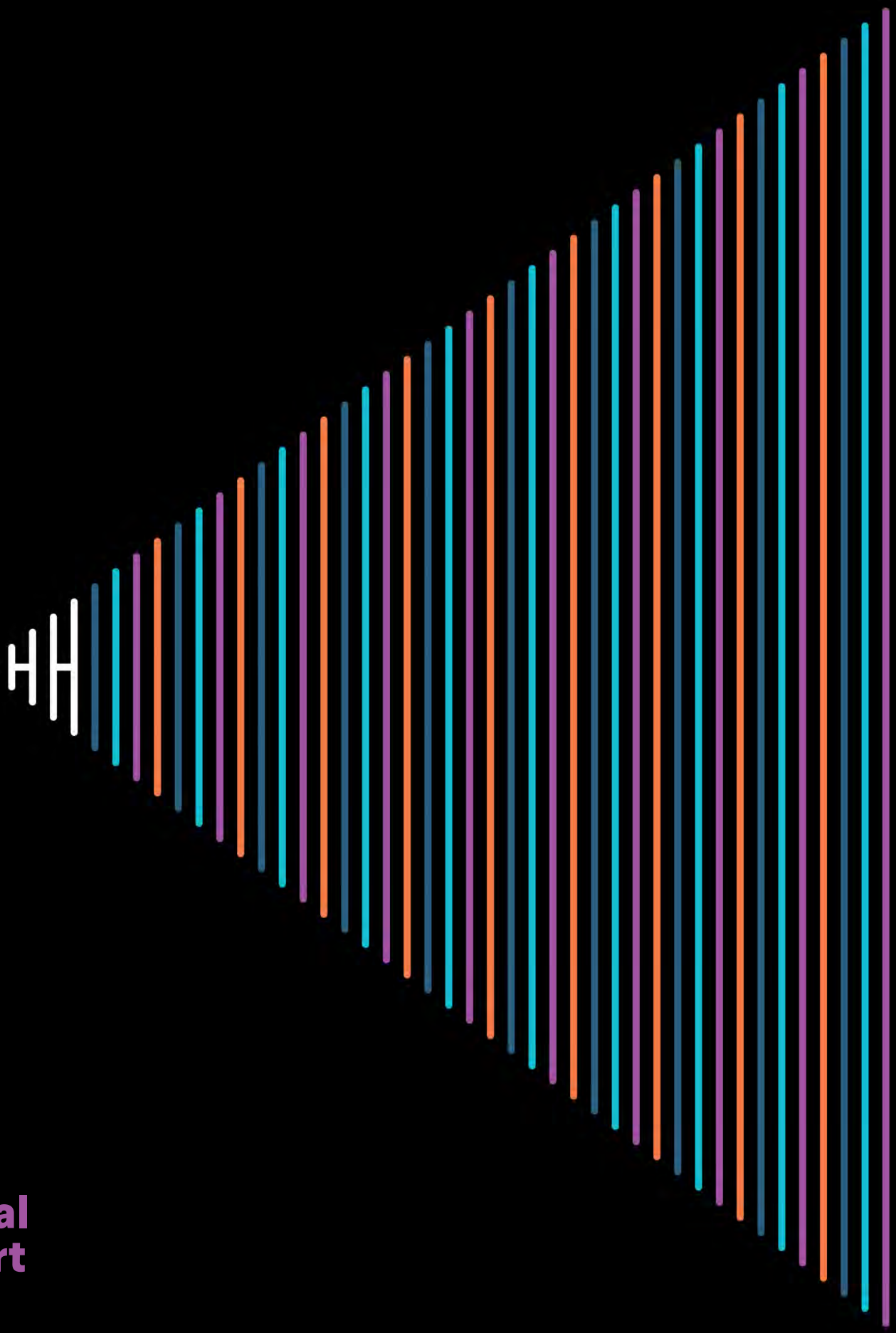

2017-2018 Annual Report


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THE HEARING HOUSE

We hope to provide useful information to stakeholders about our clients, services and outcomes through this report.

Should you have any feedback, please direct this to the CEO of The Hearing House via reception@hearinghouse.co.nz; or to the report's primary author: Janet Digby, janet@levare.co.nz.

Thanks to everyone in the team who contributed to this report, particularly Carolyn Malem (Clinical Administrator) who led the mahi this year.

The Hearing House, Te Whare Whakarongo, is a charity established in 1998 to teach children with hearing loss to listen and speak. Since early 2018 services have expanded to include adults and a new home at The Stichbury Bidwill Centre.

Our organisation's mission is to maximise the communication potential and quality of life of those with hearing loss through effective partnerships.

"Mehemea ka moemoe ā ahau, kia ahau anake. Mehemea ka moemoea tātou, ka taea e tātou." **Te Puea Herangi**
(If I dream, I dream alone. If we all dream together, we can succeed.)

This last year saw big changes at The Hearing House. Most notably was the inclusion of the adult cochlear implant programme, the appointment of a Clinical Director and a new partnership with the University of Auckland. We also welcomed all staff back under one roof at The Stichbury Bidwill Centre. The centre was named in honour of two donors who provided cornerstone funding for the redevelopment in Greenlane.

Features of the new centre include a community room, and whānau and sensory integration rooms, which mean clients and professionals have even more opportunties for learning and development.

At 30 June 2018, there were nearly 300 children, rangatahi and their families and more than 500 adult clients receiving services from The Hearing House. As a result, our organisation has continued to grow, now employing 29 staff, including habilitationists, rehabilitationists, audiologists and administrators, as well as early childhood educators for our on-site preschool.

Team members strive to provide the best service for clients of all ages as they move through triage and assessment, and receive programme services, whether it be for their private or publically funded cochlear implant(s) and/or hearing aid(s), or for children attending our Joyce Fisher Preschool. Services are provided free-of-charge to children with hearing loss receiving services from the public cochlear implant programme, and to those children under the age of five who receive hearing aid habilitation. Adults pay for parts and repairs for their cochlear implants as do those adults with hearing aids who attend the Severe to Profound clinic.

About 70% of all funding for services provided by The Hearing House comes from government via the Northern Cochlear Implant Trust. The remaining funding is raised from the charitable sector.

Young children who receive services require an abundance of listening and language stimulation to achieve their communication potential. As a result, for this group, The Hearing House focuses on intensive therapy and building parents' skills to carry out therapy at home, as part of normal life. Older children and teenagers receive school-based therapy though our partner, Kelston Deaf Education Centre.

While children receive habilitation services, adults receive needs-based rehabilitation which often focuses on helping them make the most of their device so they can function in specific situations.

Both adults and children with cochlear implants and/or hearing aids benefit from comprehensive specialised audiology services. This includes adults who attend the Severe to Profound Clinic, which supports those who have a significant hearing loss and do not qualify for cochlear implants.

2017-2018 in numbers

The Stichbury Bidwill Centre

Former New Zealand cricketing legend Lance Cairns talked about the life-changing impact of having a cochlear implant when he spoke at the official opening of The Stichbury Bidwill Centre in July 2018.

The centre, in Greenlane, Auckland is the new home for the organisation – which now provides services to more than 800 deaf children and adults with cochlear implants and hearing aids.

"The difference in life is just so incredible," Lance said. "I want to see far more people being implanted because of the difference it makes to life, to everything.

"I went from hiding, I didn't want to go anywhere or talk to people, and now everything is normal – back to a real life," he said.

The centre was officially opened by Associate Minister of Health Hon. Julie Anne Genter on July 6th 2018.

The $8 million centre, funded by 35 very generous individuals, trusts, foundations, corporates and the government, is also a hub for organisations that specialise in the area of listening and spoken language.

SoundSkills, the Stuttering Treatment and Research Trust (START) and the Hearing Research Foundation are tenants in the new centre.

Alison Winstanley, 17, is profoundly deaf and has two cochlear implants. She spoke at the official opening and said she is "not unique".

"There are lots of children like me who are now becoming young adults and we are a new generation of hearing and speaking deaf people.

"We will be able to pursue our dreams and there will be no limit to what we can achieve in the future."

Minister Genter acknowledged the inspiring stories shared by Lance and Alison. "They really illustrate the transformational benefits of cochlear implants and all of the support that enables people to use them. I'm humbled to think of all the people, children and adults alike, who will find assistance within these walls to do three of the most essential things – to listen, to speak and therefore to connect."

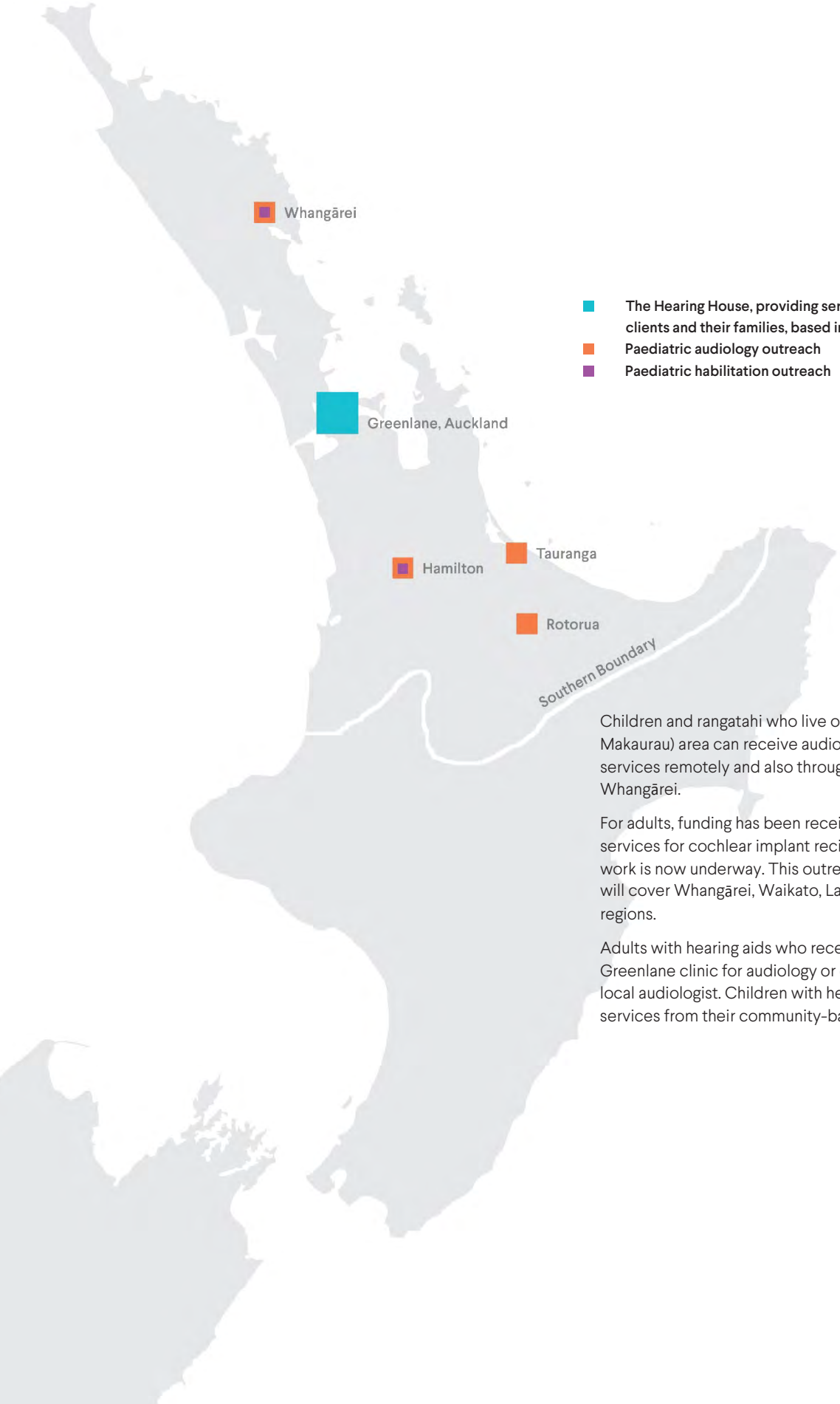
The Hearing House has been supporting deaf people for 20 years and Chief Executive Scott Johnston says it is exciting to be based in a state-of-the-art facility that is fit for purpose and will future proof the charity for the next 20-30 years.

The centre has four therapy rooms, four audiology booths, an online services room, an adult rehabilitation room, a whānau room and a community room. The new building also has a lift which improves access to services.

"The facilities, functions and technology within this building mean we can provide the best services possible for all the clients that come here," Scott said.

The Hearing House was lucky to consider kaumatua Jim Rauwhero as a friend, through our connection with Hinengaru Thompson-Rauwhero. Sadly, Jim passed away in October 2018. His death is a great loss to our service and we offer our condolences to his family, his friends and also to his Te Puea Marae.

