Deaf community views on paediatric cochlear implantation

Briana Putnam, Sara Pivac Alexander, Kathleen McMenamin, David Welch

ABSTRACT

There are two models used in the literature to describe those who are d/Deaf: the medical and the cultural models. The medical model describes deafness as an unwanted disability that needs to be treated through the use of medical devices like cochlear implants (CIs). The cultural model describes the word "Deaf" (written with a capital) as a culture and membership of the Deaf community as a privilege. It also places emphasis on the importance of sign language in Deaf culture. Historically, the Deaf community has been opposed to cochlear implantation in children, but little is known about current attitudes, or the attitudes of the Deaf community in New Zealand. This research used an online questionnaire to ask deaf, hard-of-hearing (HoH) and culturally Deaf people in New Zealand about their views on paediatric cochlear implants. Culturally Deaf respondents were compared to those who were not. The study's findings were mixed, suggesting that there are still reservations about the benefits of CIs for children born deaf. It identified key areas for consideration: a bilingual/bicultural approach to CI habilitation in children, and the need to fully inform parents of all of their options. The study also highlighted the multitude of cultural and non-cultural factors that need to be considered in both the decision-making and habilitation processes for treatment of a deaf child. An understanding of how the Deaf community's perspective differs from that of health professions in New Zealand is important in considering what is best for deaf children.

The medical model of deafness describes deaf, written with a lowercase "d," as a profound degree of hearing loss[1] and an unwanted disability.[2] One treatment is the cochlear implant (CI), a surgically implanted device that directly stimulates the auditory nerve electrically.[3]

Early cochlear implantation has been found to improve deaf children's communication opportunities, as well as their educational and future employment prospects.[4–6] It provides most deaf children with enough sound information to develop some auditory-verbal language.[7]

An opposing view is the Deaf cultural model, written with a capital "D."[8,9] In this model, deafness is not a disability but a a marker of cultural affiliation, paralleling ethnically based cultures, with sign language as the defining language.[10,11] Membership of Deaf culture may be beneficial; deaf children, even those with CIs and use of aural/oral speech, have improved self-esteem if they feel connected to the Deaf community.[12,13] At the same time, some literature seeks to imply that signing may interfere with CI users' learning of spoken language,[14,15] though these interpretations are questionable.[16]

Since these models misalign, there is debate about whether paediatric cochlear implantation is beneficial or a challenge to the Deaf community.[11,17] However, much of the evidence is from older American research.[17–19] There has been little research in New Zealand.

More than 90% of deaf children are born to parents who can hear and use spoken language to communicate.[20,21] This means that most parents must decide about cochlear implantation and rehabilitation options for their deaf child without prior knowledge or experience.[22] For many parents with children newly diagnosed with deafness this can be a frightening time filled with grief and uncertainty.[23] Deciding to go ahead with cochlear implantation and focus on rehabilitation can be incredibly stressful for parents and families. Medical professionals play a primary role in this decision-making process,[22] and very early intervention is recommended in the medical model,[24] so it is important to understand the wider perspective.

Analysis of the literature revealed that the concerns of the global Deaf community regarding paediatric cochlear implantation could be grouped into five main themes:

1. **Cultural consequences:** A child with a CI might feel part of neither the Deaf nor the hearing world.[25,26] Children may feel excluded from hearing culture because CIs do not provide fully normal hearing, because they are visible and because they may promote negative attitudes to deafness.[27] They might also feel excluded from the Deaf community because CI habilitation has a strong focus on learning auditory-verbal language and integrating with the hearing society.[28,29] This has been described as the deaf child's "identity crisis."[25] For this reason some oppose CIs in children, and some argue for a bilingual/bicultural approach to habilitation after cochlear implantation.[30–32]
2. **Psychosocial outcomes:** Although some children with CIs achieve similar speech and language outcomes to their hearing peers,[33] CIs do not completely "cure" deafness.[30,34,35] Many children still need extensive input from support services and remain behind their hearing peers in spoken-language outcomes.[36–39] Compared to an entirely oral approach to CI habilitation, introducing deaf children to Deaf culture and teaching them sign language is shown to enhance their learning of spoken language, not hinder it.[16,31] This approach also improves their self-esteem, confidence and educational outcomes.[12,13,40,41] Acquiring New Zealand Sign Language (NZSL) is complex, lengthy and requires specialised support. There are some organisations who provide this support, such as First Signs[42] and NZSL@School,[43] but NZSL funding and awareness remains limited.[34,44,45]
3. **Risks and lack of benefits:** Complications of cochlear implantation in children are rare nowadays. But potentially serious complications still occur in around 1% of cases.[46,47] Minor complications, such as headaches, skin issues, tinnitus and ear infections, occur more commonly, in around 5% of cases.[47] Regardless of the actual proportion of children who have complications from cochlear implantation, there is evidence that parents and Deaf community members who disapprove of CIs for children tend to state the risks of surgery as a major factor in this decision.[48–50] The risks may also be perceived as more significant if CIs are not deemed as essential and there are other communication options.[44,51]
4. **Appearance:** CIs have an external component that is magnetically connected to the internal, surgically implanted device.[52] This may prompt teasing and bullying.[53] Advertisements for CIs highlight the discrete nature of devices,[54] implying that those who purchase the devices may prefer them to be hidden.
5. **The process of cochlear implantation:** Learning to use a CI is part of the process of cochlear implantation. The device is turned on at around two weeks after surgery.[55] After this, the family must attend an intensive follow-up appointment schedule and be dedicated to providing extensive support and language practice at home.[56]

Aim

Our primary aim was to investigate the current views of deaf, hard-of-hearing (HoH) and culturally Deaf people on paediatric cochlear implantation in New Zealand. A secondary aim was to explore whether those who define themselves as culturally Deaf have different views to those who do not (but who are still deaf or HoH). We also explored whether views on paediatric cochlear implantation are related to other factors such as CI experience in the family, Deaf cultural experience and sign language experience.

Methods

Participants

The target population included those who defined themselves as deaf, HoH and/or culturally Deaf. Participants were recruited through an advertisement in the weekly newsletters and Facebook groups of Deaf Aotearoa New Zealand and Auckland Deaf Society. These are two major organisations for d/Deaf and HoH people in New Zealand. They provide researchers with a large potential study population. Responses from 66 people who were deaf, Deaf and/or HoH were used in the analyses. They ranged from 18 to 70 years of age.

Researchers' background

The project supervisors included an active member of the New Zealand Deaf community who advised and approved of the research process. Two of the other researchers (both hearing) had some involvement in the Deaf community (eg, volunteering, personal family experience) and all four researchers had previous academic experience in the field of audiology and/or Deaf culture/NZSL. Their experience enabled informal consultation with Deaf people, who gave advice on how to approach the topic in an ethically appropriate way and make the questionnaires relevant to Deaf New Zealanders. Auckland Deaf Society and Deaf Aotearoa both provided letters of support for the study and willingly published the advertisement on their Facebook pages and in their newsletters.

Materials and procedures

The current study drew on previous research into Deaf culture and the CI debate. Key themes were adapted into an online questionnaire, available in both English and NZSL, that measured and explored Deaf, deaf and HoH people's views on CIs for children.

A mixed methods study design was employed for this research and complementary information was gathered.[57] This included multiple-choice questions, matrix-style questions and Likert scales, and open-ended questions that were analysed qualitatively to capture richer thoughts, feelings and perspectives.

A 72-item questionnaire used previously in research in parents of deaf children[58] was adapted and shortened into 21 questions with some changes for relevance (eg, we changed "I am concerned that my child will be rejected by the deaf community because of the implant" to "Do you worry that a child with a CI will not be accepted by d/Deaf people?") Including a capital "D" is important to the Deaf community and was highly relevant to this study.

The five main themes about the paediatric CI debate from the literature (Cultural Consequences, Psychosocial Outcomes, Risks and Lack of Benefits, Appearance and Process) were used to develop the questionnaire items for five "belief scales."

The questionnaire also contained general items about CIs developed from past research, such as, "If you had a Deaf/deaf/hard-of-hearing child, would you get a CI for them?"

There were also four open-ended questions at the end of relevant sections:

- Do you have any other worries about CIs for a child? Please tell us.
- Are there any other things you believe about CIs for a child? Please tell us.
- Is there anything else you think audiologists need to know about your views on CIs for a child?
- What does your decision to get a CI depend on? If you are not sure, explain why.

Data analysis

Belief scale scores for participants were created in SPSS software. Assessment of internal reliability was based on Cronbach's Alpha (α). A score of 0.6 reliability is acceptable for exploratory research such as this.[59–61] The belief items had three possible responses. We coded "not sure" as 0.5, "no" as 0 and "yes" as 1. The "tick all that worry you" item responses were coded as 1 if the participant selected that they were worried about the item and 0 if they did not select that they were worried. We were then able to combine the belief items and "tick all that worry you" items to conduct a confirmatory factor analysis and extract a five-factor solution.

We combined participants' scores for each item of the belief scales by taking the mean response across all the items identified as part of each scale for each participant. We then used t-tests to compare the overall responses from the Deaf and the non-culturally Deaf participants.

We used a general inductive approach to code the qualitative data.[62] Similar quotes were coded into nodes using NVivo 12 software. The codes were compared and those with similar ideas were coded into a larger theme. The data were re-read and re-coded into organised subthemes and analysed until no new themes arose. One author, in consultation with a second, carried out the thematic analysis. Once they had decided on themes, the two remaining authors read the themes independently. They focused on representing participants' full range views and avoiding the authors' own opinions.

Results

Quantitative findings

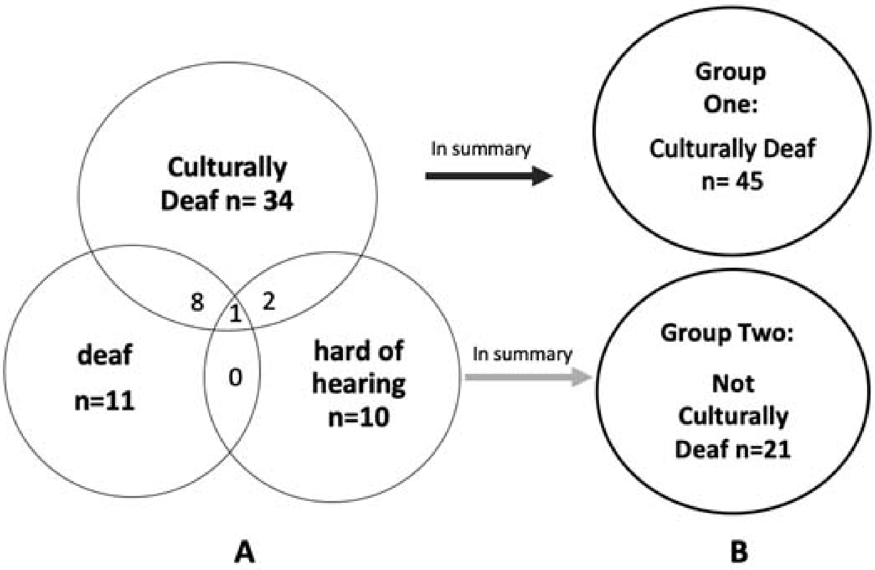
Four options could be selected for cultural/hearing status: deaf, hard-of-hearing, culturally Deaf of none of the above. Those who selected "none of the above" were excluded from the study as they did not meet the eligibility criteria. Those included were organised into two groups: culturally Deaf and non- culturally Deaf (Figure 1). We therefore compared views of those within the Deaf community who defined themselves as culturally Deaf to those also within the Deaf community who did not.

Sixty-eight percent of the participants were culturally Deaf. Both groups had an age range of 18–70 years and a mean age of approximately 40 years. In both groups, 38% of the participants had a CI and less than 20% had a child with a CI (culturally Deaf group: 8/45 (17%); non-culturally Deaf group: 1/21 (5%)). More than half of the participants in each group had friends with a CI (culturally Deaf group: 40/45 (89%); non-culturaly Deaf group: 11/21 (52%)).

Confirmatory factor analysis extracted a five-factor solution that conformed reasonably well with the *a priori* scales designed (Table 1). An exception was item 24: that a child might "not be accepted by hearing people" was designed as part of the Cultural Consequences factor, but it loaded more strongly on the Appearance factor, and so was removed from analyses.

Given this discrepancy in the factor loadings was very small, we preserved the factor structure as defined on the basis of

Figure 1: Formation of two comparison groups (B) from the distribution of participants' self-definition of hearing and cultural status (n=66) (A).



an otherwise congruent pattern of loadings. The five subscales had Cronbach's alpha (α) scores between 0.665 and 0.937, which suggested acceptable internal reliability.[59–61] The analysis verified the five themes that were identified by the literature search:

1. Cultural Consequences
2. Psychosocial Outcomes
3. Risks and Lack of Benefits
4. Appearance
5. Process

Cultural Consequences

More culturally Deaf than non-culturally Deaf participants believed that children with CIs would be more likely to experience negative cultural consequences (t(64)=2.145, p=0.036; Figure 2).

