2019 NDIS Act Review and Participant Service Guarantee (Tune Review)

Submission on the Experience of Cochlear Implant Users

Overview

As the leading providers of technology, services, support, and advocacy for Australians with cochlear implants, Cochlear, CICADA Australia Inc, CICADA Queensland and First Voice welcome the opportunity to make a submission to this Review.

10,957 National Disability Insurance Scheme (NDIS) participants, or four per cent of the total number of participants, identify hearing impairment as their primary disability[1]. While we don't have access to accurate data on how many of these participants are cochlear implant (CI) users, approximately 9,000 current CI users could potentially be eligible to participate. These Australians were implanted before turning 65 and did not turn 65 prior to the commencement of the national roll-out of the NDIS in 2016

Our organisations conducted an online survey of CI users, their carers and families, to help us and the Review, better understand their experiences with the NDIS's administration and decision making.

Survey responses - key findings and observations

- Respondents have a relatively low overall satisfaction with NDIS – 64% - particularly compared to rate of satisfaction reported by NDIS (90%) in its most recent quarterly report[2]. However, a higher number of respondents were satisfied their current plan was sufficient to meet their objectives (71%)
- The majority of respondents waited for more than a month for access and planning processes to be completed, and over 6 months for some adults
- Improving understanding of hearing loss and cochlear implantation by planners and others involved in the administration of NDIA would help address dissatisfaction for both adults and children
- Ensuring plans include funding for replacement cochlear implant sound processors (which are essential for the functioning of a cochlear implant) is a major focus for adult respondents; and
- Speech and language services are currently the focus of child respondent's NDIS plans. The role played by Hearing Australia and early intervention service providers featured in positive comments about their NDIS experience.

The NDIS presents an enormous opportunity for those with severe to profound hearing loss – as it does for thousands of Australians with other disabilities. For many CI users, particularly those aged 26 to 64, the NDIS is the first time they have been able to access government support for their disability post-implantation. This includes funding to maintain their cochlear implant sound processor (sound processor) and replace it with a new one when necessary due to wear and tear, obsolescence or clinical necessity.

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[1] Report to COAG Disability Reform Council for Q4 of Year 6June 2019, p79 **Table E.11 Participant profile per quarter by disability group - NATIONAL** https://www.ndis.gov.au/about-us/publications/quarterly-reports)

[2] As above p 34

However, as our survey has illustrated, the introduction of the NDIS has also presented challenges particularly for the transition of Australia's world leading system for helping children with hearing loss. Excellent progress has been made in some areas including the introduction of:

- a nationally consistent eligibility criteria that ensures all young children with significant permanent hearing loss can access the NDIS. Previously, the eligibility criteria varied from state to state, and sometimes even by location.
- An Australia-wide rapid referral pathway for children aged 0-6 with hearing loss that makes it possible for children to receive an NDIS-funded plan within three weeks of the families' first appointment with Hearing Australia. This is crucial as early intervention therapy must start by six months of age to prevent long-term language delay. Following the initial phase of the NDIS rollout, many children had to wait until 18 months of age before their services were funded.

There are additional actions that could be taken to ensure we preserve the world-leading outcomes for children and deliver on the promise of the NDIS. In particular, First Voice, CICADA and Cochlear, strongly believe it is critical to maintain Hearing Australia as the exclusive provider of audiological supports for children aged 0-6 rather than introduce contestability as planned in July 2020.

We hope the survey provides useful insights for the Review on the unique experience of cochlear implant users and can help contribute to the development of process and decision- making improvements that will result in a better experience with the NDIS.

NDIS and Cochlear Implant Users Survey

The online survey was open from 6 October until 25 October. It was promoted and distributed by the First Voice member organisations, CICADA Australia Inc, CICADA Queensland and Cochlear using email, websites and social media. We designed the survey to reflect the questions raised in the Review's online survey and Discussion Paper while tailoring for CI users.

Below is a summary of key results and analysis. A full copy of survey questions and results for adults and children has been provided as attachments.

Who responded?
We sought responses from both CI users, their families/parents and carers. Where a family/parent or carer responded we asked them to answer as though they were the recipient.

A total of 150 people responded with 52% aged between 19-64 (or responding on behalf of someone in this age bracket) and 16% aged between 0-18 (or responding on behalf of someone in this age bracket). The remaining respondents (32%) were aged 65 and over. This is a slight over-representation of adult CI users compared to the age distribution of cochlear implant surgeries (see Table 1 below).

Most adult respondents were from NSW (39%), Victoria (24%) and the Australian Capital Territory (ACT) (19%) with smaller numbers from Western Australia (WA) (4%), South Australia (SA) (3%), Northern Territory (NT) (3%) and Tasmania (3%). The child respondents were heavily weighted in NSW (46%) and Queensland (21%) with 13% from SA and then smaller numbers from Victoria (8%), ACT (4%), WA (4%) and Tasmania (4%). There were no notable differences in responses between respondents from different states.

- 87% of respondents were approved NDIS participants
- 85% had approved NDIS plans
- 85% of adult participants use their NDIS plan solely for their hearing needs, while this was the case for 68% of child participants

Participant pathway – processes and timeframes

While the majority of adult and child respondents were at least slightly satisfied with each stage of the pathway, there was still significant levels of dissatisfaction.
For adult respondents, the stage receiving the lowest satisfaction score was plan development (65% satisfied). For child respondents, approval of access received the lowest rate of satisfaction (67%).

The amount of time taken for processes to be completed, the complexity of processes and lack of understanding of hearing loss and cochlear implantation from those administering the NDIS, were common themes contributing to a lack of satisfaction. This is explored in more detail below.
For a majority of child and adult respondents, it took more than a month for both approval of access to the NDIS and approval of their plan.

Time taken for access	Adults	Children
Wait time >1 month for **access** approval	68%	57%
Wait time >1 month for **plan** approval	51%	52%

Adults reported longer wait times than children. For adults whose access took more than a month for approval, 46% took more than 6 months. For plan approval it took between 2 and 6 months for 86% of the respondents who said it took more than a month. None of the child respondents reported waiting more than 4 months for access or plan approval.

Supports and services

Adults

Maintaining and replacing assistive technology particularly sound processors was the focus of adult respondents. The majority of respondents with approved plans use the NDIS for sound processor parts and accessories (40%), and other support technologies (30%). While 17% have already used the NDIS to access a replacement sound processor, 29% intend to use the NDIS to access a replacement.

Lack of funding for replacement sound processors was a common theme for adult respondents who were dissatisfied with their plan or their overall NDIS experience.

Children

Child respondents predominately use the NDIS for speech and language services (45%) with only 26% using the NDIS for parts and accessories. None of the respondents reported using the NDIS for replacement sound processors. This can largely be explained by the availability of replacement sound processors for children and young adults (aged 0-26) through the Community Service Obligation component of the Hearing Services Program which is administered by Hearing Australia. This program is due to fully transition to NDIS in June 2020, which is a significant concern for CICADA and First Voice groups.

Funding and plan management

A small majority of both adult and child respondents with an approved plan self-manage their funding (66% and 64% respectively). More children respondents have their funds managed by the NDIA (27%) than adults (15%) while more adults have an independent manager (18% compared to 9%)

Adult respondents have an average of 81% of their funding for hearing related needs whereas child respondents have a slightly lower average of 71%. This is consistent with the higher number of child respondents who reported accessing the NDIS for another disability in addition to hearing loss.

Around 60% of child respondents with an approved plan have used or are using all of their funding, this in contrast with 28% of adult respondents. Most adult respondents were unsure if they would use all of their funds. It is not clear why this is the case but may be linked to the comments explored below that plans are including funding for items/services the respondent doesn't think they need.

