

Essential components of support for children who are deaf or have a hearing loss under the NDIS

Consensus statement from providers of specialist early intervention for children with hearing loss, June 2017

Background

Breakthroughs in therapy within Australia over the last decade mean that with the right support system and specialised services, children who are deaf can be taught to communicate as well as any other child (with spoken or signed language), enabling them to succeed independently in life – as if they didn't have a hearing loss.

However the NDIS has disrupted that system – it is delaying the start of funded therapy; it is underfunding specialised services and overfunding ineffective services; is denying support to young children who will fall back later in childhood due to their disability; and is resulting in children having poorer communication ability than their predecessors.

An appropriate system must be immediately implemented to support the hundreds of children currently failing due to the NDIS and to save the NDIS hundreds of millions of dollars in future permanent disability costs.

The introduction of the NDIS is resulting in a huge backward step for children with hearing loss in Australia. Immediate action must be taken to prevent a generation of children growing up without the language they require.

Requirements of a dedicated support system for children with permanent hearing loss

A specifically-funded system must be introduced immediately that provides for:

1. An effective and rapid guided referral pathway to service

- A guided referral pathway is necessary, designed to meet the international minimal standards of 1 month to diagnosis, 3 months to hearing aid fitting and 6 months to funded therapy

Funded therapy is now often delayed until the child is 12-18 months of age, resulting in poor language development

90% of the parents of these children have no personal experience of childhood hearing loss. As a result they don't know what is needed, what is possible, or what goals are possible. Guided pathways – to ensure a family engages with a service that will meet their needs – were previously available in some states, but have been lost with the move to the NDIS. A funded nationally-consistent referral pathway is required that ensures children meet the international minimal standards.

- This guided referral pathway needs to be funded by the NDIS and provided by Australian Hearing

There is currently no national referral pathway

The referral pathway needs to be provided by people who have expert knowledge in childhood hearing loss and must be accessible across Australia. Australian Hearing already receives all children after they have had their hearing loss diagnosed, so is ideally placed to provide this service if funded to do so; due to its national footprint, expertise, and independence.

- Australian Hearing must remain an independent and objective referral pathway – it must not also provide therapy services

Australian Hearing has started down the pathway of providing therapy (initiated due to the possibility of privatisation and contestability), which would pose an unacceptable conflict of interest

The move of Australian Hearing into therapy services (in addition to its monopoly position in audiology services) would prevent it from providing this 'independent advisor' role. The roll-out of therapy services is only in pilot at this time, so could be halted without significant hardship to families or the organisation.

2. National Reference Packages

- Package values must be designed to be appropriate to be able to deliver the desired outcomes, based on need – requiring standard packages of over \$20,000 for children with profound hearing loss – and ensuring support for children during their most critical years

Current packages are 30%-50% less than what is required to enable good outcomes, ensuring a lifetime of dependency

The current package values provided by the NDIS (and those in the draft National Reference Packages) are far below the cost of effective service. They are completely insufficient to make good language possible for children with hearing loss. As a result, children will not be able to develop the communication, academic and employment outcomes they should; resulting in a lifetime of dependency on both the NDIS and social services. The cost of the required therapy is higher for the first few years of a child's life, but then as the child develops age-appropriate language the cost rapidly drops and becomes much cheaper for the NDIS. The critical years for development are 0-6 (key period of language development) and 6-12 (key period for development of interpersonal communication and social inclusion). Further information on this will be provided separately.

- Package design must support holistic multidisciplinary service

Current packages do not require the holistic multidisciplinary service needed to achieve outcomes, meaning ineffective services are being funded

The current packages (and those in the draft National Reference Packages) reflect the expectation that all of the therapy effect is conveyed in direct service. Direct service does not result in the development of appropriate spoken language, as shown by the experiences of children receiving these services. Evidence clearly demonstrates that specialised holistic multidisciplinary / transdisciplinary service is required to produce outcomes; however this service comes with 30-50% increased cost.

- Packages must be available to all children diagnosed with permanent hearing loss, in proportion to their need, to achieve desired outcomes

Children with unilateral or mild hearing loss are being denied packages, even though this will result in disability later in childhood

All children with permanent hearing loss need to be provided with services in proportion to their needs. The NDIA has accepted this, however many children are still being denied funded packages.

3. Funding requirements

- Funding must be provided against overall provision of reference packages, not restricted to direct service

Programs that deliver outcomes require many components in addition to direct service but these aren't funded – packages must allow invoicing on the holistic package, not incentivise direct service alone

The funding focus on direct service incentivises the volume of inputs and does not support the production of outcomes. The funding packages must be tied to the provision of an appropriate program and demonstrated outcomes, not to an arbitrary number of direct service hours.

- Funding must be limited to only support services that deliver the reference packages against agreed quality assurance requirements

Ineffective services are currently receiving funding, even though they do not result in outcomes

Already the input-funding focus of the NDIS has resulted in many children being provided with straight speech pathology or other direct services. We are seeing children receiving these services not progressing in their language and then turning to a specialised service with profound language delay. Package funding must be limited to those services that deliver those packages against quality assurance requirements. Prior to the NDIS, State funding was restricted to specialist services and this resulted in excellent outcomes; with the opening up of services these outcomes are being lost.

- Funding must be consistent between children with similar levels of need

Huge variations currently occur between children with equivalent levels of service need

The implementation of a funded guided referral pathway, along with a nationally consistent set of reference packages, will ensure consistency of funding between children with similar levels of need.

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