Our services



- The Hearing House, providing services to adults and paediatric clients and their families, based in Greenlane, Auckland
- Paediatric audiology outreach
- Paediatric habilitation outreach

Children and rangatahi who live outside the Auckland (Tāmaki Makaurau) area can receive audiology and/or habilitation services remotely and also through regular clinics held in Whangārei.

For adults, funding has been received to provide outreach services for cochlear implant recipients and planning for this work is now underway. This outreach will begin in 2018-19 and will cover Whangārei, Waikato, Lakes and the Bay of Plenty regions.

Adults with hearing aids who receive services can attend the Greenlane clinic for audiology or can receive services from a local audiologist. Children with hearing aids receive audiology services from their community-based audiologist.

Funding

Funding from government covers around 70% of the costs incurred by The Hearing House in providing services to children and adults with hearing loss. To make up the gap and provide sufficient breadth and quality of services, The Hearing House relies on fundraising from the charitable sector.

Government funding received by The Hearing House contributes to the provision of services to cochlear implant clients who have one or two publicly funded cochlear implants. These clients make up the majority of those who receive services from The Hearing House and its partner Kelston Deaf Education Centre. No funding is received from government for habilitation services provided to children or adults with hearing aids.

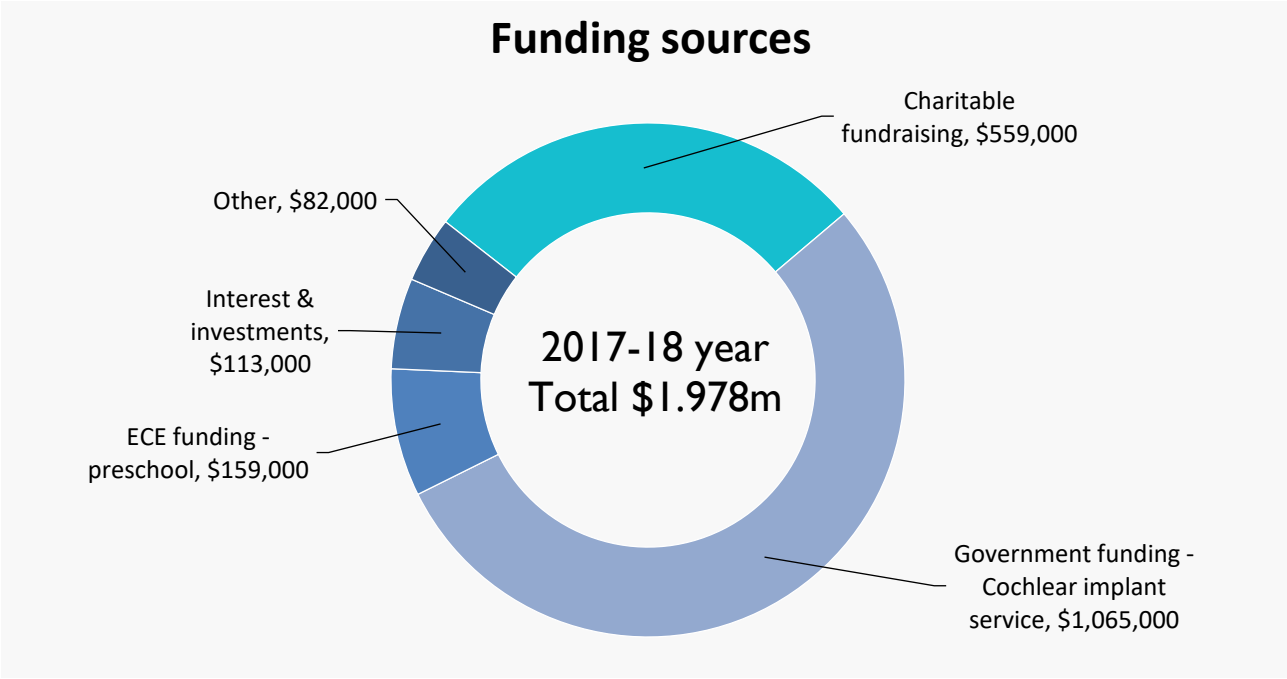
Revenue and spending costs described in Figure 1 on the next page relate to the paediatric programmes and exclude those associated with Kelston Deaf Education Centre habilitation staff. Adult programmes have only been part of the service since January 2018 and so those financials will be included for the first time in next year's Annual Report.

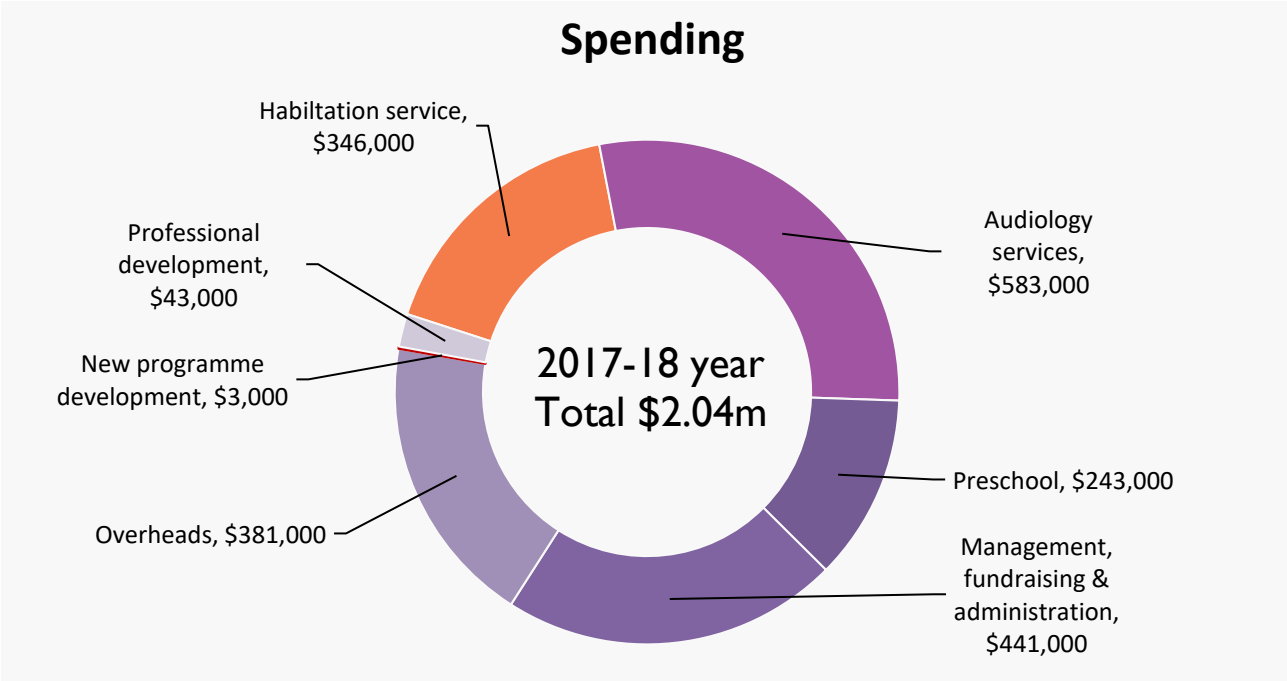
In June 2018 a part time Clinical Director, Dr Holly Teagle, was appointed. Dr Teagle spends two days a week at The Hearing House in this role, and the remainder of her week as an Associate Professor in Audiology at The University of Auckland's School of Population Health.

"The new building is a lot better and looks more hi-tech. It's better because it's open up to any age and I can go there in the future when I become an adult. I think the people who made the new building possible are kind and courageous."

- Aaron Gilby, 11

Figure 1: Paediatric funding and expenditure (2017-2018)





Habilitation - Children

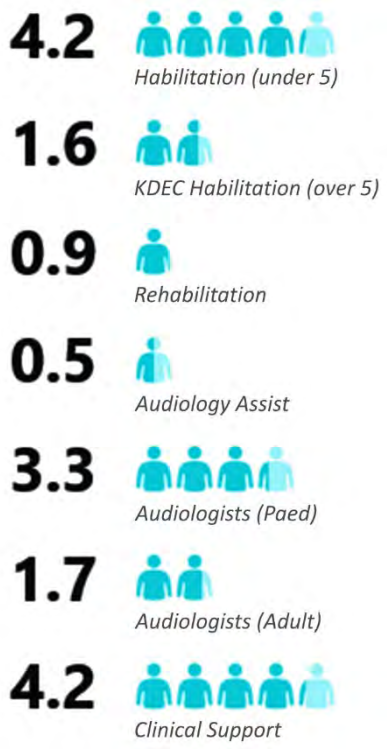
Habilitationists are part of the assessment team and they also work with clients and families to enable children to reach their full communication potential.

One-on-one therapy for families is generally offered at The Hearing House until the child turns five. Parents/caregivers, as the natural teachers of language, are taught skills and strategies to apply during their daily interactions to cultivate their child's spoken language potential. Children whose hearing loss develops after they have learned language may require less intensive habilitation support.

Habilitationists from our partner Kelston Deaf Education Centre (KDEC) work with children and young people over the age of five, providing a school-based service, and liaising with teachers and Resource Teachers of the Deaf (RTD).

The Hearing House habilitation staff work collaboratively with many other professionals, including Ear, Nose and Throat (ENT) surgeons and Ministry of Education staff, including Advisors on Deaf Children (AoDC).

Figure 2: Full time equivalent staff members



In 2017/2018, habilitationists travelled regularly to Hamilton and offered habilitation there for families living in the Waikato, Bay of Plenty and Lakes areas.

Approaches

For many younger children habilitation involves Auditory-Verbal Therapy to enable them to learn how to listen and speak, where possible at the same level as their hearing peers[1].

Some children benefit most from an Auditory Language Enrichment programme (ALE) which continues to follow the principles of Auditory-Verbal Therapy, but where these principles are adapted to meet the additional needs of the child.

Children on an ALE programme use listening to develop understanding and, where possible, communicate using spoken language. They may also use additional means to communicate, such as lip patterns, Key Sign, gestures, PECS (Picture Exchange Communication System) and augmentative alternative communication.

Rehabilitation - Adults

Rehabilitationists are also part of the assessment team and they offer rehabilitation services to adults adjusting to a new implant as well as to those with hearing aids through the Severe to Profound Clinic.

The schedule for rehabilitation is always customised to meet the needs of each client, and this is informed by the test results from their first appointment.

Once the client has had their cochlear implant for a year, individual rehabilitation is often focused on assisting clients with their functioning in specific situations, such as using the telephone. Group sessions are also offered by the adult team to assist groups of clients, again with specific issues, including things such as making the most of assistive listening devices.

Clients may receive further funded rehabilitation from Life Unlimited, based on a programme of care developed by the adult cochlear implant team.

Adults attending the Severe to Profound Clinic also receive rehabilitation services from the rehabilitationists, based on their needs.

[1] The Hearing House was the first centre to provide such early intervention services – based on an Auditory-Verbal approach to children in New Zealand.

This type of therapy accelerates the natural way language develops to enable children with a cochlear implant(s) or hearing aids to catch up with the listening skills and language of their peers.

Audiology

Qualified audiologists carry out testing to establish cochlear implant candidacy as well as providing post-operative audiology services for children, young people and adults.

The organisation's audiologists ensure cochlear implants are optimally programmed for the specific needs of each recipient.

Paediatrics

In the first year following surgery, each cochlear implant recipient is seen at least 10 times by the programme's audiology staff. After their first-year following implantation those under five years of age are usually seen bi-annually, or more frequently if issues arise. Children over five are usually seen annually.

Audiologists are responsible for monitoring each child's audiological progress and they utilise various measures to establish progress and benefit. Audiologists from the service also provide training sessions to professional groups such as RTDs.

As children with a hearing loss often receive a number of specialised services, The Hearing House audiology staff work with many other professionals, including Ear, Nose and Throat surgeons; other audiologists; RTDs; and AoDCs.

Children with hearing aids receive audiology services from their local district health board, rather than from The Hearing House's audiology team.

Adults

Cochlear implant candidates and recipients

In the first year following surgery, each cochlear implant recipient is seen a number of times by the programme's audiology staff, including at one month and six months after switch-on, and based on individual needs.

Programme audiologists support local community audiologists with both hearing aid support and cochlear implant troubleshooting, particularly where the client has mobility issues making it difficult to come to Greenlane.

Adult Severe to Profound Clinic

This is a specialised clinic for those with severe to profound hearing loss which was established eight years ago. The adult team provides support to those who choose the service as their audiology provider. The team also provides information to audiologists in the community.

Referrals are accepted from audiologists in the community when they are not sure what to do next. The team conducts assessments and provides a treatment plan for each client's audiologist to follow.

Some clients who have a cochlear implant in one ear and a hearing aid in the other also choose to receive support from this service.