Satisfaction with NDIS processes and decision making

Overall satisfaction with the NDIS experience is at 64% (where participants ranked slightly satisfied to extremely satisfied). For child respondents, overall satisfaction was at 67% with adults

slightly lower at 61%. This is compared to the overall NDIS participant rating of 90 per cent reported by the NDIA as part of its latest quarterly report[3]

Overall, 71% of respondents agreed that their current NDIS plan met their current needs. For both adults and children establishing eligibility received the highest levels of satisfaction (85% and 86% respectively).

Difference in satisfaction – Adults v Children

Whilet overall current satisfaction of the NDIS program for child and adult participants does not vary greatly, 13% more adults felt their current NDIS plan did not meet their needs.

	Adults	**Children**
Overall current satisfaction with NDIS	72%	74%
Current NDIS plan meets needs	67%	80%

While overall satisfaction is at 64% there was slightly higher rates of satisfaction for the specific parts of the pathway and those varied between adults and children.

Lowest ranking satisfaction scores	**Adults**	**Children**
Satisfaction with overall NDIS experience	61%	67%
Developing NDIS Plan	65%	73%
Approval of NDIS access	76%	67%

Why are participants dissatisfied?

There are several key themes emerging from the comments of those respondents who said they were dissatisfied with one or more aspects of the NDIS. As noted above, a key driver of dissatisfaction was the timeframe for completion of various stages of the NDIS pathway. Another common theme was that respondents don't feel their NDIS planners understand their hearing disability or CI technology, and therefore are not appropriately addressing their needs.

Other common themes arising from comments include:

- Package dissatisfaction - didn't get what was needed
- Long wait times/slow process

[3] Report to COAG Disability Reform Council for Q4 of Year 6June 2019 p 34 https://www.ndis.gov.au/about-us/publications/quarterly-reports)

- No funding for replacement sound processors
- Confusing/difficult processes
- Poor communication/service
- Process not handled competently - errors in plan
- No guidance/assistance

The survey results and related comments also indicate that experiences of the NDIS program varies between adult and child CI users.

The most common complaint from adult participants concerned a dissatisfaction with their current plan, while this was the least common complaint for children. Children also reported an ease of process due to help from Hearing Australia.

Children found greater obstacles in proving their disability, and when faced with multiple disabilities. In contrast adults raised more concerns surrounding a perceived lack of control over their plan, and greater frustrations with NDIS processes.

Example comments

"I want to be able to cover the most important thing in my life - my Cochlear Implant Processor - which is $8,000 per ear. That is the only thing they will NOT cover, yet they are offering me urinary incontinence pads, house cleaning, wheelchairs, and other random stuff. CRAZY."

"I have been given money for speech therapy but I can talk. I am a public speaker"

"I asked for a review and it took me over 6 months to have nothing changed so I gave up"

"I'm not sure if I am eligible, the information is not clear or readily accessible"

“The program is too generic, it is biased to the hearing perspective, and not suited to needs of deaf people.”

"I was not listened to."

“System regularly changing.”

Why are participants satisfied?

Respondents provided fewer comments about why they were satisfied with the NDIS or specific parts of the pathway. However, from the comments that were provided, there were some common themes across adults and children:

- Suiting needs at present
- Given me access to things I otherwise could not access
- Simple enough process
- Given me more than what I need

Example comments:

"NDIS gives me access to rehabilitation ser[v]ices I otherwise could not afford"

"I had to self-fund everything before"

“The plan takes into account all my hearing needs/goals”

Of those that expressed overall satisfaction with the process, many of them also reported that getting to their final satisfactory result initially had some difficulties, such as:

- Initial problems/obstacles needed to overcome
- Clunky process
- Plan approved before given quotes for participant's requirements

Example comments:

"I had some initial teething issues with payment and the portal. Eventually my local federal member sorted it out"

"I found understanding what was required of me difficult, and getting it all together was quite a chore. In the end and with the help of a local area coordinator it all fell into place and so I was happy."

