

10,000

TEN THOUSAND **MORE** VOICES

Your experience of Children's Audiology Services

Regional Report 2019



Share your story, shape our service

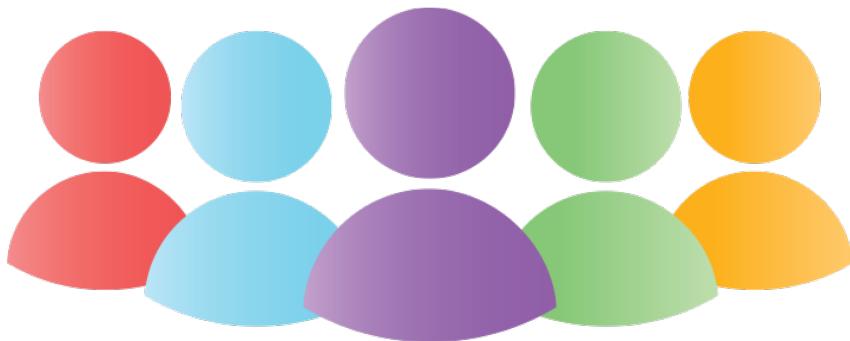
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ACKNOWLEDGEMENTS

The 10,000 More Voices team would like to express their heartfelt thanks to the parents and children who took the time to submit their personal experience of Audiology Services, from across the Region. We are aware that parents and guardians carrying many demands upon their time and we are grateful for their valuable contribution which has enabled a rich and meaningful analysis of this report.

Thank you also to the Regional Audiology Forum, chaired by Mr Linus McLaughlin who contributed to the design, supporting us to hold firm to the principles of Co-Production – to the young people and parents from NHSCT who provided insightful comment and reflection to shape the design at our design workshop. Also thank you to those who supported the distribution of the survey across the region – to the leads of Audiology services – we acknowledge the demands of your roles and the giving of your time to ensure we engaged with your service users and parents. Through this important engagement we were able to gather many insightful experiences to influence and shape Audiology services across Northern Ireland.

"Today was brilliant, the way the Audiologist interacted with him and she put him at ease. She talked calmly and made eye contact... she was at his level and he responded to her"



Many extracts from the stories and free text questions have been included throughout this report, some of which have been edited to ensure anonymity of participants. If you are interested in discussing any of the information presented please contact the Regional Office or local trust facilitators as detailed in Appendix 2.

CONTEXT

Data collection commenced in April 2019 and ended August 2019.
In total **148** stories were collected across the region.



Trust

- **49** from Belfast Health and Social Care Trust
- **42** from Northern Health and Social Care Trust
- **31** from South Eastern Health and Social Care Trust
- **11** from Southern Health and Social Care Trust
- **15** from Western Health and Social Care Trust



Reason for Attending Audiology Services*

The top 3 reasons for attending were

- **47%** - I have hearing loss
- **24%** - I am told I have to go
- **17%** - I need help with my hearing aid



Age of Children in the Stories

- **53** x 0-3 yrs
- **70** x 4-11 yrs
- **21** x 12-16 yrs
- **4** x 17-18 yrs



Who Responded

- **128** x I am the parent of the patient
- **6** x I am the guardian of the patient
- **14** x I am the patient



Rating

- **97** x Very positive
- **40** x Positive
- **9** x Not sure
- **1** x Negative
- **1** x Very negative

* More than one answer could be given

ANALYSIS OF SURVEYS

Key messages and areas of reflection highlighted in this report have been identified using a range of analysis tools, these provide rich insight and understanding into the experience of the children, parents and guardians engaging with Audiology Services.



RESULTS

Data collection commenced in April 2019 and ended August 2019.

In total **148** stories were collected across the region.

1

Partnership

90% of respondents stated the result of the assessment was the driver in the plan of care.

2

Meaningful Engagement

60% stated they were given the opportunity to ask questions, believed and listed to and involved in the decisions.

3

Holistic Approach

80% of responses indicated physical needs were a priority, 30% also highlighted the importance of social impact and emotional support.

4

Person Centered Care

59% of respondents identified themselves as individuals in the Audiology Service.

5

Impact of Audiology

63% of respondents felt Audiology Services supported them to set goals.

6

Personal Outcome

69% of respondents highlighted attending Audiology supported them to plan for the future.

7

Communication

50% of responses indicated communication was easily understood, timely and provided all the necessary detail. This is highlighted as an area for improvement

8

Observation of the Service

59% of responses recognised the knowledge and skill of the Audiologist and compassionate approach.

KEY MESSAGES

The following is a summary of the findings from the regional data. Each Trust will also review local Trust data to inform further service improvement.

- **The patient and family experience of paediatric audiology services is largely positive and in line with the draft Paediatric Audiology Quality Standards.**
- **Audiology Services are recognised as a key source of support and guidance for both the patient and family in relation to physical, emotional and social concerns.**
- **Audiology Services provide person centered and individualised care with particular reference to children with complex needs.**
- **Parents identified a need for more support forums to connect with other families to provide support and advice and to facilitate children to meet with their peers who have hearing difficulties.**
- **Suggested areas of improvement highlighted are:**
 - Easier access to replacement batteries.
 - Development of a leaflet for first appointments.
 - Guidance for groups e.g. youth clubs or sports teams.
 - Support to access training on British Sign Language.
- **Further explanation of the transition phase for teenagers and services in relation to children with complex needs can be explored in a separate briefing paper and would be highlighted as areas for further exploration in future projects.**

1.0 INTRODUCTION

The 10,000 More Voices Initiative has been commissioned and funded by the Health and Social Care Board (HSCB) and the Public Health Agency (PHA) to provide a person centred approach to improving and influencing experience of health and social care services. 10,000 More Voices is underpinned by the principles of Experience Led Co-Design, of which partnership working between those who use and deliver healthcare services is a key element.

It was agreed by the Regional Patient and Client Experience steering group that capturing the experience of children and their families attending Audiology services would provide valuable insight and learning into the Quality Standards for Paediatric Audiology Services and help provide quality assurance of the audiology services for children, young people and their families. The target audience included all children attending audiology with hearing problems and their families. This did not include new born services. This report presents the findings of the service user survey.

The survey was designed in collaboration with a group of service users and their families in Northern Health and Social Care Trust and adopts the Sensemaker® methodology to provide analysis of the qualitative data.



Lead by each Trust Patient Client Experience Facilitator and Project link (detailed in Appendix 1) 148 stories were collected through face to face conversation, return of a survey by post or through the online service. The collection of stories took place from April 2019 to August 2019 and was conducted across all the five Health and Social Care Trusts.

2.0 AIM

The aim of this study was to integrate the voice of the service users and families into the standards set for Paediatric Audiology Services in Northern Ireland.

Objectives include:

1. To explore the experience of service user and families engaging with Audiology Services.
2. To reflect upon the key messages and integrate findings into local service improvements and provide input into Paediatric Audiology Services.

3.0 METHODOLOGY

3.1 Method

10,000 More Voices promotes the principles of co-production through engaging service users at the start of each project through the design of the survey. In January 2019 a group of teenagers and their parents met with the 10,000 More Voices team at Braid Valley Hospital, Ballymena, to share their experiences of living with hearing loss and engaging audiology services across Health and Social Care Trusts. These conversations identified key important concepts and informed the design of the survey.

Upon approval of the survey design data collection commenced in April 2019. All data collection is anonymous with no personal identifiable detail recorded. All raw data was collated on the Sensemaker® Analyst Online programme by 10,000 More Voices team to support the analysis and identify key themes mapped to the Paediatric Audiology Services. The survey collected qualitative information of the experience of Audiology and further explored how services could be improved. Section 4.0 presents the collective data and analysis of the findings using Sensemaker®.

3.2 Using Sensemaker®: Understanding the responses.

When completing the survey respondents were first asked to describe the experience of attending children's Audiology Services. The second section contained a number of statements to support the respondent to "self-index" or analyse their experience.

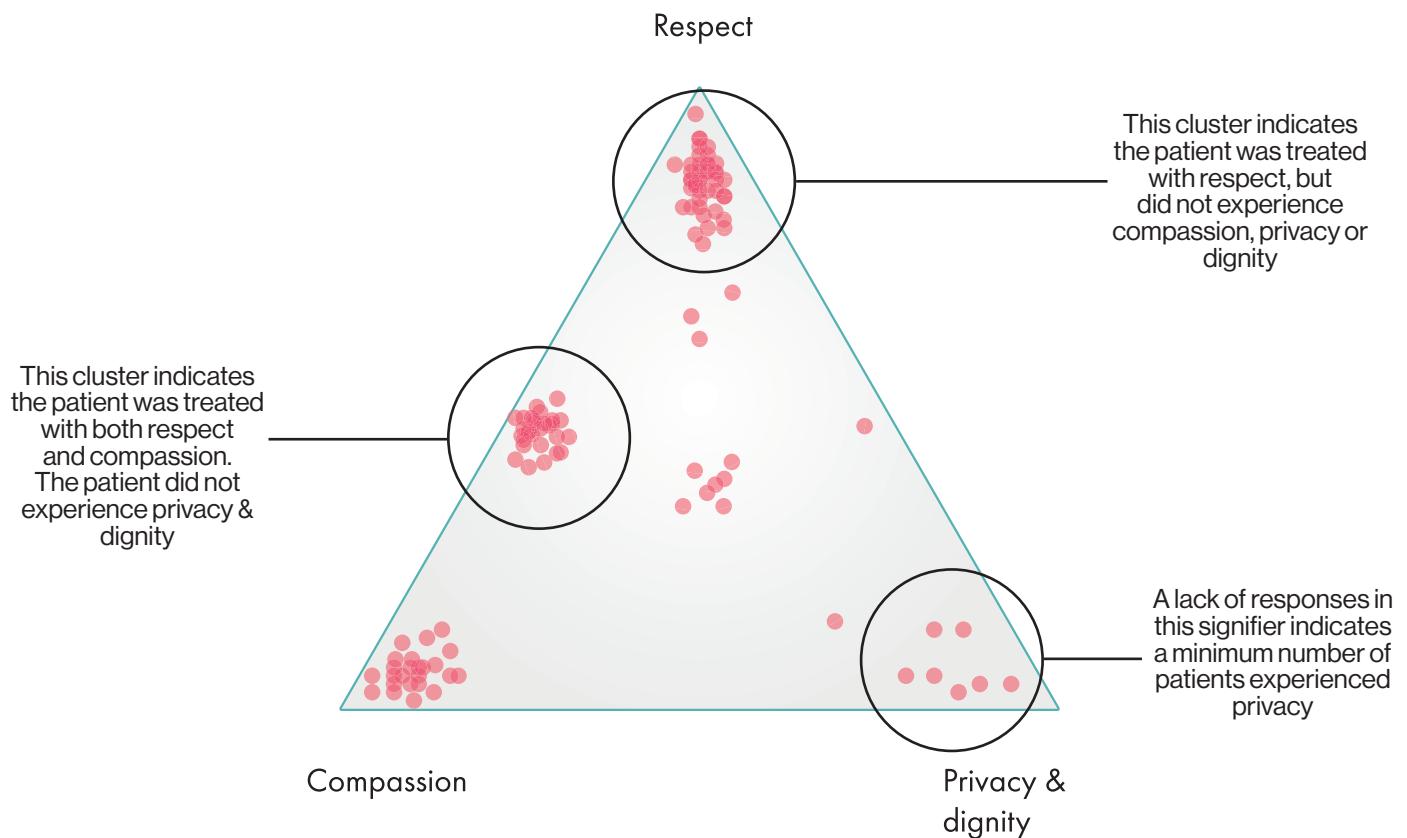
The following sections (4.0 Findings) will display a series of triangles (known as triads) and scales (known as dyad), which contain clusters of response to the statements. In relation to triads, respondents were asked to mark in each triangle the position which best describes their experience in relation to three pre-specified response (known as signifiers). If none of the response applied the respondent could tick "this does not apply to me". The closer the marker is to any one statement, the stronger this relates to the experience.

Each dot within the triad represents an individual experience of the child, parent or guardian. A high concentration of dots in a specific area identifies an emerging pattern in relation to the signifier. An example of responses to a triad is demonstrated in Diagram 1.



Diagram1. Example of a Triad

Responses to statement: In my experience I was treated with ...



3.3 The challenges and learning from the Project methodology

- Sample selection for the study was opportunistic. The project endeavoured to reach all possible service users for Paediatric Audiology Services. This included an online survey available via social media however the majority of the surveys were completed through face to face contact with children and their families attending audiology during the data collection phase.
- It is recognised if the survey was to be repeated the survey would be reviewed and changes to open questions made.

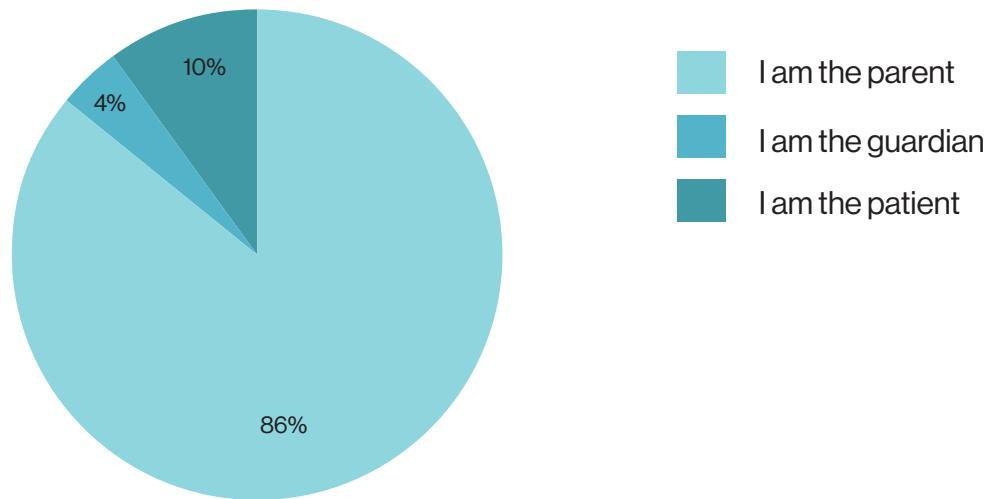
4.0 FINDINGS & ANALYSIS

Presenting the voice of the service user

4.1 The Context

To support understanding of the service user experience the following diagrams present the context of the service user. The first question in the survey asked the respondent if the story was being shared by the child or by the parents. Diagram 2 demonstrates that 90% of responses were shared by the parent. The 10% of stories shared by children were all over the age of 10.

Diagram 2. Responses to the question “What description best describes you?”



This is unique to 10,000 More Voices to capture the experience of children and on a small number of surveys for children to directly share their experience.

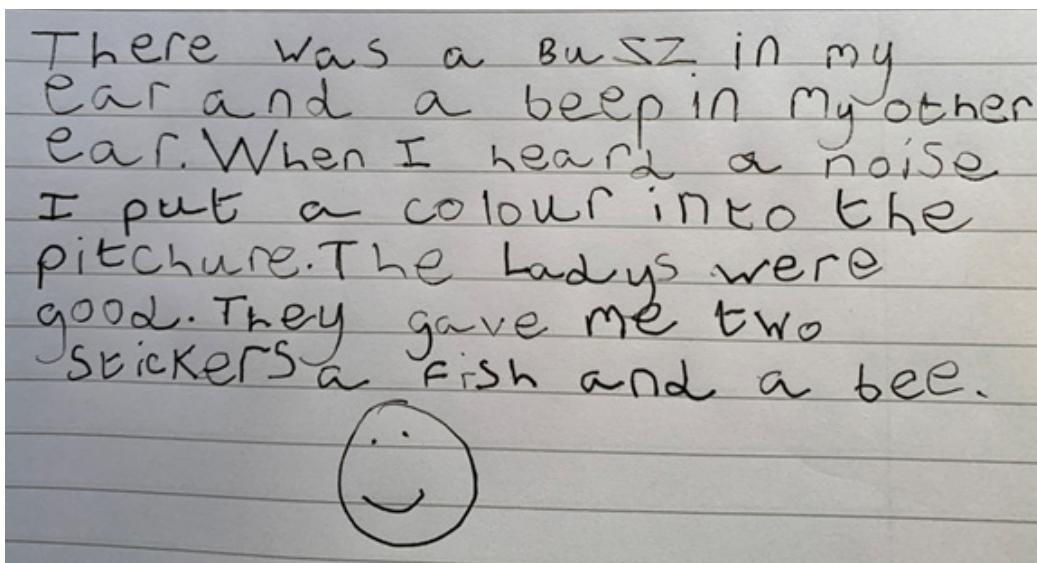
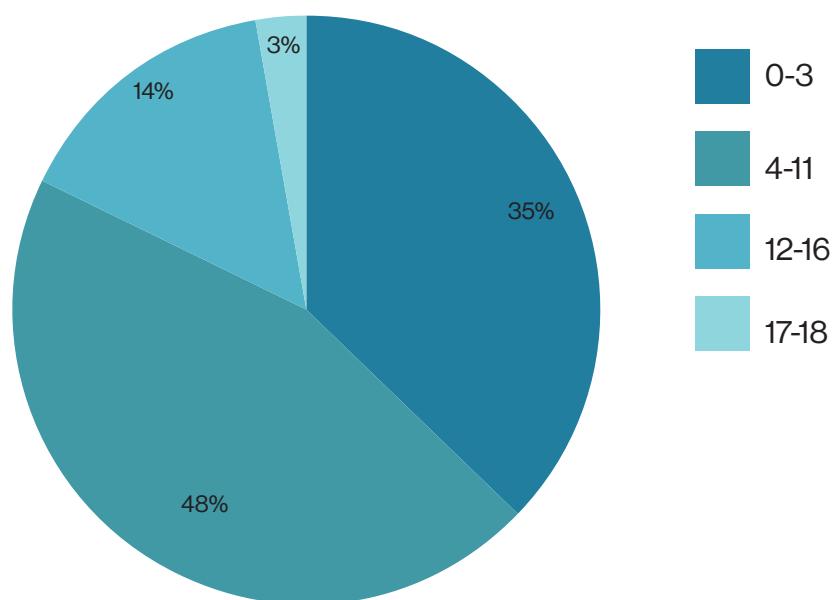


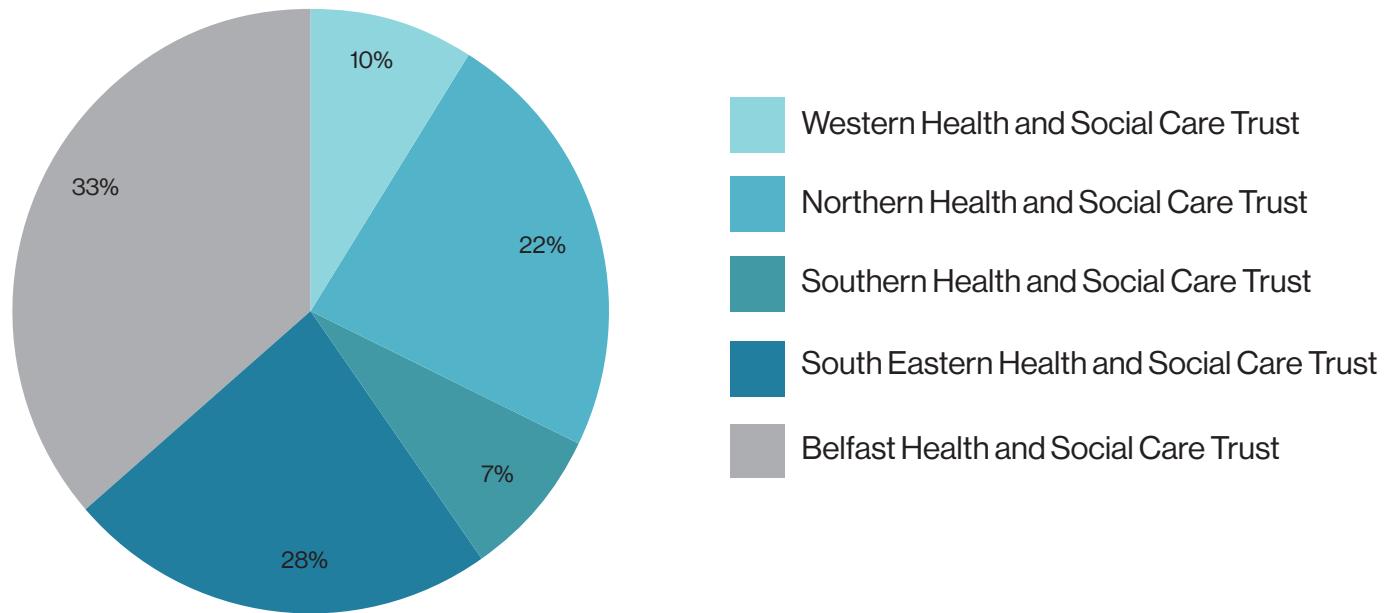
Diagram 3 illustrates the complete range of ages of the children represented in the stories collected.

Diagram 3. What age is the child in the story?



A full demographic profile of the children in the stories is available in appendix 2. All Health and Social Care (HSC) trusts across the region engaged with the project as demonstrated in diagram 4.

Diagram 4. In which trust is your service located?



It is noted capacity for face to face data collection was reduced in Southern Health & Social Care Trust and in Western Health & Social Care Trust as there was no Patient & Client Experience Facilitator in place. This limited the numbers collected in the timeframe. In both trusts there was additional effort to support survey completion through the online product and through the postal system.

Diagram 5 illustrates how long the family had engaged with audiology services. The greatest proportion of responses was from families who are only engaging services within the last 12 months and attending for their first assessment. There is also a widespread of experiences shared by families who have engaged the service up to and over 10 years. When asked to share their story families were asked to reflect upon the most memorable experiences across the time they have attended Audiology.

Diagram 5. How long have you attended the Audiology Services?

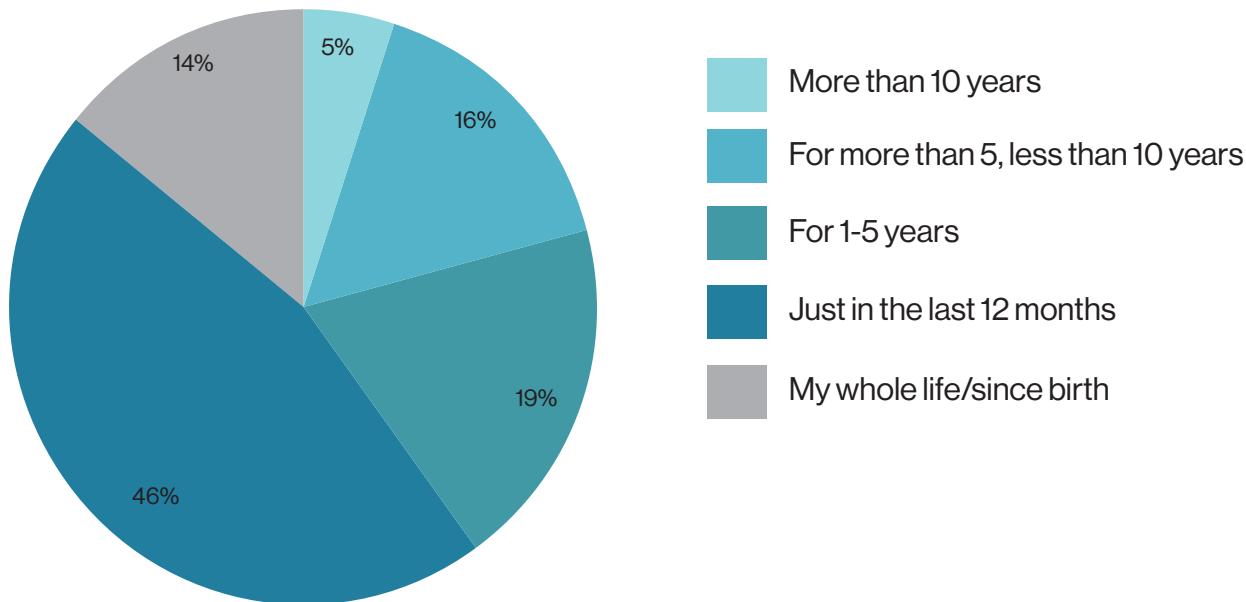
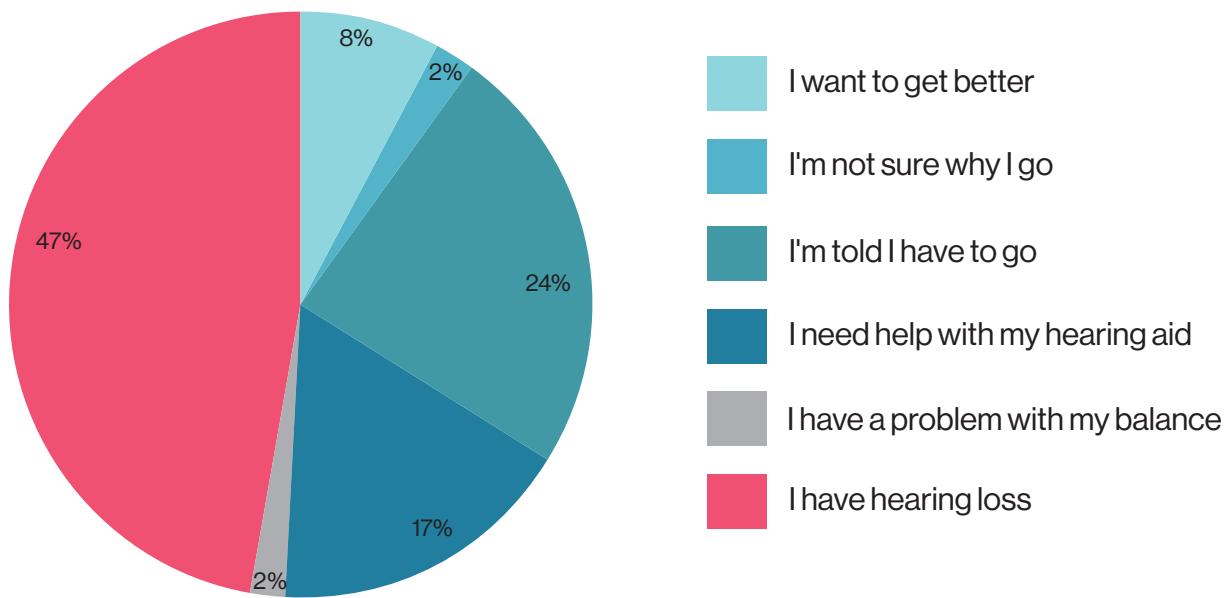


Diagram 6 reflects the reasons the service user and their family attended audiology services. In this question respondents could select more than one reason. The greatest proportion (47%) selected experiencing hearing loss. 24% attended as they were told to.

Diagram 6. Why do you attend Audiology Services? (you can tick more than one)



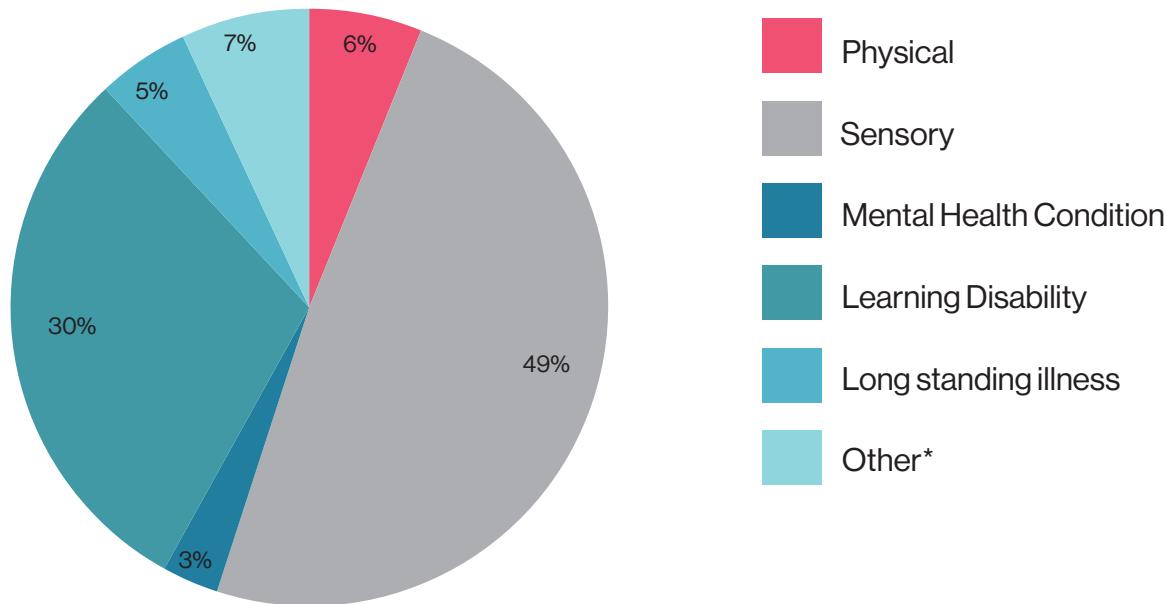
It is also interesting to note 16% of parents stated in their story they attended audiology due to a referral by the health visitor to explore delays in speech development or due to hypersensitivity to noise which was not included in the question.

As part of the context questions there is standard question in relation to disability. This is answered from the perspective of the respondent.

"In accordance with the Disability Discrimination Act 1995, a disability is defined as a physical or mental impairment which has a substantial and long-term effect on a person's ability to carry out normal day-to-day activities. Under this definition do you consider yourself (the patient) or your child as having a disability?"

52% of respondents identified yes to this question. Diagram 7 indicate the various types of impairment identified in the survey (more than one answer could be selected).

Diagram 7. Under the definition of disability if you have answered yes, indicate which type of impairment applies to the patient?

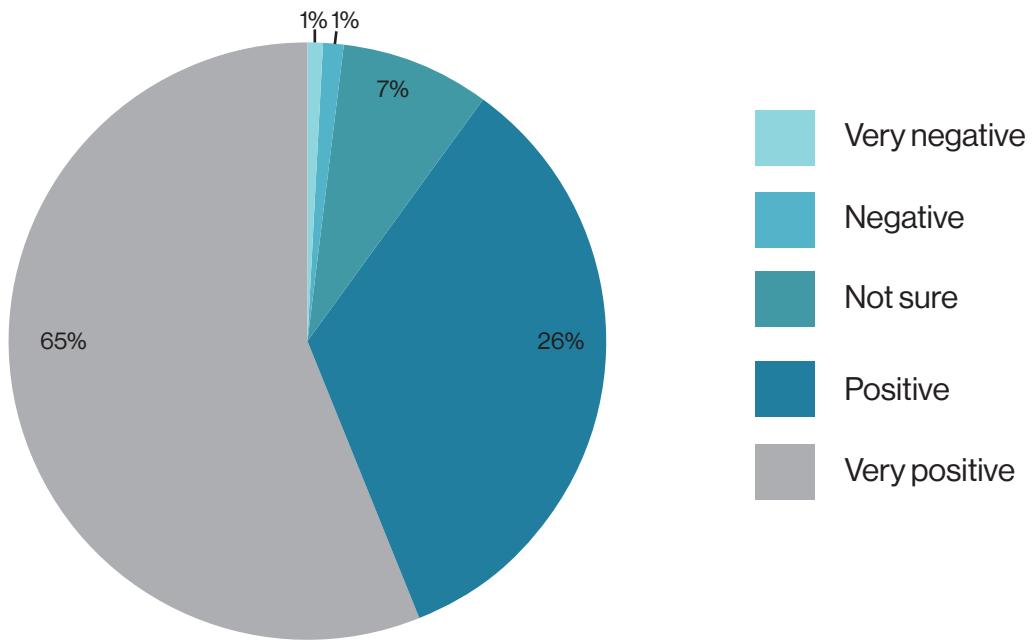


(*other impairments identified include autism, congenital heart defect, dyspraxia, asthma, Charge syndrome)

It is evident the audiology services work with children with complex needs. 32% of stories included terms such as "my child has additional needs", "diagnosis of autism" and "special needs". This is further discussed in section 4.2, the Triads.

The final multiple choice question in the survey asked the respondent to rate the overall experience attending audiology services. The overall emotional tone of responses was positive with 90% stating it was a positive or very positive experience as illustrated in Diagram 8.

Diagram 8. Responses to the statement – “Thinking about your last Audiology appointment, was this experience....?”



The following word cloud helps to illustrate the positive aspects that parents and children highlighted in their narrative. These will be further expanded upon in Section 4.2. A small number of responses (2%) indicated a negative or very negative experience. In the narrative the respondents reflected upon difficult long delays awaiting appointments and long waiting times for diagnostic assessment which caused distress during an appointment. In the narrative of stories rated “not sure” 8% of reflections included lack of compassion with individual staff, difficulty accepting the diagnosis, delays with car parking, lack of communication and uncomfortable experiences with moulds or investigations. In contrast, from the positive word cloud, it is evident that parents and children highly value and have experience of a service which is easily accessed at the point of need and a clinic which offers timely and adaptable responses to the child and their needs.

Diagram 9. Word cloud of the positive experience shared by parents and children attending audiology services.



4.2 The Triads

The following section presents the responses in relation to eight statements. The main messages are highlighted as main clusters and indicate the majority of responses however it is also important to take cognisance of the smaller patterns emerging which can indicate areas for further reflection and development. Each triad is analysed using the narrative shared and the results further demonstrated using anonymised quotes from the database.

4.2.1 Partnership

Statement 1 considers the concept of partnership with the child and their parents. Respondents were asked to consider the elements which influenced the plan of care – assessments, routine and personal desire or choice. In relation to partnership working the challenge is to consider how a balance can be sought to support the child and parent to be part of the plan of care.

Diagram 10. Triad 1. At my appointment the plan of care is influenced by...



Diagram 10 illustrates 90% of respondents (main cluster) highlight the results of assessments to be a driver in the plan of care. This is in keeping with Standard 3- Assessment, detailed in the Paediatric Audiology Quality Standards. Within this standard it states “The assessment process should inform a clearly defined management plan”. 32% were clusters only towards the bottom left corner indicating in their experience results of the assessment were the main driver in the plan of care.

“My son attended a hearing test because we weren’t sure if there was an issue. The girls who took him through the game were great at keeping him focused and at explaining everything to me”

The main challenge is how the plan of care is written in partnership with the child and parent/guardian. This is highlighted as an important factor for Standard 4 of the Paediatric Audiology Quality Standards - Audiology Individual Management Plan (IMP). This standard states the plan should be agreed with parents and/or the child or young person. 44% responses highlight desire and choice to be part of their experience. The minority cluster at the top of the triangle indicates the child and family felt they were the main driver to the plan of care. Interestingly all the stories relate to a parent engaging with the service with young children under age 5. Three parents reflected upon the responsiveness of the Health Visitor when they raised concerns and the support of the audiologist in reassuring and informing the parent and child.

Another minor cluster is evident between my desire/my choice and the results of the assessment. Respondents in this cluster reflect upon how they were kept informed throughout the appointment and were able to engage openly with the audiology team.

"They explained everything to me step by step as it was happening"

The third signifier "It is what we always do – it is routine" was indicated to a lesser extent. A number of these stories related to routine fitting of hearing aid from families who had been part of the service more than 2 years, however a number of responses had a more negative emotional tone. These stories reflected upon a more closed experience with lack of engagement such as receiving a diagnosis without support or did not feel they could ask questions at the time of tests. This illustrates barriers to partnership working and results in a less positive experience whereby the parents or child are not empowered to be a partner in the plan of care.

"Our appointment ran over... but she never mentioned it and spent a full hour with us making sure he was all sorted. She always has a smile for us and even when I need things explained she takes the time to help"

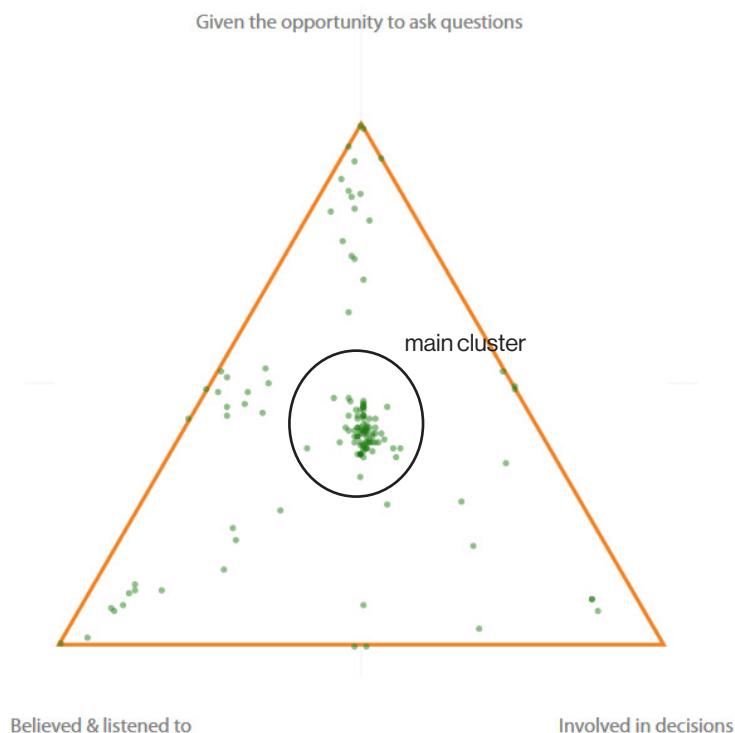
Open communication as an important element of partnership working is also further explored in Statement 2.

"...they did not explain why they are carrying out the tests... or explain the results after each [test]..."

4.2.2. Meaningful Engagement

Statement 2 explores meaningful engagement for the child or parent to communicate openly with the audiology team through asking questions, being believed and listened to and being involved in decisions, as part of the assessment.

Diagram 11. Triad 2. During my appointment I was...



60% responses indicated that during the appointment they experienced all three signifiers. This positive response is further illustrated in the narrative.

"From the word go the staff here have been open and up front I need to know everything I need to know... Not withholding information means a lot to me as a parent"

"... my little boy is autistic ... we were both very worried about attending... but the audiologist reassured us. Answered all our questions without making us feel silly..."

"... We were told about the implants and the surgery... He [the doctor] answered out questions... We also chose what type of implant we want... With our permission they [audiologist] arranged for us to speak with another parent..."

There was one respondent who did not complete this triad but expressed concern about the communication they experienced during their appointment.

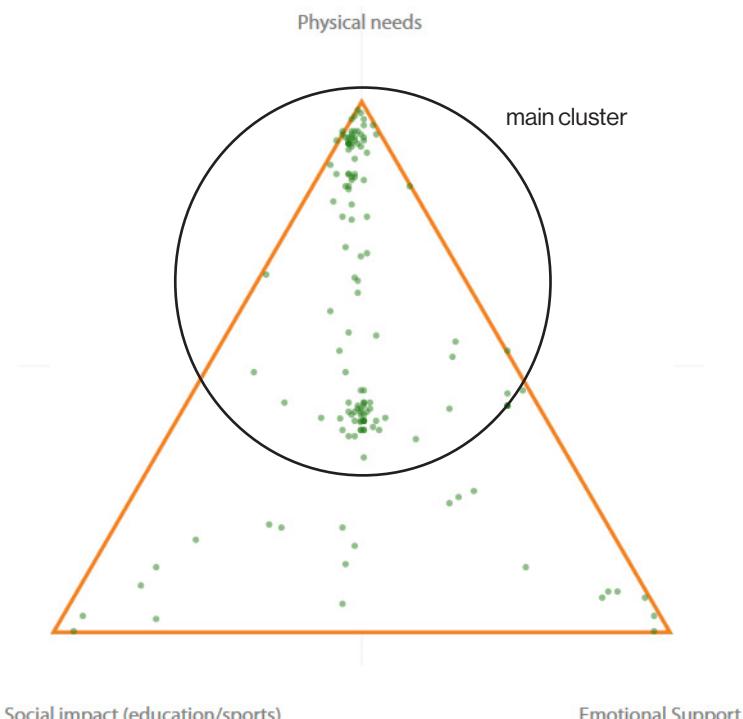
"... although everyone was very friendly we were not prepared and the news came as a shock... the language was confusing, audiology terms, measurements to us common folk was over our heads"

Reflecting upon Standard 2 of the Paediatric Audiology Quality Standards- Information Provision & Communication this illustrates one of the challenges in ensuring the phrases and words are understood by service users. Communication is an underpinning theme throughout this report and is further explored in Statement 8.

4.2.3 Holistic Approach

The third statement considers the impact of the Audiology service upon the person as a whole, exploring physical, emotional and social elements of the child. The main cluster for statement 3 (80% of responses) indicated the physical needs as part of the appointment. 40% indicated the physical need is the only/main priority for attending audiology. This is evident for parents and children attending in relation to first moulds and the maintenance of their hearing aids. It is positive to note 30% of responses indicated that all three elements – social impact, emotional support and physical need were part of their experience of audiology.

Diagram 12. Triad 3. At the appointment priority is given to...



Within the narrative a number parents shared the positive impact the audiology service had upon both the child's emotions and concerns in relation to the clinic appointment, especially for children with autism or learning disability...

"... He was very nervous and hard to engage but the audiologist took her time and talked to him... at the beginning he wouldn't wear the headphones but after she talked to him and made it fun he played all the games"

"Today was brilliant, the way the Audiologist interacted with him and she put him at ease. She talked calmly and made eye contact... she was at his level and he responded to her"

"the audiologist is a constant support in my daughter's life"

And also examples of emotional and social support for parents attending the clinic, with staff demonstrating empathy for the parents' anxieties...

"... they never make me feel like a burden... If I am worried about something I can just ask... even if I have to bring my girls [siblings of the patient] they accommodate me... there is no eye rolling. Excellent"

"... I was incredibly late for our first ever appointment... due to car park issues. My son needed his nappy changed ... we were all so upset... I tried ringing but no one answered... then we arrived and audiologist could not have been nicer. She played with my son until I changed the baby's nappy. She always has a smile... amazing person"

"Phoned with a drama of a broken hearing aid during GCSE exam. One programmed immediately and available right away! Fabulous service"

Respondents reflecting upon their emotional response to a diagnosis demonstrated the importance of additional support at this time.

"...most memorable expereince was the day I found out that my child had a permanent hearing loss and was fitted with hearing aids for the first time. Was probably more traumatic for both parents and we feared the worst how this would impact our child going forward... we didn't know what to expect and what it would mean for their future development and wellbeing"

"We were not prepared. We had known there were hearing issues but we had expected it would resolve...we were left feeling totally deflated..."

"... finding out I was partly deaf – it felt like my whole world had changed. That I was going to be known as Deaf girl. I was so scared about what was going to happen next. I was only 11 year old. I hated it. I was so upset and at the time I didn't really understand what was going on ..."

"Finding out our newborn had a hearing loss was a particularly hard experience, I found there was so much to take in straight after being told results.The doctor explained things so positively and I love that he spoke directly to our child"

Also a number of other agencies were identfied as being important in providing support to children at the time of diagnosis and highlighted by parents as key to supporting their child.

"... In school she [daughter] has had the same assistant right through till P7 and now is moving with her to grammar school. This is great"

"We felt isolated... we had consultants, teachers of the deaf, speech therapists ... but I didn't get any personal experience from them just professional knowledge. When I was advised to contact NDCS [National Deaf Childrens Society] I began to feel more cofident in dealing with the diagosis... the NCDS key worker answered all my questions"

"... our greatest support is from the Teacher of the deaf"

When asked how to improve upon audiology services holistic support and information was highlighted - a mother who attended audiology services with all her children expressed a need for additional holistic support...

"My only criticism is the lack of support or information on actual hearing loss. They were presented with hearing aids and no information on the issues or difficulties associated with socially, physically or emotionally with hearing loss"

The following are suggestions from parents and children on how they could be supported better with social and emotional aspects of hearing loss.:-

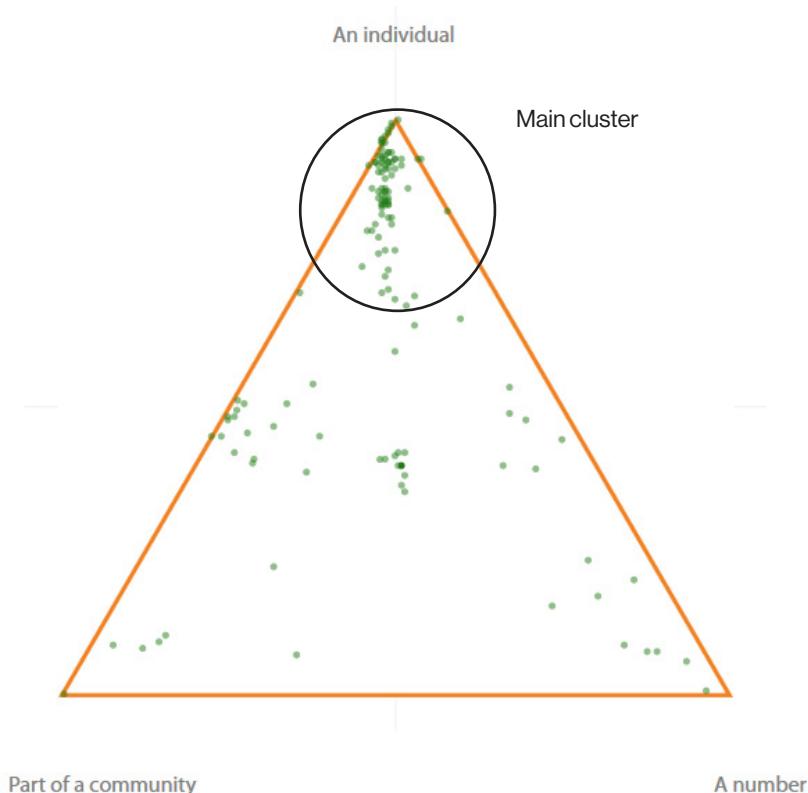
- 1- Information on services/schemes to support children with hearing loss
- 2- Information leaflets to share with school, youth clubs or sports clubs
- 3- Local support groups to share experiences through information evenings
- 4- Engage or partner with National Deaf Childrens Society, Action Deaf Youth and Child and Adolescent Mental Health Services – share this information at clinic level
- 5- Peer to Peer support for parents of deaf children (particularly on rural areas)
- 6- A forum to speak with parents and teenagers who have cochlear implants

This is further discussed in statement 5.

4.2.4 Person Centered

The fourth statement reflected upon how the patient or parent felt attending audiology – did they consider themselves to be individuals? Part of a community? Or just a number?. Responses are illustrated in Diagram 13.

Diagram 13. Triad 4. At the appointment I am...



The main cluster of 59% identified themselves as individuals in the audiology service. This is an important element of person centred care, supporting the assessment to be focused on the child which is a vital element of Standard 4 of the Paediatric Audiology Quality Standards. Parents with very positive experiences shared how the audiologist really knew their child...

"We are generally seen by the same team/nurse and they know my daughter by name... my daughter loves to go... each visit is consistently good"

"My sons moulds made his ears crack and bleed... the audiologist spent time with him on this problem over the course of a few appointments and trial and error. At no time did she make our request feel trivial and she did not rush. My son has learning difficulties and this was so important to us both"

In narratives with more negative emotional tone the responses were focused on feeling like a number. A key theme relating to these responses is the waiting times for appointments in relation to hearing or long delays experienced at the clinic.

"The negative side is the waiting time to be seen or to have anything done. My child is waiting to have grommets in and is on urgent list I have been told this could take 97 weeks... her hearing is getting worse everyday"

"My sons moulds made his ears crack and bleed... the audiologist spent time with him on this problem over the course of a few appointments and trial and error. At no time did she make our request feel trivial and she did not rush. My son has learning difficulties and this was so important to us both"

"My son was referred for an appointment over concerns about hearing loss but no appointments were given because of staff sickness. My son was two and half before he was fitted with hearing aids. He missed out on a critical time for developing language"

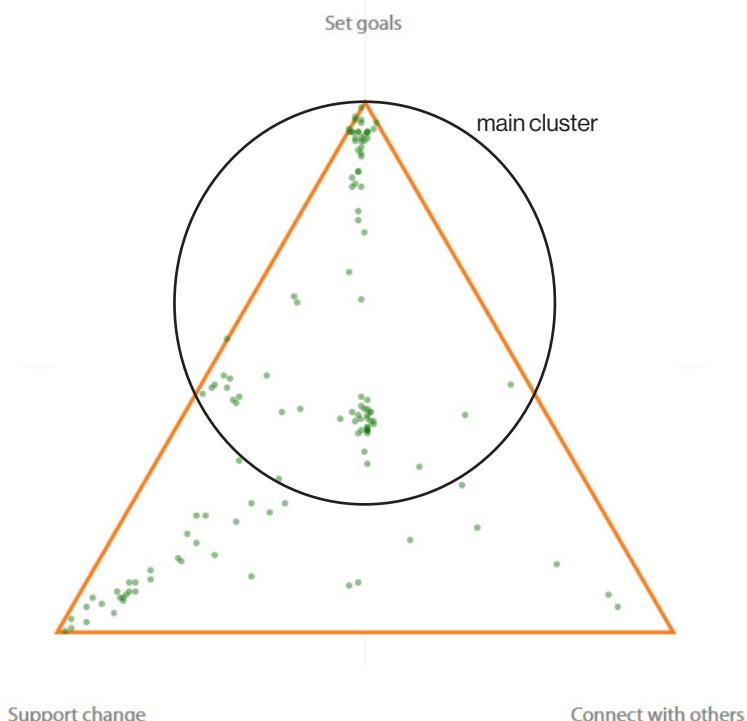
Also in this small cluster a family shared their frustrations in relation to learning British Sign Language. As a family they highlighted they were never advised on or directed to a service to teach British Sign Language. From their perspective they felt like a "number" for this reason. They stated...

"... because our daughter and our family were not given the chance to learn sign language she is not only isolated from the hearing community but also she is isolated from the deaf community"

4.2.5 Impact of Audiology services

Statement 5 considered the impact of audiology service through appreciative enquiry - looking at three positive outcomes which may be experienced from attending audiology as demonstrated in Diagram 14.

Diagram 14. Triad 5. Attending Audiology helps me to...



The main cluster represents 63% respondents felt audiology services supported them to set goals. There is also a central cluster of 24% who felt attending audiology also supported them to make change and to connect with others as well as set goals.

It is also significant that connecting with others is only a minor cluster and therefore a possible area for development to support families with diagnosis to connect with support groups and information in the management of hearing loss. When responders were asked the open question "What could Audiology Services do to support you more?" responses indicated the importance of meeting with others in a similar situation as demonstrated in the following quotes

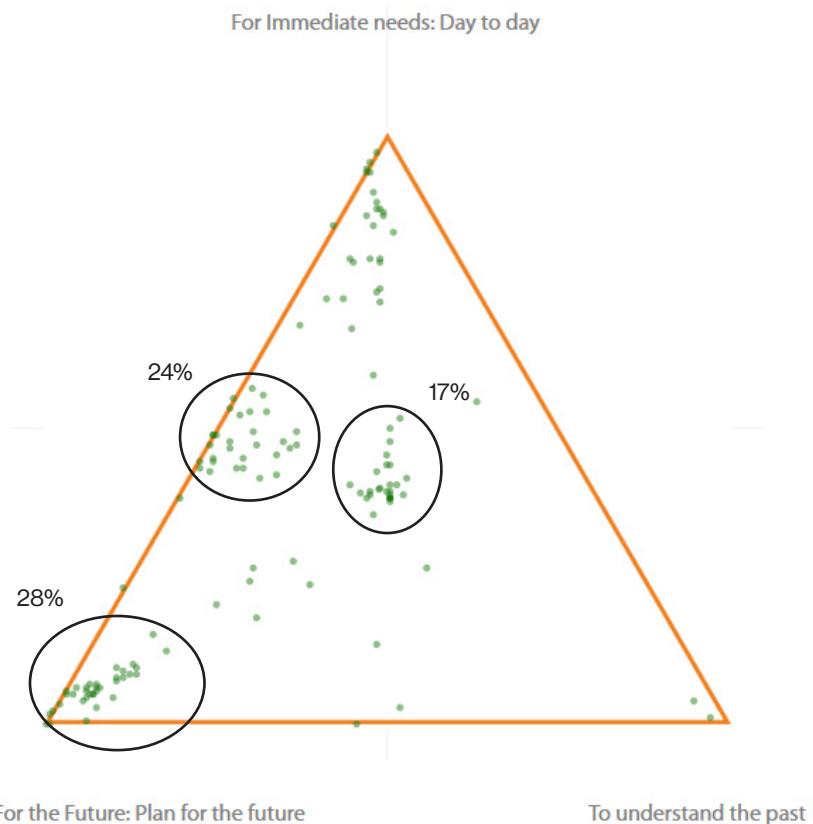
"I would like a locally based support group where my child can meet other children with similar problems, as she often feels she is the only one with these problems. I would like to know more about the tests, their results and what they mean, an information evening would be beneficial"

"...Also catch up sessions/drop in sessions would help where I could meet other parents/ people using hearing aids"

4.2.6 Personal Outcome of Audiology

Statement 6 considered how attending audiology impacted upon the past, present and future as shown in Diagram 15.

Diagram 15. Triad 6. Attending Audiology prepares me for



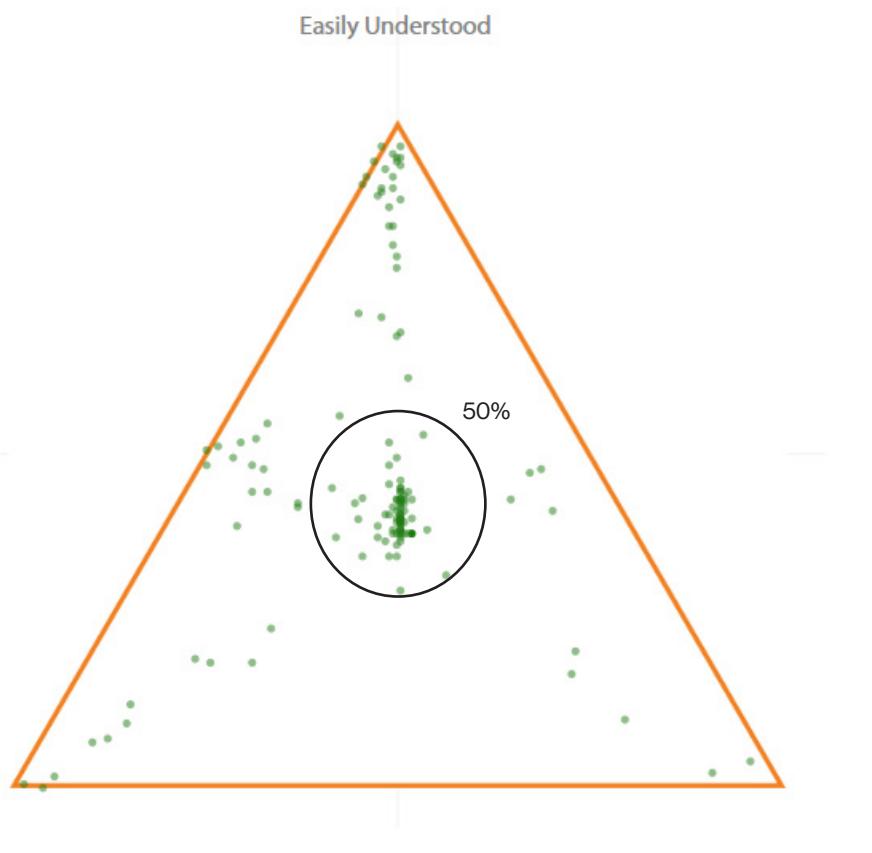
The main cluster (28%) identified that attending Audiology supported the child & family to plan for the future. 24% related to both planning for the future and meeting immediate needs. This is a positive reflection upon how audiology supports children and reinforces the comments in Statement 5 where the majority felt Audiology helped them to set goals. This is a positive reflection on Standard 4 of the Paediatric Quality Standards – Audiology Individual Management Plan.

"There were lots of questions, uncertainties, frustrations, unknowns We arrived expecting the issue could be resolved but in the end it was a permanent issue and our child would have to wear hearing aids from then onwards. We had to think through what this would mean for her and how we would support her..."

4.2.7 Communication

The penultimate statement considers the effectiveness of communication in relation to the assessment. Positively 50% of responses indicated that communication was easily understood, timely and provided all necessary detail.

Diagram 16. Triad 7. Communication regarding the assessment was...



Within the narrative a number of responses highlighted how the communication in relation to the services could be improved upon as outlined in the quotes-

"...I didn't know what to expect, it would be good to have an information leaflet, that is both adult and child friendly, sent out with the appointment letter so as I could explain to my son what was going to happen..."

"... Practical note getting through on the phone takes far too long 30 mins to 1hr on hold"

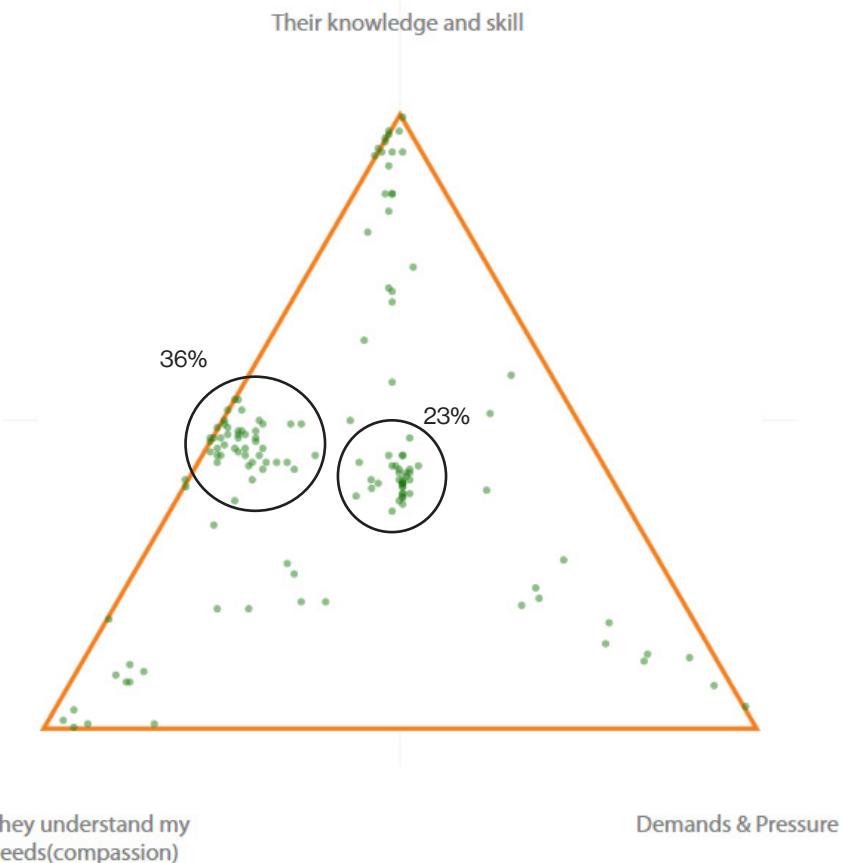
"An email inbox/ online booking system for appointments would be helpful. Many deaf people struggle to use the telephone and the lines are often congested with long waits."

These suggestions support Standard 2 of the Paediatric Quality Standards which states "each service has in place processes and structures to facilitate communication with children, young people & families".

4.2.8 Observation of Service

The final statement asked responders to consider what they observed about the staff during their appointment as illustrated in Diagram 17.

Diagram 17. Triad 8. During my appointment what I noticed most about the staff was...



The main cluster of responses demonstrated 36% recognised the staff to be compassionate and also knowledgeable and skilful. Reflecting upon Standard 6 of the Standards for Paediatric Audiology – Skills & Expertise – the signifier “their knowledge and skills” was identified by 75% of the responses overall.

Within the narrative respondents reflected positively upon both the clinical skills of the team and also the skills of support and communication.

“The two girls working in the clinic were fantastic. They explained the procedure and supported me emotionally when I was upset about my youngest son (the patient) not getting much one on one attention at home due to having an older sibling that is close in age and demanding of my attention. They reassured me and were great with my son”

“The staff are really friendly; they make you feel comfortable and at ease...made the tests really comfortable and fun to do. They explained everything really well...”

“On behalf of my children, who both attend my most memorable experience would be the child friendly nature of the staff – you never feel pressurised or judged in any way...”

For a small number of respondents demands and pressures were recognised as a concern. The narrative behind these responses had a more negative emotional tone, reflecting upon concerns about staffing levels and delays experienced with first assessments or onward referrals.

"... I feel appointments should be handled better. I had an instance where a deaf teacher told me of an impending appointment which I hadn't been notified of no letter/no telephone call. Left me no time to plan and make work arrangements to enable me to attend"

"..My son being referred for an apt over concerns for hearing loss and no apt given as staff off sick"

"..Promised a six month review by a consultant this never happened on time... There is only one child audiologist.... In the instance that this audiologist is off sick / unavailable nobody is in a position to deal with my child's case"

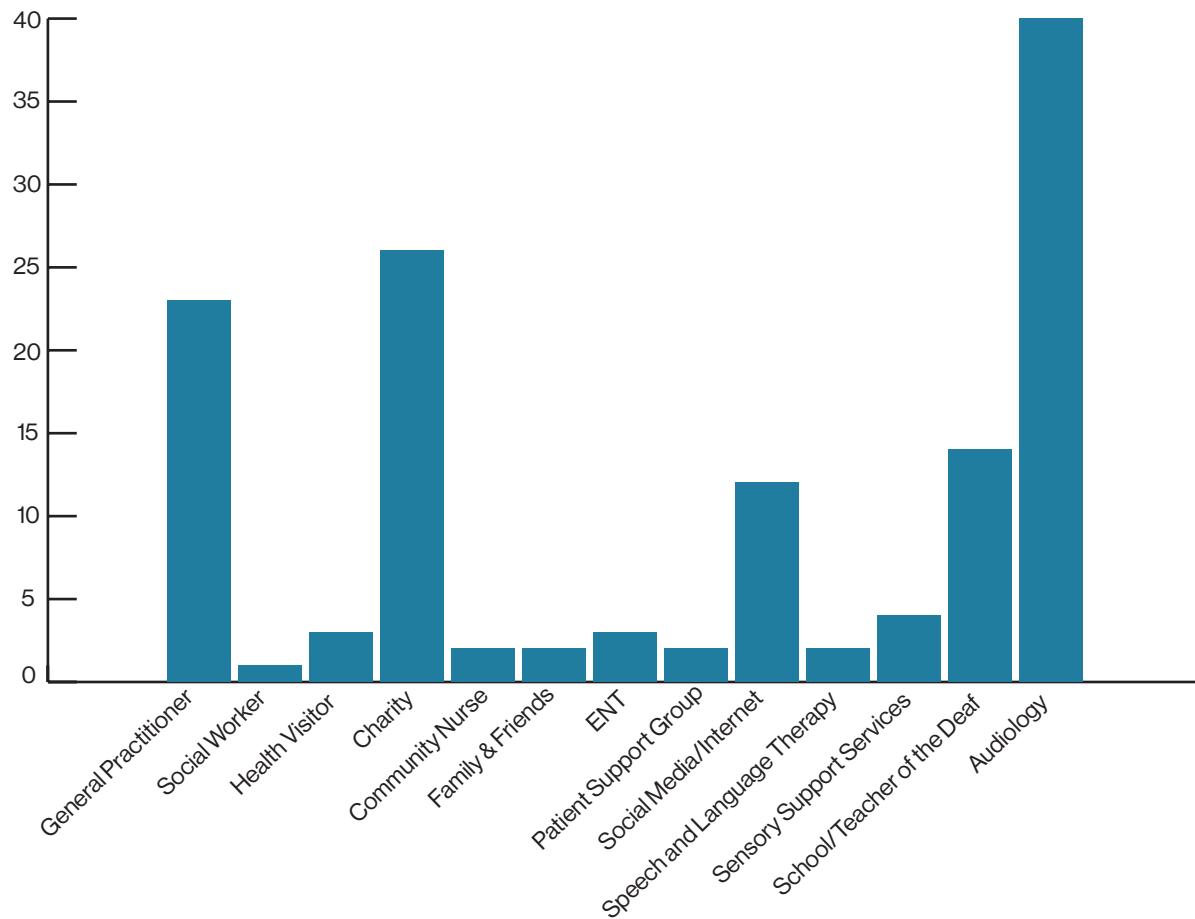
Issues raised in relation to access and workforce are raised in a small number of stories; however this demonstrates a challenge to Standard 1 – Accessing the service, detailed in the Paediatric Audiology Quality Standards

4.3 Open Questions

The next section of the survey asked three open questions. The responses to these questions have been integrated into the analysis of the triads however the following summarises these response.

Question 1: If you needed help today with anything related to hearing where would you go?

Diagram 17. Response to Question 1



*responses included various areas of help.

The main source of help was the Audiology Clinic. This is reflected in the narrative, in particular when there is an issue with the hearing aid. It was recognised issues with hearing aids had a great impact upon the child and parent. Where there was positive emotional tone parents reflected upon how the service worked hard to meet their need in a timely manner.

"... We attended audiology for new hearing aid moulds & audiologists also checked over programming of hearing aids. On return home my son felt them buzzing & became v distressed. I phone immediately to Audiology at 4.56pm and she kindly agreed to reprogram new hearing aids & leave them in [another department] as I wouldn't get back in time before department closed..."

For a small number of respondents who had a negative experience they expressed concern in relation to waiting times and that there was nowhere to go for help at the weekends in relation to the hearing aid and the provision of batteries.

Responses to this question identified the wide range of organisations which children & parents engage with. This list highlights the importance of collaborative working and the large network which audiology is part of. This is highlighted in Standard 8 of the Paediatric Audiology Quality Standards which states "... ensure effective collaborative working & communication within the team & outside agencies".

Significantly parents recognised the importance of the community and voluntary sector. Charities identified in the narrative were Sense, NDCS, Action on Hearing Loss and Action Deaf Youth. Older children identified the websites of these charities to be helpful and also various Facebook groups for teenagers and parents. There were limited numbers who sought help through support groups. This is an area identified by parents for improvement, reflected in Question 3.

Question 2. What is the most difficult part about living with a hearing problem?

The following list summarises the difficulties experienced by children and their families in relation to a hearing problem. The list is the top 10 difficulties highlighted, from number 1 being the difficulty highlighted the most.

- Speech Development – not being understood.
- Social Isolation (self-conscious, engaging groups).
- Anxiety in relation to adult years, work, sports etc.
- Staying positive.
- Lack of understanding/support in the school.
- Hearing in loud environments.
- Problems with the hearing aid – delays for remould/keeping hearing aid on.
- Lack of understanding from other health professionals e.g. A&E, administration staff.
- Confusion between other health professionals of the plan of care.
- Using my phone in public.

Question 3. What could Audiology Service do to support you further?

It is important to note that 58% of responses stated that the Audiology services supported them fully and did not provide any further suggestions of improvement. This is a positive reflection of the experience of children and their families. Suggestions that could improve Audiology services are summarised in the following list (in no particular order), and are mostly in respect of improving communication with patients and families:

- Information on services/schemes to support children with hearing loss.
- Information leaflets to share with school, youth clubs or sports clubs.
- Local support groups to share experiences through information evenings.
- Engage or partner with NDCS, Action Deaf Youth and CAHMS – share this information at clinic level.
- