firstvoice
THE FUTURE IS HEAR

To the Joint Standing Committee on the National Disability Insurance Scheme

Inquiry into the provision of services under the NDIS Early Childhood Early Intervention Approach

Responses to committee questions at the public hearing held in Adelaide on Wednesday, 27 September 2017

From First Voice

RESPONSES TO QUESTIONS FROM Ms MACKLIN

In the time available it has not been possible to gather information reflecting the national situation in regard to the questions below. The answers are therefore based on information and experience from the Cora Barclay Centre in the SA NDIS Children's Trial Site, which is the only jurisdiction where all children (aged 0-18 years) with hearing loss have been able to join the scheme.

QUESTION 1: RE CHILDREN WITH HEARING LOSS BEING EXCLUDED FROM THE SCHEME

There are currently 14 children on service with the Cora Barclay Centre who meet the NDIS eligibility criteria who have been denied access to the NDIS. There are others who have held back from applying due to the negative experiences of other families and have therefore elected to wait for the promulgation of the long-awaited new NDIS hearing loss access criteria that have only recently been released.

Six (6) of the 14 children have bilateral losses and 8 have unilateral loss.

Children with bilateral loss comprise: 1 Moderate loss; 1 Moderate/Mild loss; and 4 with Mild bilateral loss.

Children with unilateral losses comprise: 1 with Profound loss; 2 with Severe loss; 3 with Moderate and 2 with Mild.

Two (2) children are under 5 years of age and the remainder of school age, mostly junior primary.

The majority of children were denied access during 2016 and have received full Cora Barclay Centre services without any NDIS funding for up to 21 months.

Reasons for denying eligibility are communicated to the family, not the children's service provider. Parents advise that the main reasons given to them are:

- your child has no measurable functional impairment
- your child does not need support yet, you should wait until they do
- your child's level of hearing loss is such that they are not eligible
- your family should access mainstream services, not the NDIS
- your child is over age 6 years.

This situation is discussed in some detail in our written submission to this inquiry. It is deeply worrying that after 4 years of submissions and discussions the NDIS does not have policies and processes in place that ensure that children who are deaf or hard of hearing receive the ECEI services they need, from birth, to *prevent* their childhood hearing loss from creating lifelong functional impairment and disability in relation to their language, communication, learning and social participation.

QUESTION 2: RE LONG DELAYS IN CHILDREN ENROLLING IN SPECIALIST LISTENING AND SPOKEN LANGUAGE PROGRAMS

It has previously been reported to the Joint Standing Committee–NDIS that there has been a significant blow out in the average age of commencement of specialist early childhood intervention services at the Cora Barclay Centre since the commencement of the NDIS ***(Cora Barclay Centre submission to the JSC inquiry into hearing services in the NDIS (16 Feb 2017) and supplementary submission (March, 2017).*** This blowout has been from a pre-NDIS average age of commencement of *under* 6 months to *over* 12 months of age.

No clear reasons were apparent for this change; some children had received no early intervention services since diagnosis and others had received services from alternative providers without success. Overall, it was postulated that the introduction of the NDIS had created an environment of uncertainty regarding referrals under which government agencies and health professionals were reluctant to actively encourage families to find a specialist provider as a matter of urgency or to direct families towards long-established providers with proven, evidence-based outcomes.

An analysis of Cora Barclay Centre new referrals also reveals a marked decline since the NDIS in referrals of bilaterally severe and profound babies who have historically been the client group most attracted to our highly specialised, evidence-based multi-disciplinary ECI program with its proven speech and language outcomes. This is a worrying trend and the reasons behind it are not apparent. It has been conjectured that some families may have simply chosen the state government early intervention provider to avoid the demands and vicissitudes of accessing the NDIS.

As previously advised First Voice, RIDBC and other key providers and stakeholders believe that these referral problems would be overcome by the NDIA appointing Australian Hearing as its exclusive "early childhood access partner" for children with hearing loss to support families in making fully informed choices in relation to the development of their child's communication (speech or sign).

Cora Barclay Centre statistics show there have been 48 new ECI referrals since the NDIS started of whom 11 (23%) commenced services with us 12 months or longer after confirmation of diagnosis. These include 3 who have taken longer than 2 years.

Three examples of long delays and their impact are given below:

1. Child A, now 4 years of age is profoundly bilaterally deaf. Child A commenced service at the Centre at 2½ years with no language at all after a period of service with another provider. The parents were aware of all service provider options but did not visit our Centre as would have most likely occurred pre-NDIS. The family was uncertain as to their preferred mode of communication for their child (speech or sign language). On commencement with the Cora Barclay Centre, the child immediately had bilateral cochlear Implants and is now making steady catch-up progress with language currently equivalent to a 12-15 month old child (though still having a 2-3 year language delay with school rapidly approaching).

2. Child B, now 2 years of age, is profoundly bilaterally deaf. Child B was diagnosed at birth, not referred to us at the time for consideration and commenced service with another provider. Child B started ECI at our Centre at 1 year 11 months (only 1 month ago) and has only 1-2 word sentences - and language equivalent to a 9-12 month old. Mother has immense grief with not getting started with our specialist ECI program earlier as she has seen children of the same age/hearing loss now speaking in full sentence structure.

3. Child C, was diagnosed at birth with severe bilateral hearing loss and is now 10 months old. *Child C is yet to commence ECI services with any provider.* Providers have been informed of the child's diagnosis but no further information is known other than (it would appear) that the parents are not being actively encouraged to engage with a provider.

QUESTION 3: RE THE INCREASING GAP IN FUNDING TO CHILDREN WITH HEARING LOSS AND THEIR FAMILIES

In the early stages of the NDIS Children's Trial (July 2013 – August 2015) many deaf or hard of hearing children received Funded Plans broadly commensurate with the cost of their multi-disciplinary ECI programs.

As outlined in our written submission, funding levels markedly reduced – both for initial plans and reviewed plans – following the introduction of the NDIS ECEI national policy and funding guidelines in August 2015.

Plan values have further decreased over the past 12 months as the trans-disciplinary package approach has been neglected by NDIA planners in favour of funding based predominantly or exclusively on hours of therapy.

The NDIA SA has recently acknowledged publicly that there is a downwards trend in plan values in South Australia.

Three recent examples of Funded Plans with a substantial funding gap are given below:

Child A:
5 years of age; Bilateral profound hearing loss;

Requested funding/cost of plan	$15,700
NDIA Funding -	$9,650
Gap -	**$6,050**

Child B:
3 yrs of age; bilateral moderate hearing loss; missed in newborn hearing screening process and not fitted with hearing aids until 2 years old with consequent delays in receptive and expressive speech impacting on social participation.

Requested funding/cost of plan	$15,700
NDIA Funding -	$7,373
Gap -	**$8,327**

Child C:
4 years; Bilateral profound hearing loss

Requested funding/cost of plan	$15,700
NDIA Funding -	$7,850
Gap -	**$7,850**

In responding to this question it should be acknowledged that the NDIA is currently developing reference packages specifically for funding children who are deaf or hard of hearing. This work has been ongoing since around April 2016 and has included input from the NDIA's representative Expert Reference Group on children's hearing services. Progress has been very slow but seems headed in the right direction. The sector is hopeful that it will result in families of deaf children receiving sufficient funding to cover the costs of their chosen early intervention.

For the proposed reference package approach to succeed it would need to satisfy two basic requirements:

1. sufficient quantum of funding to cover the cost of the child's hearing and communication early intervention program;
2. all of the funding being accessible for, and applied to, the child's hearing and communication needs and not to other services where the child has additional disability service needs;

As things presently stand, funding that has been provided specifically for hearing and communication services is often diverted to other purposes resulting in a shortfall in funding available for the child's primary intervention program.

It is also the case that NDIA billing and payments arrangements may prevent allocated funds from being fully and effectively utilised by the family for their intended purposes.

These issues need to be addressed.