Clinical support & systems

In addition, staff are employed to ensure recipients can stay 'on-air' by organising repairs, scheduling appointments, managing inventory, and managing the clinical administration for client referral and assessment.

The organisation also has clinical support staff who are responsible for maintaining the client booking system and the client database, ensuring reporting requirements are fulfilled and clinics and meetings run smoothly.

Joyce Fisher Preschool

The Hearing House has its own purpose-built preschool, named after Lady Joyce Fisher, whose charitable trust provided significant funding for this development.

The preschool operates using a reverse integration approach for hearing impaired children. This means that these children are part of a classroom environment that includes their hearing peers from the local community. Children who attend are between two and six years of age.

The rich language environment that hearing peers provide, and the utilisation of Auditory-Verbal Therapy principles within the programme, encourages the development of listening skills and spoken language. Teachers provide both quality language input and also reinforce language modelled by children in the preschool setting.

The preschool also provides a space for hearing impaired children to interact socially in order to promote dynamic relationships and foster confidence and creativity. In addition, a core part of the preschool philosophy is to provide regular exploration of the natural environment, which exposes the children to a variety of experiences and provides a catalyst for spoken language.

The preschool now offers six and a half hour or eight hour sessions each weekday with children generally attending three to five days a week. For each session there are at least two fully qualified and registered teachers and an experienced additional teacher.

During the year ending 30 June 2017, 35 children – 9 of whom are hearing impaired – attended the preschool. Numbers of children are dependent on spaces available and the number of days children attend.

Programmes

In addition to programmes included in the table below, we offer clients a range of events and get-togethers during the year. These include a regular playgroup, picnics, parent evenings and family workshops.

Table 1: Programmes offered by The Hearing House

Programme (cohort)	Details	Number of clients in 2017-18 year
Transition to School (all four-year-olds)	The Hearing House provides a Transition to School process which supports the parent, child and new school through this important transition. This includes work with AoDCs and other professionals.	12
Tele-CHAT and Tele-Audiology (remote MAPping) (clients outside of Auckland)	The Hearing House offers therapy/rehabilitation via Skype (Tele-CHAT) to some clients who live outside of Auckland. This programme assists clients, both young and old, by reducing travel times and enabling clients to receive a number of services from home or a local clinic.	16 (Tele-CHAT)
	Recipients of cochlear implants attend regular mapping sessions to adjust their speech processors. For some children who live outside of Auckland, the cochlear implant is programmed remotely via 'Remote MAPping'.	28 (Tele-Audiology)
Music therapy (selected children under the age of five)	These six-week workshops are provided by Raukatauri Music Therapy Centre twice a year. The aim is to allow parents to explore music with their child and to add a dimension of creativity and fun to their listening experiences. Children develop responses to pulse, rhythm and pitch, and self-confidence and creativity is encouraged.	5
Parent to parent and play groups (all children under 5)	There is a playgroup open to all parents whose children are aged under five years and are receiving services. These groups are co-facilitated by the habilitation staff and parents are able to meet and chat with other parents over coffee.	11
Focus (some children)	This programme focuses on how The Hearing House can work more effectively with families and better support those at risk of poorer outcomes for any reason.	31
Group programmes (some adults)	Group programmes are organised to allow groups of adults to come together to learn about specific topics, such as how to utilise assistive devices and on implementing strategies for conversations to increase day-to-day functioning.	Approximately 2 of these group programmes are conducted each year

Renewed confidence and getting into life

Kay Bloomfield-Bevin was 30 when she suddenly lost her hearing. But that wasn't the only thing she lost. Her hearing loss affected her relationships, she became a recluse and in the coming years this resulted in the breakdown of her marriage. Twenty-one years later she got her first cochlear implant – her world has changed so much she wishes she'd done it sooner.

Kay and her husband were share-milkers in Eltham, Taranaki. She had a 9-year-old daughter and a 2-year-old son. One day when she was working on the farm she cut her arm. That's when everything changed. Kay, now 60, was "deaf as a post" within days of a medical misadventure.

"It happened really quickly. I just went downhill, fast. Everything sounded strange. We had visitors and I thought everything sounded tinny. The next day it was almost all gone. It was horrible....horrible."

Kay says her initial reaction was to just get stuck in and carry on with life. "I kept milking and farming. I just kept going. It doesn't really hit you until way down the line. The reality hits that you are deaf. I remember crying my eyes out in the milking shed three years later."

Kay couldn't communicate with people so life became very isolated for her. She stopped her role as a dressage judge, she couldn't attend meetings, school concerts or socialise with her friends. "I was a real recluse. I never stepped out anywhere." She did, however, join an adult riding group. "When I lost my hearing I took up riding because I had nothing else. I went back to riding – in fact I thank my hearing loss for that. Every cloud has a silver lining. They were so good to me. While I was on a horse I didn't need to talk to people. The people I knew before....they really struggled with me."

Kay says her hearing loss was particularly hard on her daughter. "My son grew up with me being deaf, but my daughter was nine. I used to talk to my daughter all the time. But then I couldn't. There was frustration on both sides – I couldn't hear and I got the words mixed up. I misinterpreted her words, I was on the wrong track and she would have been frustrated as well."

Kay was 51 when she got her first cochlear implant, funded through ACC. "I dragged my feet big time because I had no idea what I'd get out of it. I was really frightened. In the end I thought, 'what have I got to lose?'. My sister supported me and pushed me."

Kay remembers walking up One Tree Hill in Auckland the day her implant was switched on. In an effort to help her get used to the new sound she counted her steps and kept repeating the numbers until she recognised the sound. It didn't take her long at all to get used to it. "It was amazing. Absolutely amazing. All I wanted to do was talk to people and talk on the phone. I couldn't believe what I had missed out on. That first implant was a real step forward. I had to learn to be social again. I'd forgotten how to socialise."

This new lease on life enabled Kay to return to dressage judging. "It gave me the boost I needed."

Kay received her second implant in June 2018. This one took a little longer for her to adjust to, but she hasn't looked back. "I can hear people without looking at them. I can walk down the road and know there is a vehicle behind me. I can get the direction of sound now. I wish I'd done it ages ago."

She has also noticed she is no longer so reliant on other people to help her, or do things for her. Kay says that following her surgeries, the death of her mother earlier in 2018 and the sale of her family home she is now getting back into things. "I'm at that place of saying 'now where do I go?'. I'm much much much, 100 per cent, 200 per cent, more confident."

Kay has also been able to go on her first overseas holiday. "I never would have gone to Rarotonga if I didn't have a cochlear implant."

Kay says staff from the adult cochlear implant team at The Hearing House have been "marvellous" and she encourages anyone contemplating getting cochlear implants to go ahead. "They don't realise what they are missing out on."

Cochlear implants are life-changing for brothers

When you first meet Pounamu and Kauri Hills there are two things that instantly stand out. The young brothers have an amazing bond, and an incredible love of life. Pounamu, five, is fiercely independent, outgoing, bright and bubbly. He loves school and is impressing teachers with his progress. Kauri, four, is a shy, happy kid who loves the outdoors. The brothers have had more than their fair share of doctors' visits and surgeries in their short lives.

They both have Stickler Syndrome – a group of hereditary connective tissue disorders – which was picked up while mum Larnell Kati was pregnant. The symptoms vary from person to person. For Pounamu and Kauri the syndrome presents itself by way of bone deformities, vision loss, hearing loss and cleft palates. They both needed help with breathing when they were born. In the coming years the boys are likely to develop arthritis at a young age, their eyesight could get worse and retinal detachment is possible. Kauri also has scoliosis – a sideways curvature of the spine. Larnell says the boys have had more surgeries than she can count – "way too may" – for cataracts, grommets and cleft palates. Kauri has also had surgeries for his scoliosis and at the end of 2018they both had hip surgery.

Pounamu and Kauri live with their mum and step dad Patrick Atutahi in Putāruru. Larnell says the boys don't let their conditions hold them back. "It's a normal everyday thing for them. They don't let it stop them."

Larnell says communication is the greatest struggle for the boys. "That's the hardest part." Pounamu and Kauri initially had hearing aids, but were referred to The Hearing House because they were no longer getting enough sound from them.

On June 18 they both underwent surgery for cochlear implants, which were switched on the next day. Pounamu has bilateral implants and Kauri has one on his right ear. "We knew it was going to be life- changing," Larnell says.

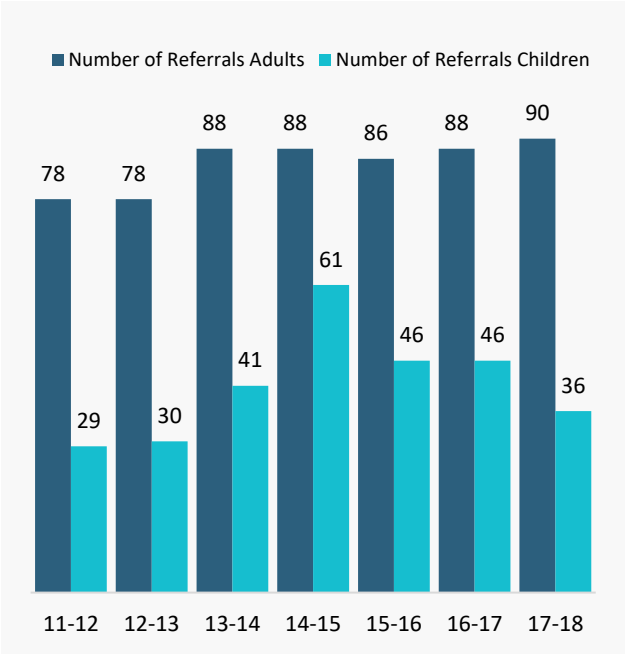
"Since then they've changed in a good way. It's made a huge difference – their attitudes, behaviours, communicating with others. They are just so much brighter. We're more than happy – it's been amazing."

Larnell says Pounamu has been making great progress at school with the teachers particularly impressed with his reading level, considering his hearing loss. Pounamu catches the bus to school by himself and catches it home, or to his nana's, in the afternoons. Larnell says the boys particularly enjoy talking to their dad David about their cochlear implants. "They loved sharing their experiences with their dad and his family. Pounamu shows his dad how to change the batteries and which one goes on which ear."

Larnell says The Hearing House is "the best". "I've found them really supportive towards us, really helpful.....everyone. We feel really welcome and the boys feel at home there."

New referrals

Figure 3: Number of children referred and number of children receiving new implants, by year



Cochlear implant referral and assessment

The Hearing House is a provider to the public cochlear implant programme in the northern region, which includes children, young people and adults living (roughly) north of Turangi.

Cochlear implant assessment involves a multi-disciplinary team which is made up of an audiologist, a (re)habilitationist and an ORL specialist. The clinical team look at a number of different factors (e.g. lifestyle, hearing loss, medical suitability) and complete a range of tests to determine if a cochlear implant is an appropriate option.

In addition, private cochlear implant services are also offered for adults, children and young people.

Referral criteria

Professionals may wish to look at the referral criteria for publicly funded implants for paediatric and adult clients which can be found here. If in doubt about a referral, professionals are encouraged to refer the case, and are welcome to call the programme anytime to discuss referrals and/or the referral process.

The public programme accepts referrals from ENT Specialists, Audiologists, AoDCs and GPs.

Children and young people

Children who are assessed by the cochlear implant team and determined to benefit from a cochlear implant will receive one or two publicly funded devices.

Children under the age of five referred to the programme waited an average of 25 days to begin assessment during the period, while those over five waited an average of 31 days[2].

In cases where a child or young person is assessed as a cochlear implant candidate, and where parents/guardians choose to proceed, surgery is scheduled within two months unless a family requests a later surgery date or unless an approval is needed from ACC. The average time between acceptance of candidacy and surgery was just under two months during the 2017-2018 year.

Adults

The public programme accepts referrals from adult candidates of any age. Candidates need to be well enough for surgery, have a severe/profound hearing loss and struggle to communicate with hearing aids. Those with additional needs are not excluded from receiving a cochlear implant.

[2] This difference is because 1) triage and the initial cochlear implant referral and assessment meeting take longer for the older group and 2) further audiological information is often required for older children and they sometimes require further testing from their local district health board.

Getting a referral

Members of the public who are having difficulty hearing speech when they are not looking at the person talking should speak to their audiologist about a referral for assessment. If they are not registered with an audiologist then is it recommended they find an audiologist in their community and make an appointment. Alternatively, they can get in touch with The Hearing House programme administrator to find out more.

On average a total of 10 referrals for cochlear implant assessments are generally received each month, of these nine are for those seeking public funding.

The average waiting time between referral and the start of assessment during the 2017-18 year was 43 days. Once all the referral information is received the assessment can usually be completed within one month.

Children receiving cochlear implants

Of the 29 children and young people who received cochlear implants:

→ Twenty-eight of these (aged from birth to 19 years of age) received publicly funded cochlear implants in the northern region during the 2017-2018 year. Of these, all but one received their first cochlear implant during this period including one child who received a second implant having received their first in an earlier funding year.