Both groups' most common concern was that a child with a CI will not learn NZSL. Forty-eight participants (72%) selected this option: 36/45 (80%) of the culturally Deaf group and 12/21 (57.1%) of the non-culturally Deaf group.

Psychosocial Outcomes

More non-culturally Deaf people perceived better psychosocial outcomes for children with CIs than Deaf people (t(63)=2.690, p=0.009; Figure 3). Eighty-five percent (17/20) of the non-culturally Deaf group and 42% (19/45) of the Deaf group believed that one or more of the psychosocial outcomes would be better for a child with a CI.

Risks and Lack of Benefits

Non-culturally Deaf people scored lower than culturally Deaf people on the Risks and Lack of Benefits scale (t(64)=2.306, p=0.036; Figure 4).

Appearance and Process

The two groups had the same opinions on the Appearance and Process scales so we have not included these graphs ((t(64)=0.812, p=0.420) and (t(64)=1.085, p=0.280), respectively)). Most participants (approximately 75%) from both groups did not think that a child would worry about how they look or be treated differently because of how they look with a CI (Appearance scale items). Around one-third to one-half of all participants thought that the process of CI habilitation in children would be stressful (34/9%), too effortful (34%) or annoying to look after (22%) (Process scale items).

Qualitative findings

Fifty-six participants (85%) responded to open-ended questions: 41 were culturally Deaf and 15 were non-culturally Deaf. Many answers were detailed and addressed a range of views regarding the paediatric CI debate.

Analysis of these data revealed three main themes:

1. Decision-making
2. Habilitation
3. Hearing community advice

Each of these had subthemes, and the hierarchy of themes and subthemes, are represented in Figure 5.

Decision-making

Respondents perceived the decision to get a CI for a deaf child as complex and influenced by many factors. They expressed concern that deaf children would feel part of neither Deaf nor hearing culture:

> *"…a CI doesn't mean perfect hearing."*

They suggested that deaf children with CIs would miss out on the benefits of Deaf culture:

> *"…being Deaf is a privilege not a loss—a unique way of seeing the world."*

These respones revealed sophisticated views of the cultural situation, where decision-making can depend on more cultural-level of thinking:

> *"…move away from the medical model onto a cultural model where a child gains."*

> *"…a cochlear implant does not make a child hearing… they are still deaf and this should be acknowledged."*

Consequently, there was concern about how decision-making without proper consideration of the cultural issues might influence a deaf child's identity:

> *"…they will be caught in the middle with no clear identity of who they are."*

Table 1: Results of confirmatory factor analysis verifying areas of concern about paediatric cochlear implantation (n=66).

Questionnaire Item		**Area of concern about paediatric cochlear implantation**				
		Cultural Consequences α=0.751	**Psycho-social Outcomes α=0.937**	**Risks and Lack of Benefits α=0.808**	**Appearance α=0.821**	**Process α=0.665**
Do you worry that a child with a CI will... (tick all that worry you)						
23	not be accepted by d/Deaf people	.506				
24	not be accepted by hearing peopl				.39	
25	not learn NZSL	.918				
26	not be involved in the Deaf community	.654				
27	worry about how they look				.811	
28	be treated differently because of how they look				.868	
Do you worry that... (tick all that worry you)						
29	a CI will be too annoying to look after					.618
30	getting a CI will be too stressful					.636
38	the time and effort needed to learn to hear and speak after getting a CI is not worth it					.624
Do you believe that:						
42	most of the technical problems that happen with the CI can be fixed					.460
Do you believe that a child with a CI will:						
31	have a better education		.884			
32	have a better social life		.743			
33	have better chances of getting a job		.810			
34	be more confident		.862			
35	be more independent		.945			

Table 1: Results of confirmatory factor analysis verifying areas of concern about paediatric cochlear implantation (n=66) (continued).

Questionnaire Item		**Area of concern about paediatric cochlear implantation**				
		Cultural Consequences α=0.751	**Psycho-social Outcomes α=0.937**	**Risks and Lack of Benefits α=0.808**	**Appearance α=0.821**	**Process α=0.665**
Do you believe that:						
36	CI surgery has too many risks			.441		
37	A deaf child will be happy enough without a CI			.363		
39	A deaf child has enough people to communicate with - they don't need CIs			.634		
40	Interpreter services are good enough - a deaf child does not need CIs			.890		
41	Online technologies (for example: Facebook messenger) are good enough - a deaf child does not need CIs			.804		

α: Cronbach's Alpha reliability score for each subscale.

b: item (24) was removed from the analysis. It did not load onto the Cultural Consequences scale as expected and weakly loaded onto (and decreased the reliability of) the Appearance scale

Factor loadings of <0.3 have been removed from the table to improve clarity

Figure 2: Percentages of culturally Deaf and non-culturally Deaf groups who selected each item in the Cultural Consequences belief scale. Culturally Deaf group: n=45. Non-culturally Deaf group: n=21.