" After appealing the original decision, I was able to get what I needed"

" At this stage I have had no problems with anything I asked for but not 100% sure what I should ask for"

" I am happy with my plan. Navigating the website is atrocious".

"It was made easier because of Hearing Australia. It took too long to get the planning meeting. And a lot of the questions are tailored towards older people not children and babies."

What do participants think could help improve their experience with the NDIS?

The survey asked for feedback from respondents on what steps could have been taken to improve their experience including by the NDIA, their planner and their hearing health provider. The themes emerging from these responses were very similar to those outlined in relation to levels of dissatisfaction. An additional theme, was the high level of confidence in, and satisfaction with, the support provided by hearing health providers.

Background

Hearing loss and cochlear implants

A 2017 report prepared by Deloitte Access Economics estimated that 3.6 million, or one in six, Australians are deaf, hard of hearing or live with hearing loss[4]. This number is expected to double to 7.8 million by 2060, largely due to the ageing population. More than one third of Australians aged 65 have a disabling hearing loss.

The Deloitte Report also estimated up to 280,000 Australians have severe to profound deafness or hearing loss[5]. A person with severe loss will have difficulty understanding normal speech even when wearing hearing aids but may hear loud voices at close distances (up to one metre). A person with profound hearing loss will always have trouble understanding conversational speech even with hearing aids and would not detect even the loudest components of shouting unaided.

There are different types of hearing loss which affect the potential range of treatment options. Sensorineural hearing loss occurs when the inner ear (cochlea) or hearing nerve is damaged or does not work properly. Common causes include: congenital hearing loss, ageing, exposure to loud noise, head injury, and adverse reactions to medications. With sensorineural hearing loss, sounds are not only softer, but also difficult to understand — especially when it is noisy.

For people with severe to profound sensorineural hearing loss, hearing aids are insufficient or ineffective. A cochlear implant system is the only viable option to give them functional hearing. A Cochlear implant systems consist of two parts:

- the surgically placed cochlear implant that is designed to be last many decades and;
- the externally worn cochlear implant sound processor which is fitted by an audiologist, is intended to be worn every waking hour of the user, and will need to maintained and periodically replaced with a new sound processor.

Both the implant and sound processor work together to address sensorineural hearing loss. Each is integral to the operation of the other component. Refer to Appendix A for more detail on how cochlear implants work

Cochlear implantation in Australia

It is estimated around 14,000 Australians have cochlear implants on either one ear or two ears (bilateral). Australia leads the world for cochlear implantation in children with around 90% of all children who could benefit from a cochlear implant being implanted. In contrast the rate of implantation for adults is at about 14%.

The following tables show the number of ears implanted in Australia each year since Financial Year (FY) 2000-2001 to FY 2017-18 (the latest figures available) and the cumulative number of ears implanted. Given a bilateral implantation rate of around 30% has been established since FY07, it is estimated around 1,200 people were implanted in FY18.

[4] The Social and Economic Cost of Hearing Loss in Australia June 2017, Deloitte Access Economics commissioned by the Hearing Care Industry Association http://www.hcia.com.au/hcia-wp/wp-content/uploads/2015/05/Social-and-Economic-Cost-of-Hearing-Health-in-Australia_June-2017.pdf

[5] As above page 20

Table 1 – Number of ears implanted annually[6]