→ One child received cochlear implants paid for privately[3].

While children are being triaged for assessment they receive a habilitation service to ensure progress is ongoing and to develop a better understanding of their language skills.

Of the 36 referrals this year, several young children were diagnosed and referred to the programme as a direct result of newborn hearing screening. Some children would have been referred to the programme previously for hearing aid habilitation.

Adults receiving cochlear implants

Funding

The Ministry of Health funds the cost of cochlear implants, audiology and rehabilitation for adult recipients on the public programme[4]. This includes the cost of a second cochlear implant array for those who have had meningitis.

Recipients of publicly funded cochlear implants must self-fund or fundraise to cover the cost of parts and other costs. These costs are significant.

The adult programme relies heavily on donated parts and processors as the Ministry of Health contract does not provide for equipment or repairs outside of warrantee. For clients on a restricted income with no other form of assistance, this stock is essential to keep their device functioning. Depending on a client's needs the programme may provide individual parts (e.g. rechargeable batteries) or a full system if their publically funded device has been lost or stolen and was not covered by insurance because the cost was prohibitive for the client.

Private cochlear implant recipients cover all costs themselves or through fundraising, including the surgery, device, rehabilitation, parts and processors. These clients include those who have received a single publicly funded cochlear implant and wish to get a second private implant.

During the 2017-2018 year, standard funding for 20 cochlear implants was supplemented by additional government funding for a further 30 cochlear implants.

In the 2017-2018 year, 143 adults were referred to this service by community audiologists. Of these, 103 were accepted to receive services meeting the referral criterion and going

[3] Families may decide to fund an implant for a child who has single sided deafness where this is not funded publicly, families of children who are not permanent residents or citizens may also decide to fund their implant and children who received single implants prior to July 2014 who are not entitled to a second implant publicly may also have their second side funded privately.

[4] To be eligible for funding under the public programme the individual must be eligible under the 'Health and Disability Services Eligibility Direction 2011' and must live in New Zealand permanently. Other conditions may apply such as whether an individual already has a cochlear implant (and therefore is not eligible for a second implant) or whether they received their implant overseas. More information can be found at https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/hearing-and-vision-services/hearing-services/cochlear-implants

through the assessment phase. Of those who were assessed 36 went onto the waiting list and the remainder did not.

Reasons why people didn't go onto the list included that they were either outside of criteria, they were medically unsuitable, or after discussing implantation they decided to not proceed with a cochlear implant.

The adult waiting list

The adult programme generally receives funding for 20 cochlear implants each year. This can be reduced if there is insufficient funding to allow all children and young people who are suitable candidates to be implanted. In these circumstances adult funding is reallocated to children and young people.

In New Zealand, adults receive a single publicly funded cochlear implant should they meet the criteria and reach the top of the waiting list.

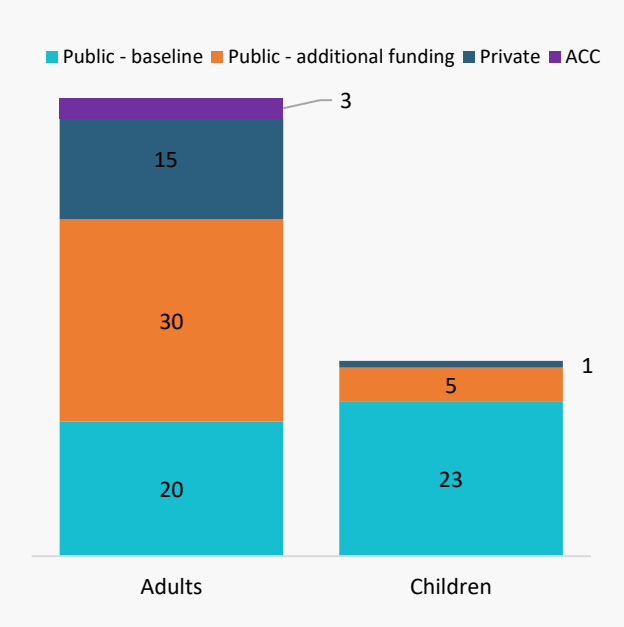
The Northern Cochlear Implant Programme allocates a quarter of its annual implant allocation every 3 months, based on those candidates who receive the highest scores from the prioritisation tool.

Throughout the assessment process and post-implantation the assessment team works with a variety of professionals, such as ENT's, GPs, mental health services and rest homes.

At the end of the period, there were 43 adults on the waiting list for a publicly funded cochlear implant. Of these, 19 had been waiting more than 18 months.

Adults receiving cochlear implants are more likely to have a progressive or acquired hearing loss than their paediatric counterparts. Within this group, some recipients also have presbycusis (age-related hearing loss). Sign language is more commonly used among adults with cochlear implants who have long-standing hearing loss, than among their paediatric counterparts.

Figure 4: Cochlear implant recipients 2017-2018 by funding source



Children with hearing aids

Each year, a number of children with hearing aids under the age of five are referred to The Hearing House and provided with habilitation services to support their spoken language development.

The decision on the number of children to support is made on a case-by-case basis and considers the capacity of clinical staff and the availability of private funding, as this service is not government funded:

→ Eleven referrals for hearing aid habilitation were re ceived during the 2017-2018 calendar year;

→ Of these, eight children were accepted for services during this period. A further six children were accepted previously and continued to receive services during the 2017-2018 year; and

→ An additional child on the programme entered cochlear implant assessment during the 2017-2018 year and therefore left the hearing aid programme.

Children with age-appropriate speech and language are referred back to their local provider.

Adults with hearing aids

Each year, a number of adults with hearing aids are referred to The Hearing House and provided with ongoing audiology and rehabilitation services based on their individual needs delivered by the Severe to Profound Clinic.

Often these are clients who do not meet the criteria for a cochlear implant, and who benefit from specialist support for their hearing loss. Clients pay to receive this service, and a good number of these clients will go on to qualify for a cochlear implant in the future as their hearing deteriorates.

"Right from switch-on day after having my cochlear implant I was impressed by the service offered by The Hearing House and associates. Detailed check-ups, adjustments, advice and tips are so helpful in helping rebuild confidence after this life-changing operation. No question or concern is silly or small, and all are addressed with the same level of care. It's good to know these experienced and caring professionals are there when you need them."
- Sue Clayton

Clients receiving services

This section describes characteristics of clients receiving services. The majority of those receiving services were those with one or two cochlear implants and information on children and adults with hearing aids is also included.

Clients with cochlear implants

Figure 5 shows significant growth in the number of children and young people in the northern region receiving cochlear implant services during the last nine years.

Figure 6 shows the growth in the number of adults supported on the programme and on the waitlist since 2011.

Deprivation status

The Hearing House records deprivation data[5] for families receiving services to help staff understand if there are access or outcome differences for these groups.

Figure 7 shows children and young people receiving services span the full range of deprivation scores, with those in deciles five and the top two deciles (the most deprived) over-represented and those in the lowest and upper middle deciles under-represented.

Figure 5: Children with cochlear implants receiving services by year and age group

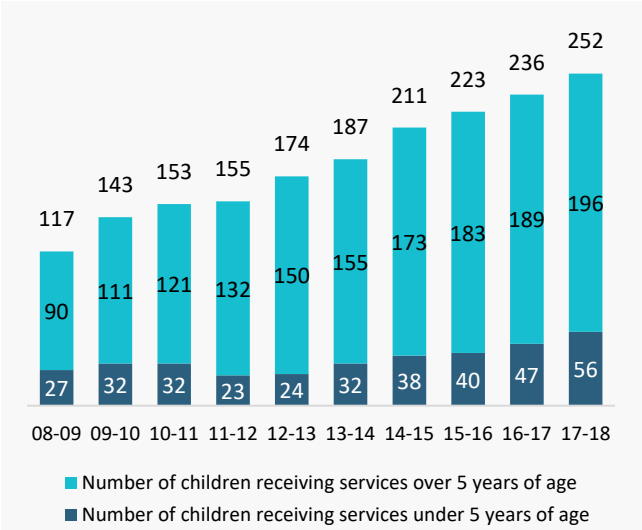


Figure 6: Adults receiving services by year

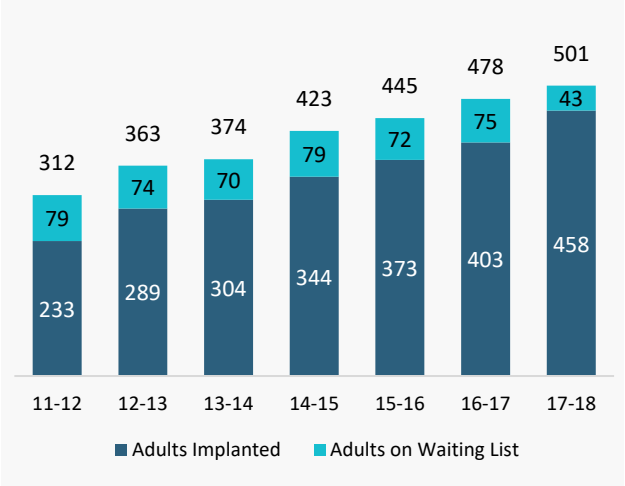
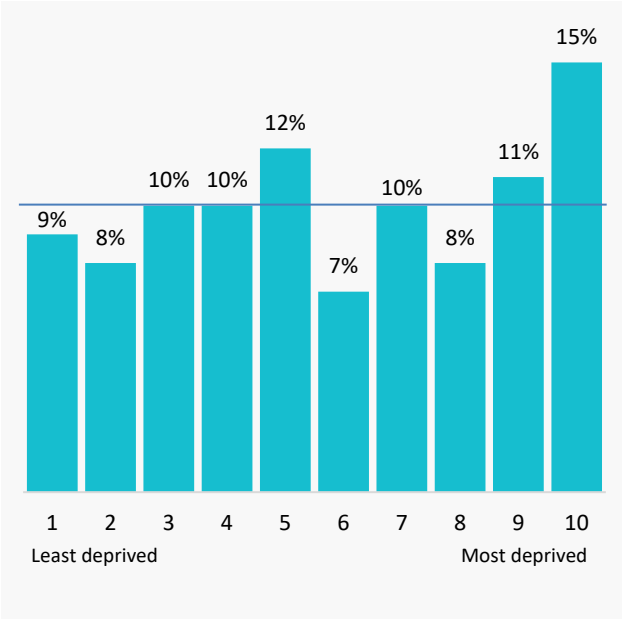


Figure 7: Deprivation of children and young people (and therefore their families) receiving cochlear implant services



[5] 'NZDep2013' provides scores relating to the deprivation status of every area in New Zealand. These scores are calculated by the University of Otago (Wellington) by combining census data relating to income, home ownership, employment, qualifications, family structure, housing, access to transport and communications. Each small area in New Zealand is allocated a score and each score applies to 10% of the population. For example, those with the highest score (10) relate to the most deprived 10% (decile) of areas in New Zealand.

Devices

More than half of the children and teenagers with cochlear implants who are currently receiving services have two cochlear implants (58%). Where clinically appropriate, bilateral implants have been routinely provided to newly referred children and young people since 1 July 2014.

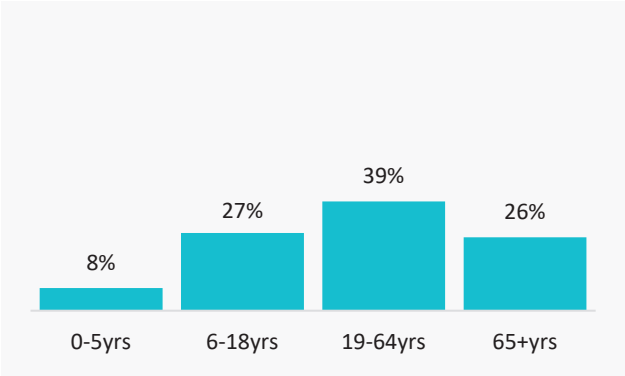
Just under a fifth of children and young people (17%) with cochlear implants have a hearing aid in their other ear, while the remainder (24%) have no device in their other ear. The number of young people with only one cochlear implant is higher than for younger children as public bilateral funding became available in 2014. It is expected that the proportion of children with bilateral implants will continue to grow.

Of the children and teenagers who have only one cochlear implant almost three-quarters have the device in their right ear (71%) compared to just over a quarter who received one in their left ear (29%). In total for the 252 children receiving services, 147 have bilateral cochlear implants, 61 have a single cochlear implant and 44 use a hearing aid in the opposite ear. The vast majority of children with one or more cochlear implants have a severe to profound hearing loss.

Age profile

The age profile of clients with cochlear implants is shown in Figure 8. The majority of cochlear implant recipients are currently aged between 19 and 64 years old.