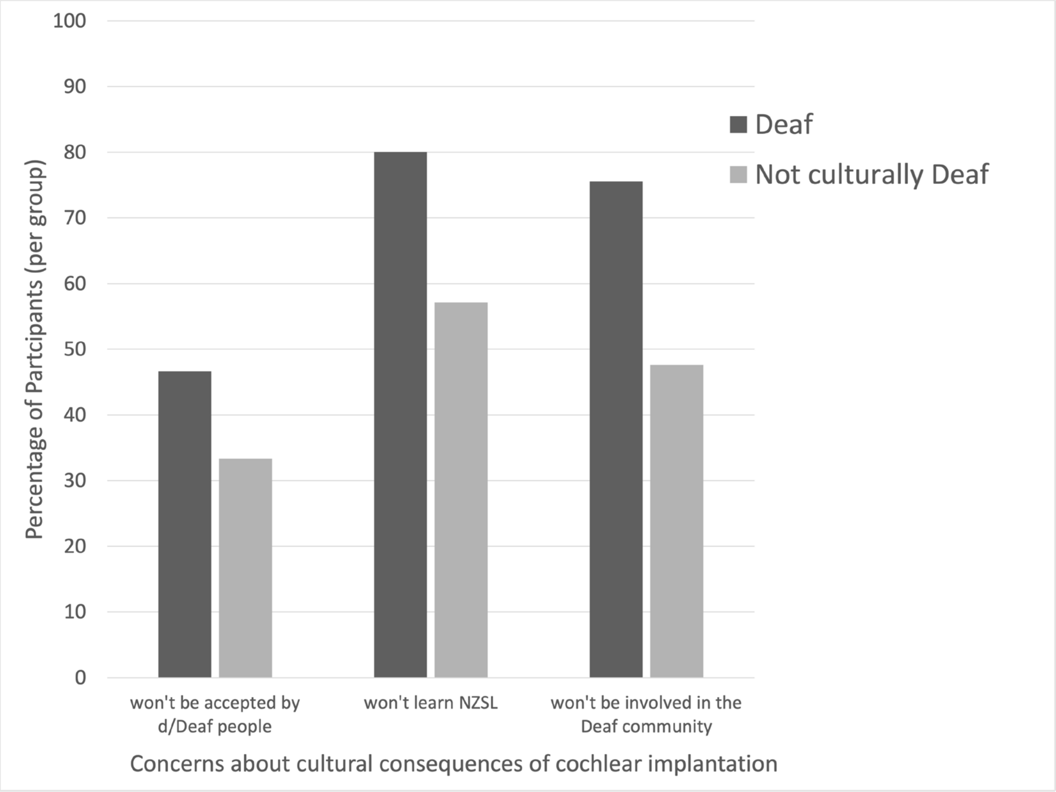


Figure 3: Percentages of culturally Deaf and non-culturally Deaf groups who believed that each outcome was better for children who receive CIs using the items in the Psychosocial Outcomes belief scale. Culturally Deaf group: n=45. Non-culturally Deaf group: n=20.

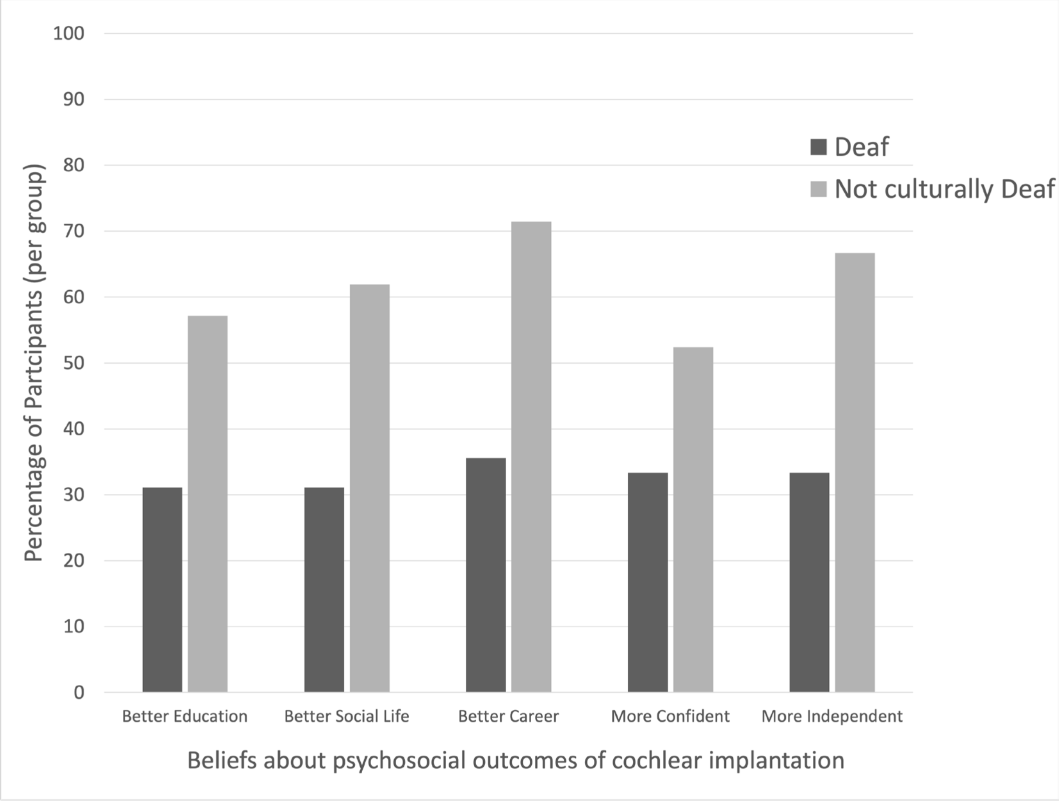


Figure 4: Percentage of culturally Deaf and non-culturally Deaf groups who endorsed each item from the Risks and Lack of Benefits belief scale. Culturally Deaf group: n=45. Non-culturally Deaf group: n=21.

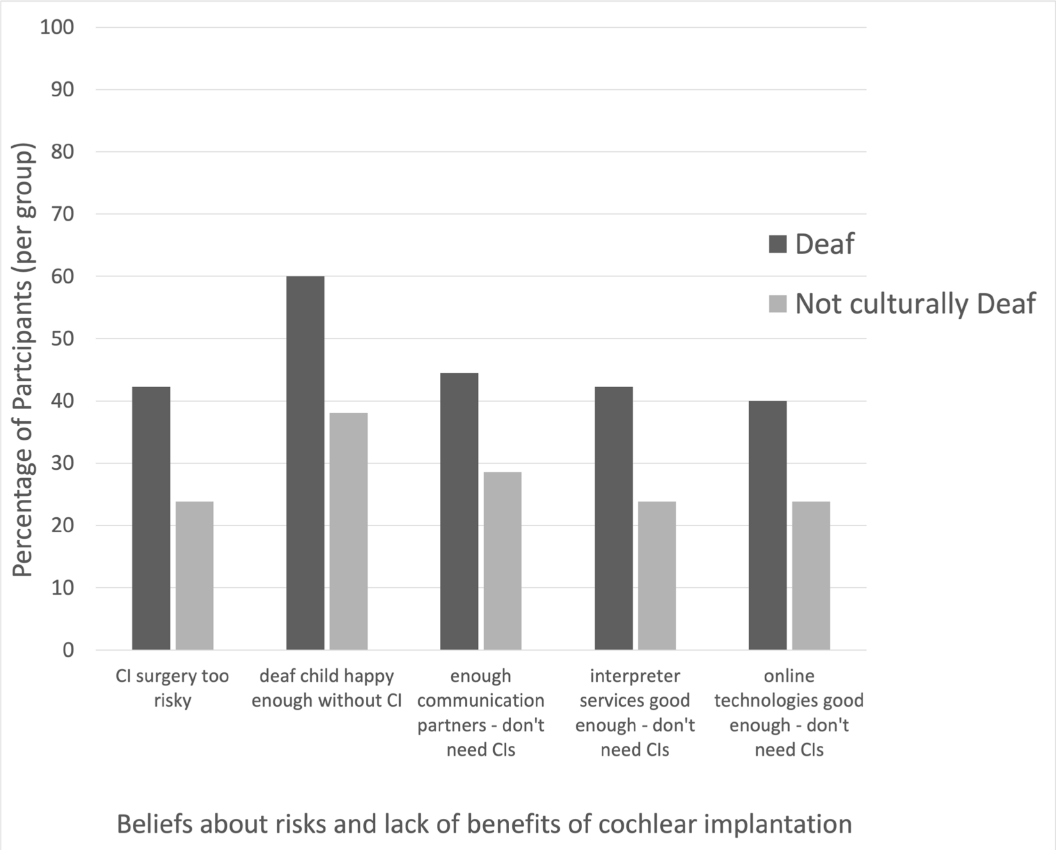
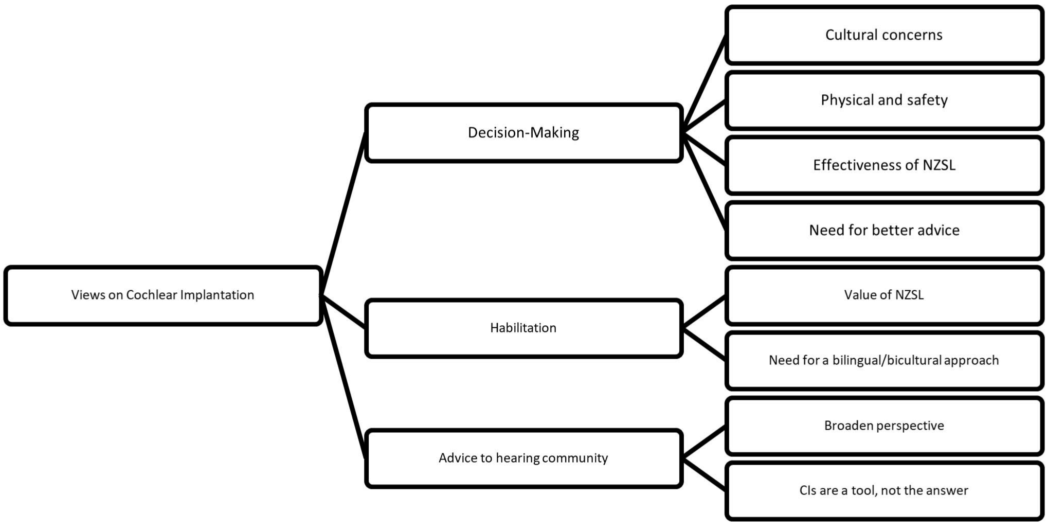