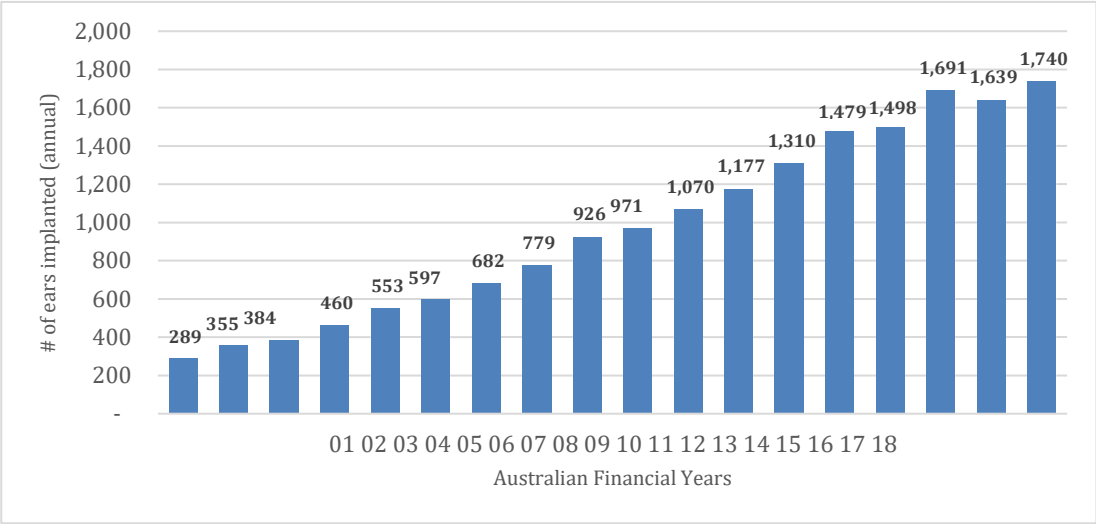


Table 2 – Cumulative ears implanted by year[7]

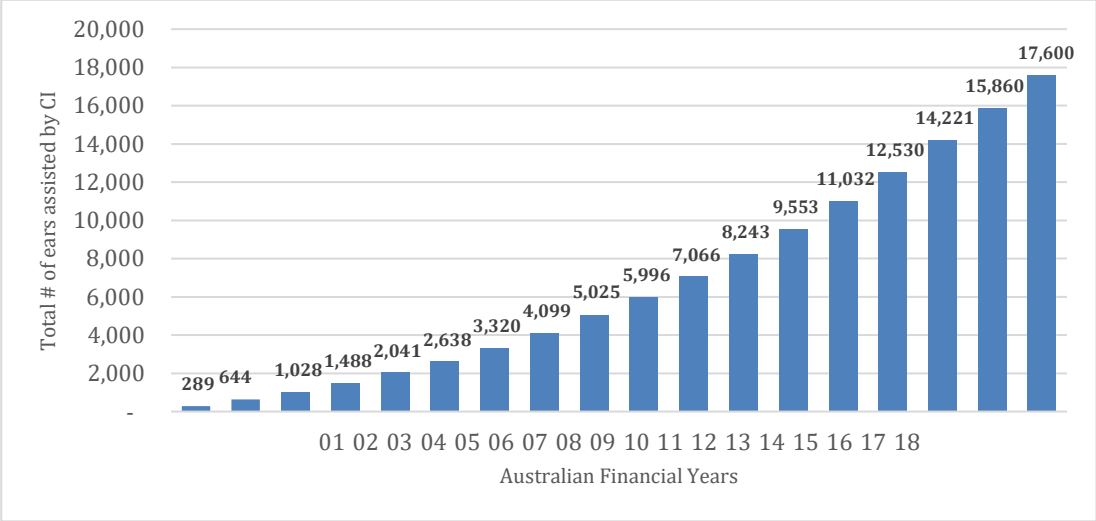
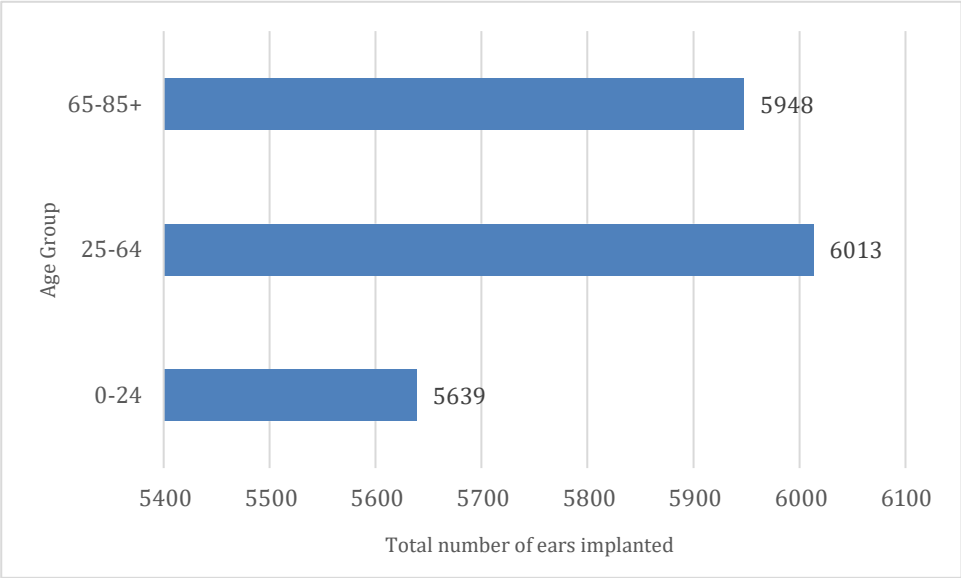