Figure 8: Age profile of those receiving cochlear implant services



The average age at first implant for a paediatric client for the 2017-2018 year was 4.4 years[6]. The average for an adult client was 58.3 years.

[6] Based on the age of the child when they received their first implant

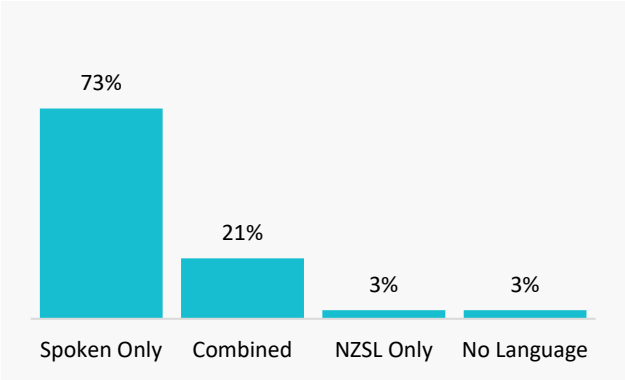
Languages spoken or being learned

Children/young people on the programme can be described as either learning one or more spoken languages, learning New Zealand Sign Language (NZSL)/Key Sign or a combination. The relative size of each of these groups can be seen in Figure 9.

Within the 'spoken language' or 'combined' categories there are 21 languages being spoken or learned.

Of those learning or using a combination of spoken and visual communication the majority were using a combination of one or more spoken languages and NZSL. Children/young people with no language may be too young to have yet developed language or have other developmental delays and may be using alternative forms of communication, such as picture boards. For them, cochlear implant use provides sound awareness and a connection to their environment.

Figure 9: Proportion of children learning or using a spoken language only, NZSL language only or a combination



School-aged children - funding for additional educational support

As at the end of June 2018, school-aged children and young people were situated in a range of school settings, as shown in Figure 10, with most children in mainstream provision.

Please note that KDEC School Provision refers to satellite units in mainstream schools. These were previously known as 'Deaf Units'. These provisions are only available in Auckland. The majority of special schools attend by children on the programme are also in Auckland.

Children and young people may receive additional funding for their school through the Ongoing Resourcing Scheme (ORS) if they are verified as 'high' or 'very high needs'. A child or young person must meet at least one of nine criteria at the 'high' or 'very high' level to be eligible for ORS; one criterion being hearing loss. However, access to this funding does not appear to be consistent across children on the programme. Thirty eight percent of children and young people do not receive ORS funding despite the presence of a severe to profound hearing loss and reliance on cochlear implants and/or trained professionals to assist with communication. Figure 11 shows the ORS status of school-aged children and young people receiving services.

Figure 10: School setting

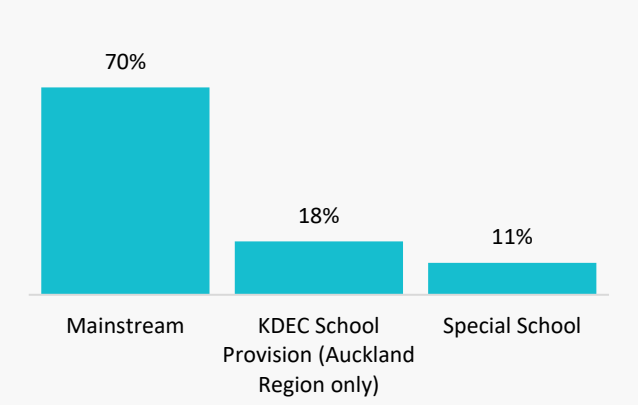
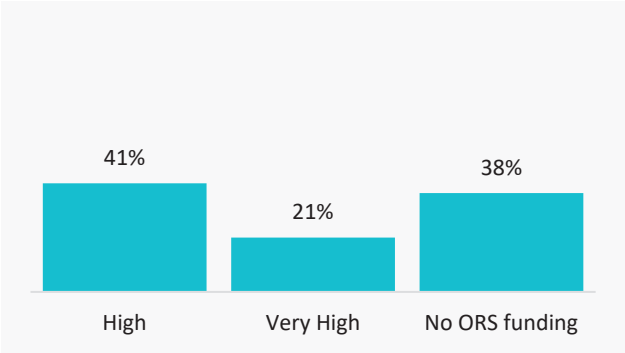


Figure 11: Proportion of children over five years of age with and without Ongoing Resource Scheme (ORS) verification[7]

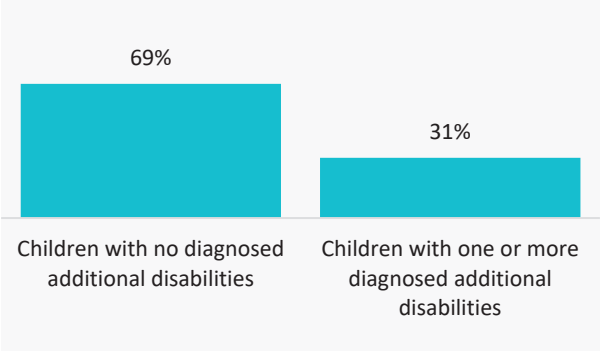


Aetiology

The aetiology (cause of hearing loss) can be either genetic (syndromic or non-syndromic) or non-genetic. Not all children with hearing loss have been tested for the cause of their hearing loss, and tests may not be able to identify a cause.

Twenty-four percent of children had not been tested for the cause of their hearing loss so it remained unknown, a further 17% of children had been tested but this was not able to identify the cause of their hearing loss. Of children with a known cause for their hearing loss, 14% have a hearing loss with a genetic cause that is syndromic in nature and 14% have an acquired hearing loss. A further 13% of children have a genetic cause for their hearing loss that is non-syndromic, 11% have a congenital hearing loss and 7% have a cause that can be either congenital or acquired.

Figure 12: Proportion of children receiving cochlear implant services with additional disabilities



Meningitis

Some hearing loss occurs as a result of meningitis. Where this is the case it is imperative that the investigations and assessment occurs quickly due to a high risk of ossification of the cochlea. Ossification is when the normal tissue of the cochlea is replaced with bone, depending on the severity of the ossification it can be difficult or impossible to place a cochlear implant.

A referral is therefore typically made very quickly to The Hearing House and the assessment process is usually completed within a few weeks.

Programme data from children implanted with one or more cochlear implants shows a greater number of these than expected live in high deprivation areas. This correlation is supported by an analysis conducted by Massey University which found that, when standardised by age, children living in high deprivation areas had five times the rate of meningitis as children living in less deprived areas[8].

[7] Due to rounding some figures, such as this one, may demonstrate percentages that are lower than or exceed 100%

[8] Environmental Health Indicators New Zealand (2018) Meningococcal disease notifications (0–14 years), 2007–2016, retrieved from http://www.ehinz.ac.nz/indicators/indoor-environment/meningococcal-disease/#Meningococcal_by_eth_nzdep on 31st of December 2018.

Children with one or more additional disabilities

Among all children and young people receiving cochlear implant services, 31% have one or more disabilities in addition to their hearing loss, as seen in Figure 12. The group of children and young people with no diagnosed additional disabilities may include children who have yet to be formally diagnosed[9].

This is higher than the rate reported in the New Zealand Deafness Notification Database[10, 11].

The presence of an additional disability may have a significant impact on outcomes and on the level of support the child or young person may require. Additional disabilities may include developmental delay(s), vision or physical impairments. Some children have a syndrome which includes a set of specific symptoms of varying severity.

[9] Depending on the age of a child at diagnosis it may be that the presence of an additional disability may not be suspected until the child is older.

[10] Digby JE, Purdy SC, Kelly AS (2016) Deafness Notification Report (2017) Notified cases of Hearing loss (not remediable by grommets) in New Zealanders under the age of 19. Enable. Auckland, New Zealand.

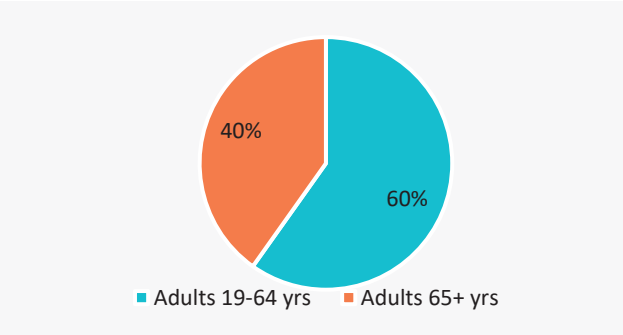
[11] The Deafness Notification Database reports 20% with confirmed additional disabilities. Please keep in mind that unlike our clients, those cases included in the Deafness Notification Database range from 'mild' to 'profound' hearing loss in one or both ears, and only include additional disabilities confirmed at the time the hearing loss is diagnosed.

Adults with cochlear implants

Diversity of adults with cochlear implants

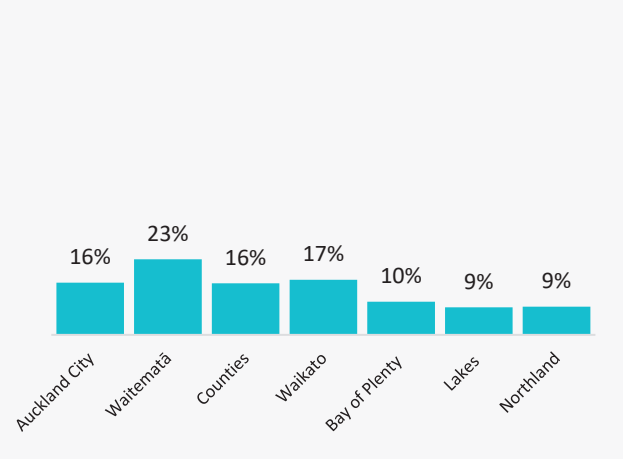
As shown in Figure 13, 60% of adult clients with cochlear implants are aged between 19 and 64 years of age.

Figure 13: Adults with cochlear implants split by age



Adult clients are located throughout the district health boards covered under the Northern Cochlear Implant Programme's catchment area. The highest percentage of clients come from the area covered by Waitematā District Health Board (the north and west of the greater Auckland region). Figure 14 shows the district health boards for adult clients currently receiving services from the programme.

Figure 14: Location of adult recipients by district health board



Ninety-three percent of adults communicate using spoken language alone, the remaining 7% communicate using a combination of NZSL and spoken language.

In the 2017/18 year 15 adults received an implant through private funding. Of these clients, five were self-funding their second implant having already received one cochlear implant through public funding.

Services for those with hearing aids

In addition to cochlear implant recipients, a small number of children and adults with hearing aids receive services to support their communication needs.

Children with hearing aid(s) who are accepted onto the programme usually receive habilitation sessions with their parent(s)/caregiver for a period of 24 months, although this is adapted based on the needs of each child.

- → A total of 12 young children received hearing aid habilitation;
- → These children ranged in age from one to four years old;
- → Two-thirds of these children had their hearing loss diagnosed before they turned one-year-old;
- → The majority of children were referred from within the Auckland region; and
- → Audiologists made the majority of the referrals to the hearing aid habilitation programme, followed by parents and then other professionals, such as speech language therapists, AoDC's and ENT specialists.

Adults who have a severe or profound hearing loss can attend the Severe to Profound Clinic. These adults receive specialised support for their needs, and some will go on to receive a cochlear implant.


251
523

Outcomes

Paediatric assessments

The Hearing House's habilitation assessment protocol is continually reviewed to meet the needs of children and young people who receive services.

For more information on assessments used by habilitationists from The Hearing House and Kelston Deaf Education Centre, please refer to the Appendix.

The assessment results described in this section refer to overall achievement on three specific types of language assessment: CELF-4[12], CELF-P2[13] and PLS-4 or PLS-5[14] and to tests on the EVT (which measures expressive vocabulary) and PPVT (which measures receptive vocabulary).

Our graduates

The results in this section relate to children with a hearing loss who have received at least six months of habilitation service from The Hearing House either as a user of a cochlear implant(s) and/or hearing aid(s).

Information in this section describes the range of language outcomes achieved by individual children[15] aged between four and five and a half years. These children were assessed using standardised language assessments[16] between 1 July 2013 and 30 June 2017[17, 18]. These children have been termed graduates and they are graduating from the early intervention programme and starting school.

The children have been split into two groups:

→ Standard graduates: This group includes children with hearing loss who did not have significant delays starting intervention, those who do not have additional needs which affect their learning.

→ Non-standard graduates: This group includes children with hearing loss who have additional disabilities that impact on their learning, and/or children who had significant delays in identification of their hearing loss or in the start of intervention.

The non-standard graduates constitute a diverse group of children that have complex needs. There has been growth in the proportion of children supported on the programme that meet the non-standard criteria. Please note that this section only includes information about children who are able to be tested using standardised assessments. There are children who are not able to be tested using these assessments[19].