Figure 5: Organisation of themes from qualitative data analysis.



Physicality and safety

Physical and safety aspects of cochlear implantation in children was another subtheme within the decision-making process. Respondents were concerned with the practicalities of wearing the external processor devices:

> *"…technology has not made the external fitting child friendly."*
>
> *"…mine falls off all the time… can't imagine how bad it can be for children."*

In addition to the practicability of wearing the external devices, respondents suggested that decision-making should account for the possibility that the implanted component might fail:

> *"…there's a chance that… CI's may not work [sic] then the child is completely deaf for life… so unfair."*
>
> *"cochlear implants may have health implications such as infections or issues with damage if the area is injured".*

Effectiveness of NZSL

Another subtheme was that decision-making should take into account the value of NZSL as a means of communication:

> *"I would focus more on the value of their visual language."*
>
> *"learning NZSL will help hugely with communication… as the child can communicate back through NZSL."*
>
> *"[deaf child] is already Deaf and can use NZ sign language."*

Furthermore, the use of NZSL was seen to benefit a child because it would provide an *entrée* to the Deaf community:

> *"The child can use NZ sign language with [a] better community to support [the] deaf child in the future."*

Need for better advice

Participants felt that audiologists and the various healthcare professionals push parents into cochlear implantation for the child without clear advice about the benefits of being culturally Deaf. Parents therefore make the decision based on biased information and emotions arising from ignorance of the full picture:

> *"fear and a lack of knowledge."*

The bias from the medical model was seen to be towards "oralism" and encouraging the child to "listen and speak only." One participants said the goal of implantation being spoken language development is "kind of like forcing Maori child [sic] to speak English or asking a blind person to tell rainbow's colours."

Habilitation

The second theme describes participants' concerns about habilitation after cochlear implantation of children.

Value of NZSL

The first subtheme conveys that the services are biased towards an auditory/verbal approach and that the value of NZSL is not always considered to be relevant for language acquisition:

> *"the factor is not cochlear implant, it is language acquisition."*
>
> *"NZSL is a natural language for Deaf, deaf, hard-of-hearing [people] regardless of if they have hearing aids or a CI or none."*
>
> *"families are not supported to have NZSL as a full language."*
>
> *"audiologists are overwhelmingly in favour of having a CI instead of learning NZSL."*

Bilingual/bicultural approach

The second subtheme of CI habilitation focused on the benefits of both the hearing and Deaf ways of life. Visual language may support hearing parents in communicating with their deaf children:

> *"while children are listening and learning speech parents and others would find communication much better if they used sign support during this time."*

Participants saw socialisation with the Deaf community as a key component of habilitation, enabling children to feel "empowered," "find their way" and "utilise tools from both worlds."

Another perceived benefit of a bilingual approach to habilitation was the practicality of having a recourse to visual language if the CI is unavailable:

> *"sometimes they are not able to wear a CI e.g. when swimming, showering,*

> *sleeping etc and they may need to have communication access in those times for their emotional well-being as well as for their safety."*

At a deeper level, the bilingual/bimodal approach to habilitation was seen to open up more options for a deaf child:

> *"having fluency in both NZSL and English allows more choice autonomy and education."*

Furthermore, it was expressed that habilitation should not be limited to a smattering of visual language, but that it should be treated on an equal footing with spoken language:

> *"NZSL is very important. I've missed out that opportunity."*
>
> *"it is important that NZSL is held to the same standards as spoken English."*

Participants acknowledged the need for habilitation in auditory-verbal language, along with sympathy for children who are trying to learn to use a communication system that is not natural for them:

> *"CI does not mean perfect hearing."*
>
> *"I have a CI myself but the CI doesn't help me very much at all during classes as I missed a lot of information."*
>
> *"poor deaf children are expected to perform like a hearing person… I have noticed parents talking to their child like they do with hearing siblings without eye contact without getting their attention… no wonder why the poor child has a language delay."*

Overall, the subtheme promotes the idea of bilingualism/bimodalism because of the greater freedom and choice it brings:

> *"[giving children the] opportunity to choose the language of learning to potentially enhance future education, aspiration and communication."*

Advice to hearing community

The third main theme was advice given to health professionals. It was recognised that the CI debate is difficult:

> *"a tough and sensitive topic with many variables."*

Broaden perspective

Participants felt that health professionals tend to focus narrowly on treating disability without having an open mind to other ways of looking at the world. This could be rectified by improved education:

> *"all audiologists must understand Deaf culture."*

CIs are a tool but not the whole answer

Participants suggested that the hearing community start treating CIs in a more measured way, that is, acknowledging that they are useful but also just a device:

> *"they are a tool to help, just the same as I wear glasses to help me see clearly, I have a CI to help me hear sound. It is not a cure nor a fix."*

This led to the idea that the device should be put behind the greater issue of the actual person, so that more flexibility is made clear to parents of deaf children:

> *"give the parents the opportunity to know more about learning NZSL, [not] just CI as the only option."*
>
> *"outline all options available to that child."*

Discussion

In this study, we found that deaf, HoH and culturally Deaf people in New Zealand have concerns about paediatric cochlear implantation. We found differences between the culturally Deaf and non-culturally Deaf groups, though both groups expressed concerns. The main differences were around the cultural consequences, psychosocial outcomes and the risks and lack of benefits of paediatric cochlear implantation. The non-culturally Deaf group tended to view CIs more positively.