Table 3 shows the number of ears implanted between FY01 and FY18 according to age group. Nearly 70% of all cochlear implant surgeries have been performed on people over 25 (34% for ages 25-64 and 34% for people aged 65 – 85+).

[6] Australian Institute of Health and Welfare, Procedures and healthcare interventions datacubes FY2001 to FY2018; https://www.aihw.gov.au/reports/hospitals/procedures-data-cubes/contents/data-cubes

[7] As above.

Table 3 – Total ears implanted by age group between FY01 and FY18[8]



While 66% of current CI users had surgery before they were 65, with a 17 year compound annual growth rate of 16%, implantation in over 65's has grown faster than all other age groups (0-24 grew 7% and 25-64 grew 11%);

Over the last 3 years, the 65 and over age segment has been the only one that has grown considerably - by 12% (0-24 grew -2% and 25-64 grew 3%). In FY18 people over 65 accounted for 43% of all cochlear implant surgeries.

Funding for cochlear implant surgery – private and public

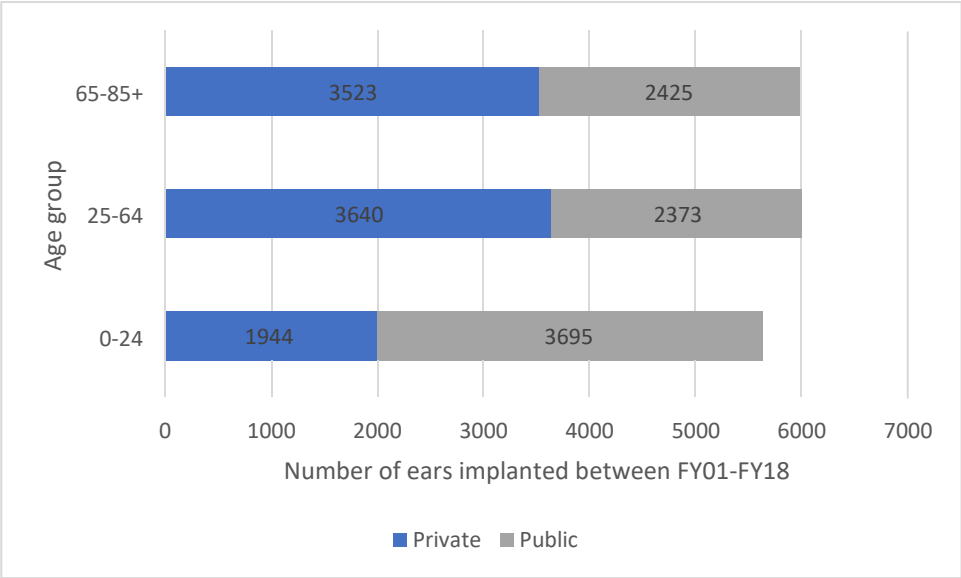
Cochlear implantation surgery is available in both the public and private health systems. Cover for cochlear implant surgery is now mandatory in Gold and Silver private health insurance hospital products[9]. As Table 4 indicates, between FY01 and FY18, the overall split between public and private has been roughly 50/50.