"The new building is a lot bigger with loads more space which means lots of different people can work there. I'm very grateful that lots of people worked so hard to build it and I always look forward to going there when I have an appointment."
- *Isla Gilby, 9*

12 Semel, E., Wigg E., Secord, W., (2006). *Clinical Evaluation of Language Fundamentals Australian Fourth Edition (CELF-4)*. Retrieved from https://www.pearsonclinical.com.au/products/view/85

13 Wiig, E., Secord WA and Semel E., (2006). Clinical Evaluation of Language Fundamentals Preschool - Second Edition, Australian and New Zealand Standardised Edition (CELF P-2 Australian and New Zealand). Retrieved from https://www.pearsonclinical.com.au/products/view/84

14 Zimmerman, I., Steiner, VG., Evatt Pond, BS., and Evatt Pond, R. (2012). *Preschool Language Scales, Fifth Edition - Australian and New Zealand Language Adapted Edition (PLS-5)*. Retrieved from ps://www.pearsonclinical.com.au/products/view/496

15 These are children who have received habilitation services from The Hearing House.

16 CELF, CELF-P and PLS – see the Appendix on page 38 for more information on these assessments. For children with more than one assessment result during this period these scores were averaged.

17 Standard score: Most standardised educational tests provide standard scores that are based on a scale that has a statistical mean (average) of 100. Most students achieve standard scores on tests that fall in the range of 85–115. This is the range in which 68% of the general population performs and, therefore, is considered the normal limits of functioning.

18 We have used this cohort (group) to ensure we can describe outcomes for a good-sized group of children.

19 For example, there are children who do not speak English in the home and therefore they are not able to be tested with an assessment that is done in English. Another example might be a child who has a severe disability (such as cerebral palsy) and who therefore cannot participate in the assessment in a standardised way, such as being unable to point to pictures which would indicate their understanding during a test. A number of children within the age and date range to be included in the outcomes data above were not tested.

Results for children from the general population[20]

When children from the general population are tested using these standardised assessments:

→ The average score for children from the general population is 100,

→ Scores between 85 and 115 are considered 'age appropriate',

→ 84 of every 100 children from the general population have language scores in the normal range or higher.

Graduate language testing results

There are 27 graduates who have been assessed using specific standardised assessments during this timeframe (CELF, CELF-P and PLS). The overall average language score (standard score) for these graduates is 80[21] and the average score for standard graduates is 94. See Table 2 for more detail regarding these results.

It is worth noting that there are many variables which can influence how well a child performs on tests like these and therefore how their language develops. These include child specific factors such as cognitive ability; variables related to hearing loss like severity and age at identification; and factors related to the level of support provided, including from special education services.

The Hearing House is working to better understand the interplay between these many variables and outcomes, including crucially between the services the teams provide and how children are doing in their assessments and later on at school.

Each year the group of children being assessed changes, sometimes in important ways, and these changes can influence the results described below.

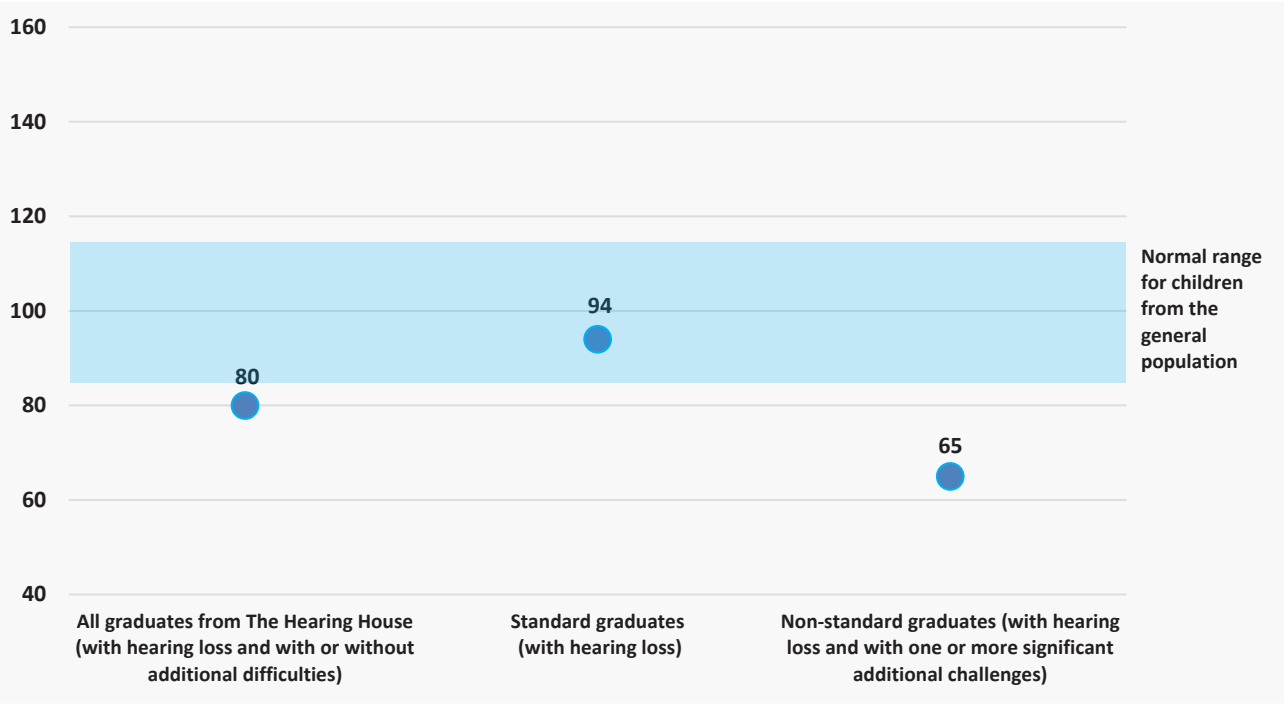
Table 2: Standard and non-standard graduates – groups of children, sample sizes and language scores

	Standard graduates	Non-standard graduates
Number of children	**n=14**	**n=13**
Language scores	→ Nine of 14 children had age-appropriate language or better. → Three standard graduates achieved language scores above the normal range. → The average language score (standard score) was 94, with a median of 100. → These children had a range of scores from 59 to 124.	→ None of the 13 children had age-appropriate language or better. → The average language score (standard score) was 65, with a median of 69. → These children had a range of scores from 50 to 92.

20 When we talk about the general population, the CELF and CELF-P tests used were standardised large samples of children from Australia and New Zealand. The PLS was standardised on a large sample of children from the United States, but this test has been 'language adapted' to fit our local setting.

21 Please note the lowest score on these tests is 40, while the highest is 160, hence the Y axis scale used here in Figure 15.

Figure 15: Average language scores for The Hearing House graduates compared with children from the general population.



Graduate receptive and expressive vocabulary testing results

There are 28 graduates in total who have been assessed using specific standardised assessments during this timeframe. (27 were tested with the PPVT, and 25 of these graduates were tested using the EVT). Some children are unable to be tested using the EVT as, although they may demonstrate receptive language (so can be tested using the PPVT), they have no expressive language.

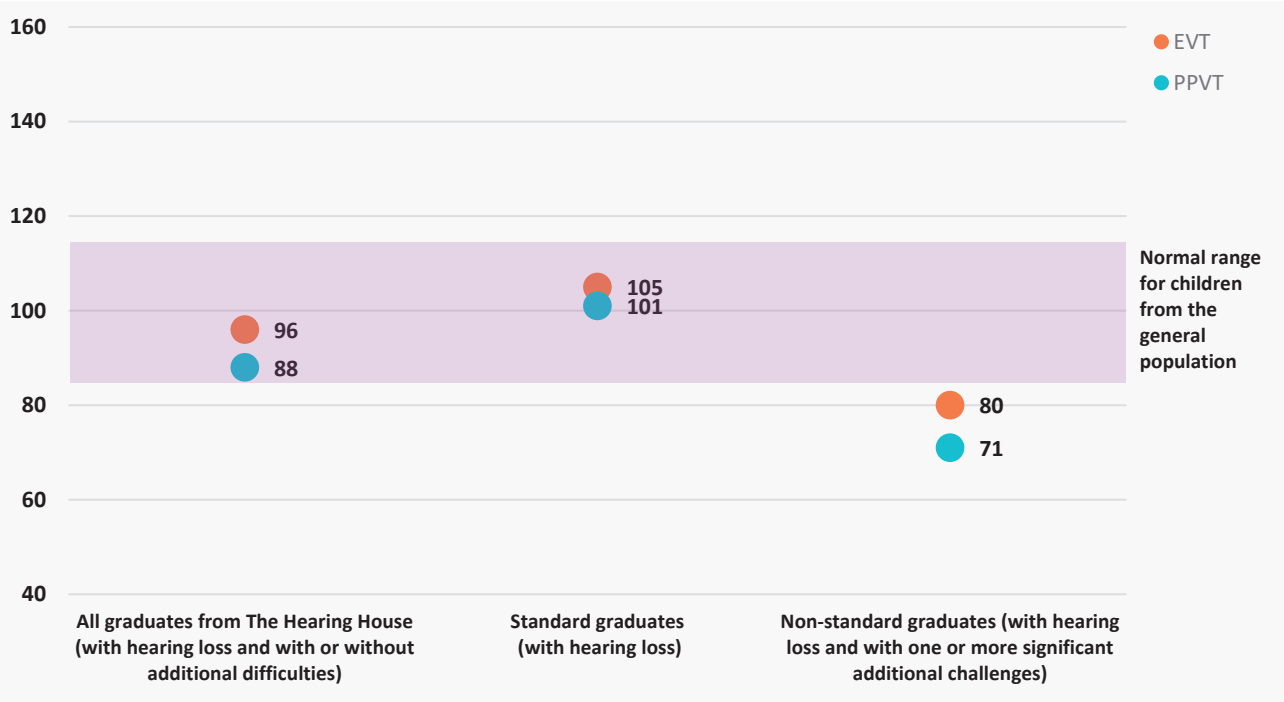
The standard score for receptive vocabulary on the PPVT is 88 and the expressive vocabulary score on the EVT is 96[22]. The average standard score for standard graduates is 101 on the PPVT and 105 on the EVT.

22 Please note the lowest score on these tests is 40, while the highest is 160, hence the Y axis scale used in Figure 16

Table 3: Average receptive and expressive vocabulary scores for The Hearing House graduates compared with children from the general population

	Standard graduates	Non-standard graduates
Number of children	PPVT: n=15 EVT: n=16	PPVT: n=12 EVT: n=9
Vocabulary scores Receptive (PPVT)	→ Eleven of 15 children had age appropriate receptive vocabulary or better. → Four standard graduates had received receptive vocabulary scores above the normal range. → The average standard score was 101 with a median of 101. → These children had a range of scores from 72 to 137.	→ Three of 12 children had age appropriate receptive vocabulary or better. → The average standard score was 71 with a median of 76. → These children had a range of scores from 42 to 97.
Vocabulary scores Expressive (EVT)	→ 15 of 16 children had age appropriate expressive vocabulary or better. → Three standard graduates received expressive vocabulary scores above the normal range. → The average standard score was 105 with a median of 104. → These children had a range of scores from 84 to 138.	→ Four of 9 children had age appropriate expressive vocabulary or better. → The average standard score was 80 with a median of 80. → These children had a range of scores from 52 to 96.

Figure 16: Average receptive and expressive vocabulary scores for The Hearing House graduates compared with children from the general population



School achievement

The Hearing House has been working to obtain National Certificate of Educational Achievement (NCEA) results so it can better understand how young people who have received an early intervention service have been doing when they reach high school.

The NCEA is the main qualification for secondary school students in New Zealand. NCEA is recognised by employers, and used for selection decisions by universities and polytechnics, both in New Zealand and overseas.

Young people, who are generally in years 11 to 13 at secondary school, study several courses or subjects and their skills and knowledge in these are assessed against a number of standards through internal and external assessments.

Students achieving a particular standard receive credits and a specific number of credits are needed to achieve an NCEA certificate. Those who do well get a 'merit' or 'excellence' for that level.

Our cohort

Only students who received an early intervention service from The Hearing House before the age of five were included in this analysis[23].

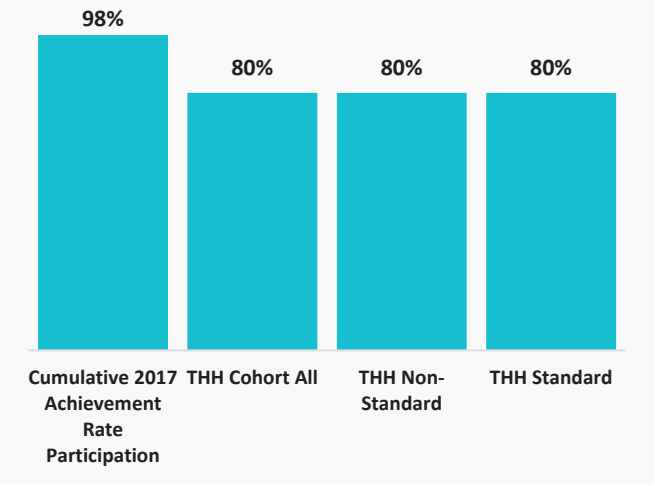
Young people whose results are reported here all have a hearing loss in both ears, and the majority (90%) have a hearing loss which is severe or profound in terms of its severity. Forty percent of those young people have one or more additional disabilities.