This findings were supported by qualitative data. Some deaf, HoH and culturally Deaf were still oppose paediatric cochlear implantation. Many called for a bilingual/bicultural approach to habilitation and better access to related services.

Language and culture deprivation

There were concerns that a lack of access to Deaf culture and NZSL for a deaf child can impact development. These concerns reflect the literature saying many children, even those with CIs, are behind their hearing peers educationally, psychologically and socially[30,63] and require extensive input from support services.[39] Children with CIs often attend mainstream schools[5] and spend a significant amount of time in auditory-verbal habilitation,[56] yet NZSL and Deaf culture may be neglected.

These findings were supported by qualitative themes such as "CIs are a tool but not the whole answer" and the need for a "bilingual/bicultural approach". Participants believed that deaf children have different language and cultural needs to hearing children. They perceived a biased auditory-verbal approach in habilitation services and felt this should be addressed.

Some participants were concerned that deaf children with CIs might not feel accepted culturally and socially. Gao described this as an identity crisis (2007), that is, deaf children might feel part of neither the Deaf nor the hearing worlds. Participants wanted health professionals to broaden their perspective and consider cultural factors as well as the medical model. They wanted deaf children to feel proud of being deaf, as does the Deaf community.[64]

Some culturally Deaf people in the study felt that deaf children do not need CIs because they already have NZSL and Deaf culture. Others were not against CIs, but felt that NZSL and involved in Deaf culture should be widely accessible in addition to spoken language habilitation and mainstream education.

This suggests that the decision to implant CIs in children is complex and influenced by many factors. It also indicates that, although in the past the Deaf community strongly opposed cochlear implantation,[65] many Deaf people in New Zealand today are more concerned about the language and cultural outcomes for a deaf child after cochlear implantation, rather than the decision of whether to actually give a deaf child a CI. However, it is important to note that some people in this study were still strongly opposed to paediatric cochlear implantation.

Bilingual/bicultural approach to habilitation

Related to the importance of NZSL and Deaf culture, many culturally Deaf participants felt that a bilingual/bicultural approach to CI habilitation is of high importance. Research has already shown that a bilingual/bicultural approach can lead to positive psychosocial outcomes.[13,41] Currently, a bilingual/bicultural approach to cochlear implant habilitation in children is not widely followed in New Zealand.

Sign language has been demonstrated to enhance the learning of spoken language.[16,31] A bilingual/bicultural approach can also improve a deaf child's self-esteem, confidence and educational outcomes.[12,13,40] This approach is shown to decrease frustration between deaf children and their families, and it is thought to empower families with more positive attitudes about deafness and improve motivation to help the child access language.[30–32,41]

Regardless of the participants' hearing or cultural status, they strongly indicated the need for parents to be fully informed about all of the habilitation options available to them, not just the medical model. This is important because more than 90% of deaf children are born to hearing parents[20,21] and many parents will not have had experience with deafness and the different habilitation options and support available.[22] This means that the range of options presented to them by medical professionals can potentially have a significant impact on their decisions about cochlear implantation and habilitation for their deaf child.

According to participants, parents have "fear and lack of knowledge" and are "confused what to do." Participants felt that the information presented to parents is biased towards the medical model and does not fairly consider the value of Deaf culture and NZSL. The information therefore does not encourage a bilingual or bicultural approach to CI habilitation. The literature supports these findings. Although NZSL and Deaf cultural support is available,[66,67] the goal of CI habilitation is to promote hearing and maximise the child's spoken language abilities.[68]

Areas for future research

This research highlights numerous areas of the debate that future research can build upon. For example, it would be useful to interview parents of deaf children regarding their experience with the CI habilitation process. It would also be useful to conduct a feasibility study around incorporating a bilingual/bicultural approach to CI habilitation in New Zealand children and the resources required for this to be possible.

It is necessary for the assessment of CI outcomes to incorporate social and cultural aspects of deafness as well as the spoken language outcomes that are already being captured. The main measure of "success" of cochlear implantation in children is the development of auditory verbal language and educational outcomes like hearing children. It is possible that different goals would be more appropriate for deaf or HoH children. Further research to define these goals is important.

In conclusion, we found that many deaf, hard-of hearing and culturally Deaf New Zealanders have reservations about cochlear implants in children. Furthermore, culturally Deaf people tended to be more concerned about the cultural and psychosocial consequences of childhood cochlear implantation and believed that there were more risks and fewer benefits. Qualitative data highlighted the value of NZSL and Deaf culture, the benefits of a bilingual and bicultural approach in CI habilitation and the importance of fully informing the parents of deaf children about all of their habilitation options.

Competing interests:

Nil.

Acknowledgements:

The authors would like to thank the Deaf community organisations who participated in the study and distributed the advertisement. We also thank DeafRadio for translation of the questionnaire and study information into NZSL.

Author information:

Briana Putnam: Section of Audiology, University of Auckland.
Sara Pivac Alexander: School of Linguistics and Applied Language Studies, Victoria University of Wellington.
Kathleen McMenamin: Section of Audiology, University of Auckland.
David Welch: Section of Audiology, University of Auckland.