However, the comparison according to age group shows 65% of people aged between 0-24 are publicly funded whereas people aged more than 25 are much more likely to use private health insurance for their surgery, with public funding rates of 39% of people aged between 25-64 and 41% for people aged 65 – 85+.

[8] Australian Institute of Health and Welfare, Procedures and healthcare interventions datacubes FY2001 to FY2018; https://www.aihw.gov.au/reports/hospitals/procedures-data-cubes/contents/data-cubes. We have used the 0-24 age group rather than 0-18 to more closely reflect the availability of funding for hearing support for people aged 0-26 under the Hearing Services Program.

[9] https://www.health.gov.au/resources/publications/private-health-insurance-reforms-gold-silver-bronze-basic-product-tiers-fact-shee

Table 4 – Comparison of CI surgeries completed with public and private funding[10]



This reflects the historic and current prioritisation of children for cochlear implant surgery in the public system and inadequate allocation of resources for adult implantation in some States.

Funding for cochlear implant sound processors – NDIS and the Hearing Services Program

It is important to note that funding for the cochlear implantation surgery and cochlear implant systems including the initial sound processor required to make the implant work, is separate to funding for replacement sound processors which will be needed throughout the life of the CI user.

Many private health funds make funding available for replacement sound processors available as an ex gratia payment in relation to a hospital product that covers initial implantation. With the exception of South Australia, the State public cochlear implant programs do not fund replacement sound processors.

Leaving aside the support that is now available under the NDIS, the Hearing Services Program (HSP)[11] is the major source of funding for CI users to maintain and/or replace their sound processor.

The Department of Health funds Hearing Australia to deliver the Community Service Obligation component of the HSP to meet the hearing needs of vulnerable groups including children and young adults (0-26), Indigenous Australians and adults with complex hearing needs who require specialist hearing services. Support for cochlear implants that is funded as part of the CSO covers:

- Repairs and maintenance for all eligible clients who have a cochlear implant, that is:
    - young Australians under 26 years of age

[10] Australian Institute of Health and Welfare, Procedures and healthcare interventions datacubes FY2001 to FY2018; Medicare online database of items processed for MBS item 41617 (insertion of cochlear implant) between FY01 and FY18
http://medicarestatistics.humanservices.gov.au/statistics/do.jsp?_PROGRAM=%2Fstatistics%2Fmbs_item_standard_report&DRILL=ag&group=41617&VAR=services&STAT=count&RPT_FMT=by+state&PTYPE=finyear&START_DT=200007&END_DT=201806

[11] http://www.hearingservices.gov.au

    - Australians aged 26 years and older who are eligible for the Hearing Services Program Community Service Obligation (CSO) program, the majority of whom are aged over 65 years.

- Replacement and upgrade of speech processors for young Australians under 26 years of age.

Based on the data above we would estimate there are around 9000 cochlear implant users who would appear to be eligible to access the NDIS. These people:

- Were implanted before they turned 65 and did not turn 65 before the national roll out of the NDIS started in July 2016
- Use special equipment because of a permanent and significant disability, and
- In all but the most exceptional cases, meet the additional guidance for hearing impairments, as set out at 8.3.3 of the Operational Guidelines[12]. below:

About First Voice

First Voice is the national voice for member organisations that provide listening and spoken language early intervention services for children who are deaf or hearing-impaired.

First Voice advocates for world-class early intervention services that give children the listening and spoken language skills necessary to achieve mainstream education, employment of choice and social integration within the hearing world. First Voice members provide early intervention services to the majority of children living with deafness or hearing loss in Australia and New Zealand, as well as centres in the UK and South Africa. This is one of the largest cohorts of children receiving early intervention services for hearing loss in the world.

Our members include some of the largest, oldest and most respected centres providing services for childhood hearing loss in Australia, New Zealand and, more recently, across the globe. They lead the world in listening and spoken language therapies for children who are deaf or hearing impaired. These include:

- Can: Do 4 Kids, South Australia
- Hear and Say, Queensland
- Taralye – an RIDBC Service, Victoria
- Telethon Speech & Hearing, Western Australia
- The Hearing House, New Zealand
- The Shepherd Centre, New South Wales, Australian Capital Territory and Tasmania
- AKUK, United Kingdom
- Carel de Toit Centre, South Africa

About CICADA Australia Inc

The Cochlear Implant Club and Advisory Association (CICADA) is a registered charity and volunteer group supporting people with cochlear implants. We provide support to hearing impaired Australians through information, education, advocacy and social events. CICDA Australian Inc is are affiliated with other and independent CICADA associations in other states and regions of Australia.

[12] https://www.ndis.gov.au/about-us/operational-guidelines/access-ndis-operational-guideline/access-ndis-disability-requirements

About CICADA Queensland

CICADA Queensland is a completely independent not-for-profit support organisation staffed by volunteers. We aim to help hearing-impaired people who have a Cochlear Implant – and people who are thinking about getting one – connect with others in a similar position and make new friends in a supportive environment. We are also involved in championing hearing-impaired and cochlear implant recipients' rights and awareness in the broader community.
CICADA Queensland is affiliated with CICADA Australia, Inc.

About Cochlear Limited

Cochlear is the global leader in implantable hearing solutions with products including cochlear implants, bone conduction implants and acoustic implants. Cochlear commenced operations in 1981 as part of the Nucleus group and in 1995 listed on the Australian Securities Exchange (ASX). Today, Cochlear is a Top 50 ASX-listed company with annual global revenues exceeding AUD$1 billion.

Cochlear aims to support cochlear implantation becoming the standard of care for people with severe to profound hearing loss. Cochlear also provides bone conduction implants for people with conductive hearing loss, mixed hearing loss and single sided deafness.

Cochlear has provided more than 550,000 implantable devices, helping people of all ages to hear. Whether these hearing solutions were implanted today or many years ago, Cochlear strives to continuously develop new technologies and innovations for all recipients.

Cochlear invests more than AUD$180 million each year in research and development and currently participates in over 100 collaborative research programs worldwide. Our promise is to help people "Hear now. And always" – aiming to provide them with a lifetime of hearing through the best possible support.

Cochlear's global headquarters are on the campus of Macquarie University in Sydney, with regional headquarters in Asia Pacific, Europe and the Americas. Cochlear has a significant international footprint, selling in over 100 countries, and a global workforce of more than 4,000employees.

With manufacturing and R&D at Macquarie University and further manufacturing facilities at Lane Cove and Brisbane, Cochlear invested more than $700 million into the Australian economy in FY18/19 including:

- more than $345m in payments to Australian suppliers
- $194m in wages to more than 1700 employees
- $72.6m in corporate tax and $12m in payroll tax
- Over $100 million in R&D investment

In the last financial year, Cochlear manufactured more than 85% of our products and conducted around 66% of our R&D in Australia. We also paid more than 80% of our corporate tax in Australia while earning more than 95% of our revenue from sales outside Australia.

Appendix A

How a cochlear implant works

Hearing with a cochlear implant

1. Microphones on the sound processor pick up sounds and the processor converts them into digital information.
2. This information is transferred through the coil to the implant just under the skin.
3. The implant sends electrical signals down the electrode into the cochlea.
4. The hearing nerve fibres in the cochlea pick up the signals and send them to the brain, giving the sensation of sound.