service delivery ...as part of a universal service obligation.</p> <p>It has been unclear to us how the NDIS will interface with the current Australian Government Hearing Services Program and the influence this will have on children who are deaf or hearing impaired. It would appear from this paragraph that children will continue to receive audiological services through Australian Hearing while accessing other services such as early intervention through the NDIS. We would support this position.</p> <p>Currently, families who attend Australian Hearing services can be assured of receiving consistent specialist paediatric services for children with congenital hearing loss. Without the safety net of a Government hearing program, families, especially those in the early stages of diagnosis, could be at risk of engaging services that are not specialised in this area and perhaps purchasing products and services that are inadequate or inappropriate for the child.</p>	We recommend that the services children currently receive through Australian Hearing continue after the introduction of the NDIS.
Chapter 3 Part 2 Section 35	<p>The details about the NDIS that are of most interest to families – the support and services they will be able to access for their child and family – are contained within the NDIS Rules.</p> <p>Having the criteria for reasonable and necessary supports in the NDIS Rules is problematic given how central these supports are to the success of the NDIS.</p>	

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Chapter 3 Part 2 Section 45	It is unclear from this section of the Bill how and when families will be reimbursed. We would not support a system where families are left out of pocket and do not seek services as they are unable to pay upfront.	
Chapter 4 Part 3 Section 69	Paragraph 1 Note 2 – A registered plan management provider of supports may in certain circumstances manage the funding for supports under a plan. Our organisations believe there is considerable potential for both actual and perceived conflicts of interests if this were to occur. We believe the two roles should remain separate.	It is recommended that these roles be kept entirely separate.
Chapter 4 Part 3 Section 73	There appears to be little rigor around the qualifications and competencies of providers. We would support a rigorous eligibility process for registration of professional service providers.	
Chapter 4 Part 4 Section 74 - 77	These provisions appear to be acceptable in protecting the best interest of the child.	
Chapter 4 Part 6 Section 99 - 103	The internal review process outlined in these sections is not transparent.  In addition, the complaints pathway for people with a disability and families is not clear within the legislation.  The proposed next step of going to the Administrative Appeals Tribunal will cause undue burden on complainants.	We recommend an independent “middle path” (such as a Disability Services Commission) to review decisions and resolve complaints in a way that is truly independent, accessible and timely for people with disabilities and their families.
Chapter 6 Part 1 Section 118	We are encouraged to learn that functions of the Agency include: Paragraph (c) – facilitating innovation, research and contemporary best practice in the sector.	

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	<p>Paragraph (d) – build community awareness of disabilities and the social contributors to disabilities.</p> <p>Paragraph (f) – to undertake research relating to disabilities.</p>	
<p>Chapter 6</p> <p>Part 1</p> <p>Section 119</p>	<p>We note the Agency has the power to accept gifts, devises, bequests and assignments. We would like clarity around how these will be utilised within the context of the NDIS.</p>	

Thank you for the opportunity to provide feedback on this significant policy that we hope will help our children and all people with disability to realise their potential for physical, social, emotional and intellectual development and enable them to contribute to the social and economic fabric of Australia.

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