Corresponding author:

Briana Putnam, Section of Audiology, University of Auckland
brianaputnam8024@gmail.com

URL:

www.nzma.org.nz/journal-articles/deaf-community-views-on-paediatric-cochlear-implantation

---

REFERENCES

1. World Health Organisation. Deafness and hearing loss [Internet]. World Health Organisation Fact Sheets. 2019 [cited 2019 Sep 28]. Available from: https://www.who.int/news-room/fact-sheets/detail/deafness-and-hearing-loss
2. Branson J, Miller D. Damned for their difference: the cultural construction of deaf people as" disabled": a sociological history. Gallaudet University Press; 2002.
3. Copeland BJ, Pillsbury HC. Cochlear implantation for the treatment of deafness. Annu Rev Med. 2004;55:157–67.
4. Archbold S, Nikolopoulos TP, O'Donoghue GM, Lutman ME. Educational placement of deaf children following cochlear implantation. Br J Audiol. 1998;32(5):295–300.
5. Dammeyer J. Psychosocial development in a Danish population of children with cochlear implants and deaf and hard-of-hearing children. J Deaf Stud Deaf Educ. 2010;15(1):50–8.
6. Percy-Smith L, Cayé-Thomasen P, Gudman M, Jensen JH, Thomsen J. Self-esteem and social well-being of children with cochlear implant compared to normal-hearing children. Int J Pediatr Otorhinolaryngol. 2008;72(7):1113–20.
7. Duchesne L, Sutton A, Bergeron F. Language achievement in children who received cochlear implants between 1 and 2 years of age: Group trends and individual patterns. J Deaf Stud Deaf Educ. 2009;14(4):465–85.
8. Cokely D, Baker C. American sign language :a student text. Silver Spring, Md: T.J. Publishers; 1980.
9. Devlieger P. Generating a cultural model of disability. 2005 Jan 1;
10. McKee RL, Connew B. People of the eye : stories from the deaf world. 1st ed. Wellington: Bridget Williams Books; 2001. 11 p.
11. Power D. Models of deafness: Cochlear implants in the Australian daily press. J Deaf Stud Deaf Educ. 2005;10(4):451–9.
12. Sutherland H, Young A. 'Hate English! Why?...'Signs and English from Deaf Children's Perception. Results from a Preliminary Study of Deaf Children's Experiences of Sign Bilingual Education. Deaf Educ Int. 2007;9(4):197–213.
13. Swanwick R. Policy and practice in sign bilingual education: development, challenges and directions. Int J Biling Educ Biling. 2010;13(2):147–58.
14. Lee DS, Lee JS, Oh SH, Kim S-K, Kim J-W, Chung J-K, et al. Cross-modal plasticity and cochlear implants. Nature. 2001;409(6817):149–50.
15. Geers AE, Mitchell CM, Warner-Czyz A, Wang N-Y, Eisenberg LS, Team CdI. Early sign language exposure and cochlear implantation benefits. Pediatrics. 2017;140(1).
16. Hall ML, Hall WC, Caselli NK. Deaf children need language, not (just) speech. First Lang. 2019;0142723719834102.
17. Gale E. Exploring Perspectives on Cochlear Implants and Language Acquisition Within the Deaf Community. J Deaf Stud Deaf Educ [Internet]. 2011 Jan 1 [cited 2019 May

25];16(1):121–39. Available from: https://academic.oup.com/jdsde/article-lookup/doi/10.1093/deafed/enq044

18. Niparko JK, Tobey EA, Thal DJ, Eisenberg LS, Wang N-Y, Quittner AL, et al. Spoken language development in children following cochlear implantation. Jama. 2010;303(15):1498–506.
19. Fischer LC, McWhirter JJ. The deaf identity development scale: A revision and validation. J Couns Psychol. 2001 Jul;48(3):355–8.
20. Cole EB, Flexer C. Children with hearing loss: Developing listening and talking, birth to six. Plural Publishing; 2019.
21. NIDCD. Quick Statistics About Hearing [Internet]. 2016 [cited 2020 Jan 20]. Available from: https://www.nidcd.nih.gov/health/statistics/quick-statistics-hearing
22. Matthijs L, Hardonk S, Sermijn J, Van Puyvelde M, Leigh G, Van Herreweghe M, et al. Mothers of deaf children in the 21st Century. Dynamic positioning between the medical and cultural–linguistic discourses. J Deaf Stud Deaf Educ. 2017;22(4):365–77.
23. Kurtzer‐White E, Luterman D. Families and children with hearing loss: Grief and coping. Ment Retard Dev Disabil Res Rev. 2003;9(4):232–5.
24. Humphries T, Kushalnagar P, Mathur G, Napoli DJ, Padden C, Rathmann C, et al. Language acquisition for deaf children: Reducing the harms of zero tolerance to the use of alternative approaches. Harm Reduct J. 2012;9(1):1–9.
25. Gao T. A Neglected Culture: How Cochlear Implants Affect Deaf Children's Self-Esteem [Internet]. Vol. 18, DIAGLOGUES@RU. 2007. Available from: http://wp.rutgers.edu/attachments/article/520/gao.pdf
26. Kluwin TN, Stewart DA. Cochlear implants for younger children: A preliminary description of the parental decision process and outcomes. Am Ann Deaf. 2000;26–32.
27. Marschark M, Zettler I, Dammeyer J. Social Dominance Orientation, Language Orientation, and Deaf Identity. J Deaf Stud Deaf Educ [Internet]. 2017 Jul 1 [cited 2019 Jun 15];22(3):269–77. Available from: https://academic.oup.com/jdsde/article/22/3/269/3858442
28. Leigh I. A lens on deaf identities [Internet]. Oxford University Press; 2009 [cited 2019 Jun 16]. 223 p. Available from: https://books.google.co.nz/books?hl=en&lr=&id=ojBEuPxJgOwC&oi=fnd&pg=PR13&dq=social+dominance+deaf+culture&ots=bcgyQFDcMA&sig=MlvoyK_JIYGNT94cF4Tzn4T0Vwk#v=onepage&q=social dominance deaf culture&f=false
29. Napoli DJ, Mellon NK, Niparko JK, Rathmann C, Mathur G, Humphries T, et al. Should all deaf children learn sign language? Pediatrics. 2015;136(1):170–6.
30. Humphries T, Kushalnagar P, Mathur G, Napoli DJ, Padden C, Rathmann C, et al. Bilingualism: A pearl to overcome certain perils of cochlear implants. J Med Speech Lang Pathol. 2014;21(2):107.
31. Spellun A, Kushalnagar P. Sign language for deaf infants: A key intervention for a developmental emergency. Clin Pediatr (Phila). 2018;57(14):1613–5.
32. Soman UG, Kan D, Tharpe AM. Rehabilitation and educational considerations for children with cochlear implants. Otolaryngol Clin North Am. 2012;45(1):141–53.
33. Hammes DM, Willis M, Novak MA, Edmondson DM, Rotz LA, Thomas JF. Early identification and cochlear implantation: critical factors for spoken language development. Ann Otol Rhinol Laryngol. 2002;111(5_suppl):74–8.
34. Fitzgerald and Associates. Scoping support for New Zealand Sign Language users accessing the curriculum Part II: A New Zealand Overview [Internet]. 2010 [cited 2019 Dec 4]. Available from: www.minedu.govt.nz/SpecialEducation
35. Antia SD, Kreimeyer KH. Social Competence of Deaf and Hard-of-Hearing Children. Oxford University Press; 2015. 305 p.
36. Mukari SZ, Ling LN, Ghani HA. Educational performance of pediatric cochlear implant recipients in mainstream classes. Int J Pediatr Otorhinolaryngol. 2007;71(2):231–40.
37. Krausneker V. The protection and promotion of sign languages and the rights of their users in Council of Europe member states: needs analysis [Internet]. 2008 [cited 2019 Jun 26]. Available from: www.coe.int/t/dg3/disability
38. Spencer P, Marschark M. Cochlear implants. Oxford Handb Deaf Stud Lang Educ. 2003;434–48.
39. Fitzgerald and Associates. Deaf Way: A New Service

Delivery Model [Internet]. 2010 [cited 2019 Jun 5]. Available from: http://deaf.org.nz/images/misc/Deaf-Way-Report-Final.pdf

40. Swanwick R, Gregory S, Daunt W, Hanifin J, Silo J. Sign bilingual education: Policy and practice. Douglas McLean Coleford; 2007.
41. Allen BM. ASL-English bilingual classroom: The families' perspectives. Biling Res J. 2002;26(1):149–68.
42. First Signs. How it works [Internet]. 2019 [cited 2019 Dec 4]. Available from: http://www.firstsigns.co.nz/now-what/after-identification-early-intervention/
43. Ko Taku Reo. NZSL@School [Internet]. Services. Available from: https://www.kotakureo.school.nz/parents-and-whanau/services/nzsl-school
44. McKee R. Assessing the vitality of New Zealand Sign Language. Sign Lang Stud. 2017;17(3):322–62.
45. Minister for Disability Issues. Towards a non-disabling New Zealand. 2019.
46. Low WK, Pok WN, Ng WN, Tan J. Accidental Explantation of a Cochlear Implant in a Child Who Developed Cholesteatoma as a Late Complication of Cochlear Implantation. Todt I, editor. Case Rep Otolaryngol [Internet]. 2020;2020:6353706. Available from: https://doi.org/10.1155/2020/6353706
47. Ahmed J, Saqulain G, Khan MIJ, Kausar M. Complications of Cochlear Implant Surgery: A Public Implant Centre Experience. Pakistan J Med Sci [Internet]. 2021;37(5):1519–23. Available from: https://pubmed.ncbi.nlm.nih.gov/34475941
48. Woodcock K. Cochlear implants vs. Deaf culture. Deaf World A Hist Read Prim Sourceb. 2001;325–32.
49. Johnston JC, Durieux-Smith A, Fitzpatrick E, O'Connor A, Benzies K, Angus D. An Assessment of Parents' Decision-Making Regarding Paediatric Cochlear Implants Un examen du processus décisionnel des parents concernant l'implantation cochléaire pédiatrique. Rev Can d'orthophonie d'audiologie-Vol. 2008;32(4):169.
50. Okubo S, Takahashi M, Kai I. How Japanese parents of deaf children arrive at decisions regarding pediatric cochlear implantation surgery: a qualitative study. Soc Sci Med. 2008;66(12):2436–47.
51. Stokoe WC. Sign language structure. Annu Rev Anthropol. 1980;9(1):365–90.
52. Scheiner RC. Clothing attachment device for an external component of a medical device. Google Patents; 2011.
53. University of Texas at Dallas. Children with hearing loss face more bullying [Internet]. 2018 [cited 2020 Jan 26]. Available from: https://medicalxpress.com/news/2018-04-children-loss-bullying.html
54. Cochlear Americas. Cochlear™ Nucleus® Sound Processor Portfolio [Internet]. 2019 [cited 2020 Jan 26]. Available from: https://www.cochlear.com/us/en/professionals/products/cochlear-implants/products
55. Northern Cochlear Implant Programme (NCIP). Paediatric Programme [Internet]. 2020 [cited 2020 Jan 21]. Available from: https://www.ncip.org.nz/paediatric-more-info
56. National Screening Unit (NSU). Universal Newborn Hearing Screening Programme [Internet]. 2014 [cited 2019 Nov 10]. Available from: https://www.nsu.govt.nz/pregnancy-newborn-screening/universal-newborn-hearing-screening-programme
57. Brannen J. Mixed methods research: A discussion paper. 2005;
58. O'Neill C, Lutman ME, Archbold SM, Gregory S, Nikolopoulos TP. Parents and their cochlear implanted child: questionnaire development to assess parental views and experiences. Int J Pediatr Otorhinolaryngol. 2004;68(2):149–60.
59. Hume C, Ball K, Salmon J. Development and reliability of a self-report questionnaire to examine children's perceptions of the physical activity environment at home and in the neighbourhood. Int J Behav Nutr Phys Act. 2006;3(1):16.
60. Norman GR, Streiner DL. Biostatistics: the bare essentials. PMPH USA; 2008.
61. Stanley RM, Ridley K, Olds TS, Dollman J. Development and psychometric properties of the Y-PASS questionnaire to assess correlates of lunchtime and after-school physical activity in children. BMC Public Health [Internet]. 2014 Apr 30;14:412. Available from: https://www.ncbi.nlm.nih.gov/pubmed/24885601
62. Thomas DR. A General Inductive Approach for Analyzing Qualitative Evaluation Data. Am J Eval [Internet]. 2006 Jun 30 [cited 2019 Nov 18];27(2):237–46. Available

from: http://journals.sagepub.com/doi/10.1177/1098214005283748

63. Thoutenhoofd ED, Archbold SM, Gregory S, Lutman ME, Nikolopoulos TP, Sach TH. Paediatric cochlear implantation: Evaluating outcomes. Wiley Blackwell; 2005.
64. Deaf Aotearoa. Deaf community [Internet]. 2020 [cited 2019 Aug 6]. Available from: http://deaf.org.nz/about-us/deaf-community
65. Blume SS. Histories of cochlear implantation. Soc Sci Med. 1999;49(9):1257–68.
66. Auckland Parents of Deaf Children (APODC). Welcome to APODC [Internet]. 2019 [cited 2020 Jan 19]. Available from: https://apodc.org.nz/
67. Martin T. Increased support for deaf and hard-of-hearing students [Internet]. 2019 [cited 2020 Jan 19]. Available from: https://www.beehive.govt.nz/release/increased-support-deaf-and-hard-hearing-students
68. Ministry of Health. Disability Support Services Tier Two Service Specification DSSC107 Cochlear Implant Services. 2018.