This resulted in a cohort of 11 students. One student was then excluded as they were not participating in NCEA[24]. Analysis has been limited to participation rates due to the relatively small cohort.

On average these students had their hearing loss identified at an average age of 11.5 months. None of the children included in this group had a progressive hearing loss. Twenty percent speak a language other than English more than 50% of the time at home, and 40% experienced delays in identifying their hearing loss. Children considered in the standard group numbered five, and in the non-standard group was also five.

Results

Figure 17: NCEA cumulative achievement rates for students at the end of Year 13 in 2017



Looking to the future

The team at The Hearing House hopes the gap between the achievement rate of students who received an early intervention service from The Hearing House and the nationwide achievement rate will close in the future. This is due to a range of factors including:

→ Earlier identification of hearing loss nationally due to the advent of universal newborn hearing screening (nationwide screening didn't begin until 2008)

→ Higher rates of cochlear implant usage than in the early 2000s when these children were born (23 children implanted per year as opposed to 10 per year in the early 2000s)

→ Provision of cochlear implants is often earlier (implantation at six months of age is now standard whereas the youngest to be implanted in this cohort born in the early 2000s was almost 9 months at implantation).

23 Seventeen students in the age range for NCEA who had not received an early intervention service from The Hearing House, having been referred for assessment after the age of five.

24 One student in our cohort group was not participating in NCEA and was instead pursuing an alternative learning pathway.

Adult Quality of Life Assessments

The results described in this section refer to one important measure, an adapted version of the Assessment of Quality of Life (AQoL) which is administered before an adult receives a cochlear implant, and then at 3-6 months post-implant.

Cohort

The results relate to adults who have received a cochlear implant in the 2017-2018 year. These adults have hearing loss in both ears. The majority of them have one cochlear implant and a severe or profound hearing loss.

Of the 50 adults implanted during the period, all completed the assessment before implantation and it is the aim to complete the assessment again before a client reaches one year post implant. Adults whose results are described below were assessed between 1 July 2017 and 30 June 2018.

Results

Results listed below show the average pre and post-implant scores which are shown in Figure 18:

- → Ninety-four percent of those who responded showed improved quality of life and improved socialisation within their communities. This may relate to the fact that recipients are getting out and socialising more, including in part due to their rehabilitation.
- → Eighty-four percent had an improved speech outcome by the end of the financial year. (Some of these recipients were very recently implanted and their scores remained static or didn't yet show an improvement. In a small number of cases it can take one to two years for improvements to be seen.)
- → The average Quality of Life score before they received a cochlear implant was at less than 2 on the scale, that is it was described as "isolated from family and friends, frustrated, lonely, social relationships not functioning, struggling to function day to day".
- → After they received their cochlear implant, the scores rose to an average of 3.2 or better, this time described as "Engaged with family, friends and community. Able to enjoy the things important to them".
- → Clients on the waiting list showed understandably lower Quality of Life scores.

Of the 110 clients who received their implant recently and reported on changes in work in a recent survey, 36% showed a 'greatly improved' work life, 18% 'moderately improved', 5% a 'slightly improved', 8% 'marginally improved' and 4% 'never improved'.

Figure 18: Rates of improvement in Quality of Life (QoL) and speech outcomes after adults received their cochlear implant(s)

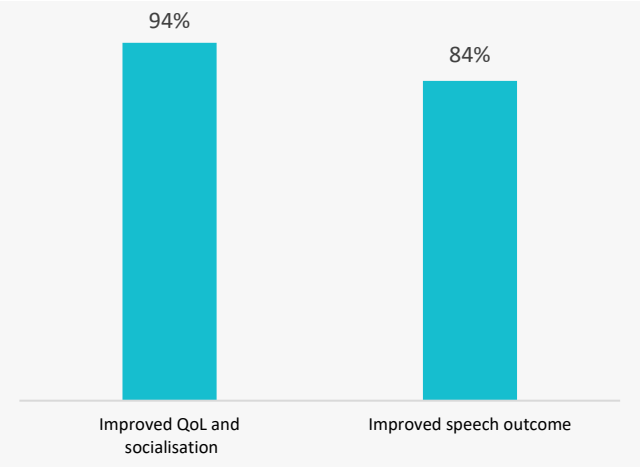
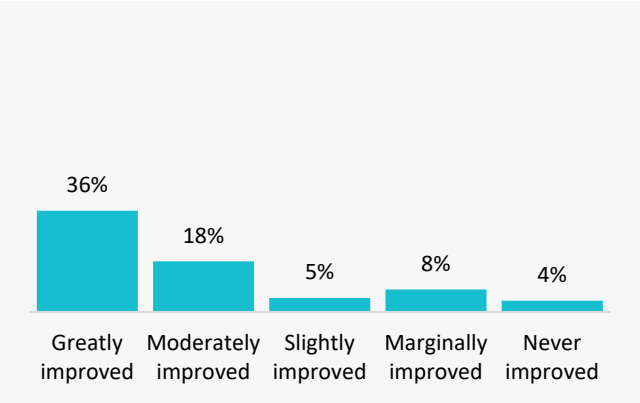


Figure 19: Changes in work-life post implantation



“It is great having the different specialists and facilities all in one place, and not needing to travel to different locations to access all the services Matthias needs. The Stitchbury Bidwill Centre has made things so much easier for both ourselves and Matthias. And apart from the great looks, it still has the same welcoming atmosphere and sense of community of the old Hearing House.”

- *Family of Matthias Berndt, 5*

Research

Participating in research

The Hearing House is focused on research which will benefit recipients and their families. We hope to do more research in the future, particularly given our partnership with the University of Auckland's School of Population Health and the considerable research expertise of our new Clinical Director, Holly Teagle, pictured left, who also has an Associate Professor role at the university.

Holly is coming fresh from her role as Co-Director of the Children's Cochlear Implant Centre at the University of North Carolina. This is the largest paediatric cochlear implant centre in the United States.

The value of research

We have been fortunate that both adults and families have been willing to participate in various research projects over the years. This generosity makes a real difference by helping to inform programme and device development and expanding our understanding about how we can contribute to maximising impact for recipients and their families.

Participation varies depending on the specific project, but it can involve anything from just having existing data analysed to projects which require more active participation such as completion of special questionnaires, having different types of assessments or trialling of devices which are still in development.

Why should you consider participating in research?

→ Some projects may provide you/your child with a chance to further develop listening skills

→ Your support will help build our knowledge and help us understand what we can do differently to benefit current and future recipients and their families

→ You may find you learn about something new, and previous research participants have said they feel good about their involvement.

Susan Brookes, pictured top-right, who received her cochlear implant in 2016, was asked "Why do you volunteer to help with hearing research?". She responded by saying, "I think the questions should be 'Why would I refuse?'".

Susan goes on to say: "I have had problems with my hearing for the last 35 years, and now have a cochlear implant in one ear and a hearing aid in the other. My social and family life has continued almost seamlessly because of the audiologists and specialists I have seen over the years; without their help I would live in quiet isolation. I may not hear well, but I do hear.

"Participation requires time, patience, and concentration. However, I find it fascinating to see what research is being done, how it is structured, and to get sent the results at the end. From my experiences, I feel I have learnt as much from the process as the researcher did.

"So, allowing myself to be used in research and experiments that might help others with hearing problems is an obvious thing to do."

External research projects are reviewed by the programme's Research Committee before they are approved. This ensures each project is well-considered and will provide benefit to our understanding of a specific issue, and hence to recipients and their families.

What you can expect if you are approached about participation in a research project?

→ You will be given written information about the project, including what participation would mean for you

→ You will have an opportunity to have any questions answered and then to provide consent to participate

→ You will be asked if you would like to see a plain language summary of the results of the study.

Research projects

An example of a current research project is one involving the adult team and some of their clients. This is a large study with the University of Melbourne looking at the impact of cochlear implantation on on-going cognitive changes in the older population. For those who agree to participate there will be a number of assessments to complete at their review appointments. These will examine the impact of the cochlear implant on quality of life, health, cognition and speech perception.

Governance

The Hearing House is a subsidiary of The Cochlear Implant Foundation of New Zealand. In early 2018, The Hearing House established a new partnership with The University of Auckland. The governance for the new centre comprises of nominees from the Cochlear Implant Foundation of New Zealand and The University of Auckland.

New Advisory Board members representing The University of Auckland are Professor Suzanne Purdy and Associate Professor David Welch. We are lucky to have these new directors on the Advisory Board as they bring a wealth of academic and hearing specific knowledge to an already impressive group.

The Foundation's Board of Trustees and The Hearing House Advisory Board are volunteers with expertise in business, law, research, academia and medicine. They are dedicated to providing governance to ensure The Hearing House provides world-class services now and in the future.

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Dr Colin Brown


"It was a sobering thought that our work had the power to improve people's lives by facilitating promotion at work, by restoring companionship in marriage, and simply by making people happier."
Sir Patrick Eisdell Moore

Stakeholder satisfaction

Paediatric

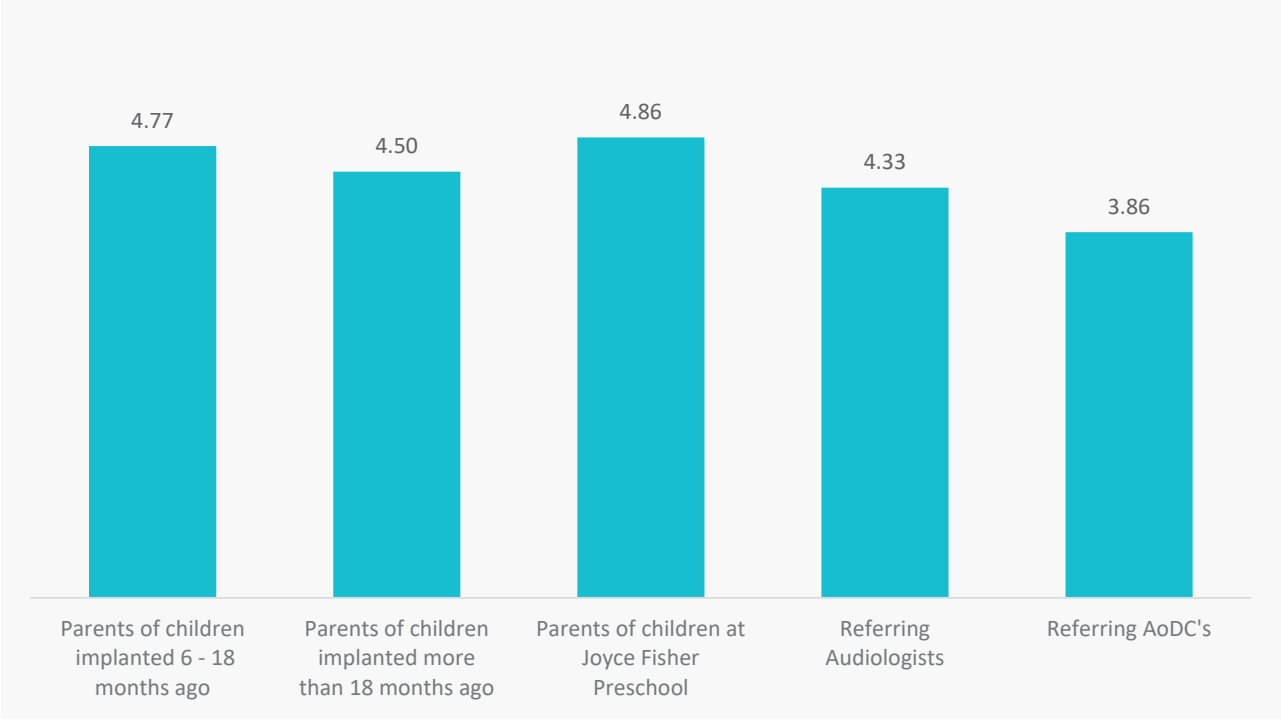
Since 2007, The Hearing House has conducted client surveys to improve our understanding of what we are doing well, and where we need to focus our improvement efforts.

In addition to seeking feedback from families, referring audiologists and AoDCs for the last two years we have also conducted a survey for families of children who attend Joyce Fisher Preschool. These surveys were completed during May 2018.

A total of 87 individual responses were received across all five of the surveys with an average response rate of 35%.

Each group was asked to give us an understanding of their satisfaction with the service on a 1 to 5 scale, where 5 was the highest possible rating. The overall satisfaction ratings given by each group are seen in figure 20. The maximum possible rating is five, scores between four and five are considered in the high to very high range, scores between three and four are considered in the high range.

Figure 20: Average overall satisfaction ratings by sample (2018)



	Sample Size	Response Size	Response Rate
Parents of children implanted 6 - 18 months ago	39	13	33%
Parents of children implanted 18+ months ago	225	54	24%
Parents of children at the Joyce Fisher Preschool	17	7	41%
Referring Audiologists	19	7	37%
AoDC's of Children on Programme	14	6	43%

Next year we will be focusing on:

→ Continuing to encourage as many respondents as possible to respond to these surveys

→ Exploring other ways to seek information from recipients and their families, for example by telephoning recipients or families and organising focus groups. This will also involve looking at seeking details from groups that don't respond to current surveys and how requests for feedback can be tailored more specifically to those groups.

→ Exploring alternative options of receiving referrals that may better accommodate the large amount of medical information that is required (and is sometimes in excess of current email capacity) for example looking into a cloud based system.

→ Revisiting the habilitation outreach timetable and looking into the possibility of offering an after-hours service or more flexible working hours for clinicians (e.g. late nights).

→ There will be improved communication and education for referrers both for referrals to the cochlear implant programme and to the Hearing Aid Programme. Including clearer and quicker communication post-referral and clearer guidelines around whether or when to refer a child (and what supporting information is required).

Adults

Previously the adult cochlear implant programme has done surveys of recipients via mail. In 2017-2018 electronic surveys were distributed to 433 adults with cochlear implants during June 2018. A total of 162 individual responses were received with a response rate of 37%.

	Sample Size	Response Size	Response Rate
Adult CI recipients	433	162	37%

Respondents were asked to comment on aspects of the programme they felt could be improved and these related to the programme as a whole encompassing the wider funding structure.

Common themes from the comments are shown below:

→ The need for more funding:

- to meet the needs of those on the waiting list (having been assessed as being an appropriate candidate for a cochlear implant);
- for bilateral cochlear implants;
- for processor upgrades; and
- for repairs and equipment.

→ Improved community awareness of cochlear implants.

→ Improved training for hearing therapists. Currently workshops for new and experienced therapists are undertaken as requested. Staff can join into hearing therapy appointments remotely if needed and are in email contact with hearing therapists who are working with specific clients, so they follow the prescribed rehabilitation programme. Once a quarter an electronic newsletter is sent to all hearing therapists.

→ Outreach, including home visits and remote programming, to reduce travel for adult recipients and those on the waiting list. Outreach clinics will commence in 2019.

→ Improved communication possibly by the introduction of a regular newsletter. The newsletter is intended to be a bi-annual publication which commenced in December 2018.

→ Improved availability of "user meets". This involves pairing a newer CI recipient with a more experienced recipient who can help with information and sometimes with rehabilitation.

Appendix A: Assessments

Assessment protocols

Rationale

The Hearing House's habilitationists have been conducting assessments on children receiving services since soon after the organisation's formation, in accordance with evidence-based practice.

Regular assessments are done for several reasons:

→ To inform planning, habilitation and the setting of personalised goals for the child through the identification of strengths, difficulties and concerns;

→ To monitor a child's progress over time;

→ To ascertain whether progress is sufficient for this stage taking into account other factors (such as age at identification, degree of hearing loss);

→ To inform family decision-making and provide information to audiologists to assist them in optimal amplification;

→ To identify areas that require further exploration by other professionals; and

→ To better understand programme efficacy, inform programme development and resource allocation.

Assessing 'language'

The three assessments (CELF-4, CELF-P2 and PLS-5) provide an overall score that describes a child's expressive and receptive language outcomes at the time of the test. This is called a standard score.

What is receptive language?

Receptive language is what a child understands. This can range from single words to complex instructions, e.g. the child might be asked to point to a picture that shows "the big spotty dog is sitting under the tree".

Receptive vocabulary is measured using an assessment called the PPVT. This test is a measure of the child's knowledge and understanding of individual words.

What is expressive language?

Expressive language is what a child says. This can include the ability to name items, put words together to make sentences and use different types of grammatical structures.

Expressive vocabulary is measured using an assessment called the EVT. This test is a measure of the individual spoken words a child can use in the correct context.

Speech

Speech is different to language. Speech comprises articulation (how the child produces individual sounds and combines them to say words), voice (how the vocal-folds move), and fluency (the rhythm of speech)[25]. Please note that speech skills are not being reported in this document.

The habilitation assessment schedule for children with cochlear implants is shown in Table 4 Assessments are conducted 3, 6, 12 and 24 months after the device is fitted/child receives their cochlear implant(s), and at 3, 4, 5, 6, 8 and 12 years of age. Assessments which are standardised are shown in the table with an asterisk. Children are assessed at 3 months post switch on, 10 and/or 14 years of age should parents request this or at the clinician's discretion.

Children with hearing aids are assessed using the tests below at the start of service and then annually based on their chronological age.

Tests have been chosen based on their topics of measurement (e.g. language, audition, speech), their reliability (consistent results for children of similar ability and internal reliability within a test) and validity (whether the test is measuring what it aims to measure).

25 Adapted from "What is speech? What is language". Retrieved from https://www.asha.org/public/speech/development/language_speech/

Table 4: Assessments which may be used, by age, March 2015 (standardised assessments are marked with an asterisk)

Area to be assessed	CA: 0-2:11	CA: 3-3:5	CA: 3:6 – 4:0	CA: 4:0 – 4:11	CA: 5:0 onwards
Language	PLS-5*	PLS-5*	CELF-P2*/PLS-5*	CELF-P2*/PLS-5*	CELF-4*/PLS-5*/CELF-P2*
	Rossetti, REEL, language sample, Bloom and Lahey, Brown's MLU, Grammatical Features checklist, Bracken Basic Concept Scale, Early Songs and Phrases List, Auditory-Verbal Listening Skills Curriculum, ELTL Sounds List, St Gabriel's Curriculum, expressive language and receptive language checklist			Language sample, Bloom and Lahey, Brown's MLU, Grammatical Features checklist, Bracken Basic Concept Scale, Auditory-Verbal Listening Skills Curriculum, St Gabriel's Curriculum, expressive language and receptive language checklist	
Vocabulary	–	PPVT-4*, EVT-2*	PPVT-4*, EVT-2*	PPVT-4, EVT-2*	PPVT-4*, EVT-2*
	Vocabulary checklist			Vocabulary checklist	
Speech	–	GFTA-2*	GFTA-2*	GFTA-2*	GFTA-2*
	Articulation attainment chart			Articulation attainment chart	
Audition	PEACH CAP Scales	PEACH CAP Scales	PEACH CAP Scales	PEACH CAP Scales	PEACH CAP Scales
General Development	E-LAP			E-LAP	

No single test can accurately assess a child's language so The Hearing House and Kelston Deaf Education Centre habilitationists use a variety of assessments along with their experience working with each child to understand language performance and to set personalised goals and plans for work with each child.

Types of assessments used

There are two main types of assessments used by the habilitationists, and each of these types has their uses. Assessments of each type are outlined in Table 5.

Table 5: Standardised versus criterion referenced assessments, a comparison[26]

	Criterion referenced assessments	Standardised norm-referenced assessments
Goal	→ Determine whether a student has achieved specific skills or understands specific concepts (Salvia and Ysseldyke, 2004). → Help us understand whether a child knows/ has specific skills before and after they receive services. → Measures specific skills and incremental progress.	→ Measure student achievement and progress made compared with large numbers of hearing students (groups) of the same age (benchmarking). → Allow comparison of various groups and their level of performance compared with hearing peers. → Measure general performance and progress made in set areas, often over a longer period of time (e.g. annually).
Strengths	→ These tests enable professionals to understand in more detail how a child is progressing and whether they meet particular pre-determined standards for achievement. → Enable judgements to be made around behaviours or progress against identified targets, e.g. to find out whether the child has learnt the material or can carry out the behaviour being assessed. → The child's level of functioning is measured on a regular basis, including through the use of criterion referenced assessments which help the therapist and parent understand the child's progress.	→ Using tests standardised on groups of hearing children allows us to compare deaf children with other peers, which is essential if we are to raise standards for deaf children, and close the attainment gap.[27] → These tests are carefully set so the results conform to a bell curve and have been found to be reliable and valid. This means it is possible to understand how a child is doing based on the normal distribution and also to understand how many children have performance within the normal range for children in the general population. → Standardised tests also have a standard error of measurement – this is a calculation of the probability that a given speech testing score is a true reflection of the child's ability. → Questions, conditions for testing, scoring and interpretations for standardised assessments are done in a consistent, prescribed way.

26 Adapted from Huitt W (1996) Measurement and evaluation: Criterion vs norm-referenced testing. Educational Psychology Interactive. Valdosta, GA.

27 National Deaf Children's Society (2013) Assessing and monitoring the progress of deaf children and young people: Communication, Language and Listening. For Teachers of the Deaf and other professionals working with deaf children. Funded by Department for Education, NatSIP, NDCS.

Weaknesses	→ These tests should not be adapted for use with deaf and hearing-impaired students as this may invalidate results. → It is not possible with these tests to compare performance of children with other groups of children. → It is not possible with these tests to understand how a child's performance ranks when compared to their counterparts.	→ Standardised tests don't tell you detailed information about nuances of performance that characterise a full range of student skill, ability and learning style. → Children with additional needs and some children who are primarily learning spoken languages other than English may not be able to be tested using standardised assessments. Some of these children are able to be assessed using criterion referenced tests, while for others outcomes may be considered based on goals and progress. → Only some standardised tests have been standardised with Australian/New Zealand children (CELF-4, CELF-P2) or are adapted for our local language usage PLS-5.

Appendix B: Glossary

Advisor on Deaf Children (AoDC): AoDC's are employed by the Ministry of Education. AoDC's work closely with parents, caregivers and other professionals involved to help a child with a hearing loss learn, develop and prepare for early childhood education and then school. AoDC's provide support and resources from birth until year 3 at school.

Aetiology (Etiology): The cause, or set of causes or manner of causation of a disease or condition. Aetiology is used in this report to refer to the cause of a childs' hearing loss.

ALE: Auditory Language Enrichment follows the principles of Auditory-Verbal Therapy but where these principles are adapted to meet the additional needs of the child. Children on this programme use listening to develop understanding and, where possible, communicate using spoken language. They may also use additional means to communicate, such as lip patterns, Key Sign, gestures, PECS (Picture Exchange Communication System) and augmentative alternative communication.

AVT: Auditory-Verbal Therapy accelerates the natural way language develops to enable children with a cochlear implant(s) or hearing aids to catch up with the listening skills and language of their peers.

Expressive vocabulary: Measured by the EVT, expressive vocabulary refers to the single words a child can recognise in the correct context.

Hearing Therapist: Provides free hearing assessments, information, hearing tests and support to New Zealand citizens and permanent residents aged 16 years and over. Part of the national Hearing Therapy service delivered by Life Unlimited.

Kelston Deaf Education Centre (KDEC): Staff from this organisation provide cochlear implant habilitation services in the northern region (north of Turangi) for children over the age of five years.

KDEC School Provision: Classes are taught by a specialist teacher of the deaf. Each student develops an individualised programme, with their teachers and parents that best meet their need to establish a strong educational and social foundation.

Life Unlimited: A charitable trust that delivers the national Hearing Therapy service funded by the Ministry of Health.

Ongoing Resource Scheme (ORS): This provides additional support for children with the highest level of need for special education, to help them join in and learn alongside other children at school.

MAPping: The process of programming a cochlear implant to the specifications and needs of the cochlear implant recipient.

Newborn hearing screening (NBHS): Newborn hearing screening (also known as universal newborn hearing screening and early intervention programme (UNHSEIP)) refers to the screening of hearing carried out soon after birth. A child is referred to an audiologist for further assessment if a 'refer' result is obtained on the screening.

Rangatahi: People from the younger generation, youth. (Maori Dictionary)

Receptive Vocabulary: Measured by the PPVT, receptive vocabulary refers to the single words a child can use verbally in the correct context.

Resource Teacher of the Deaf (RTD): RTDs are specialist teachers who assess a child's needs in either a classroom, a one-to-one setting or a child's home. Then they team up with other specialists to help teachers adapt their teaching to suit the child's needs. They work with teachers and families to set achievement goals and create learning plans for children and students who are deaf or hard of hearing. RTDs work through the Deaf Education Centres (this being KDEC in the region north of Turangi).

The Hearing House (THH): Charity established in 1998 to provide services to children with hearing loss (Audiology and Habilitation for the under 5's) within the northern region (north of Turangi). In 2018 The Hearing House began providing services to adults with a hearing loss.

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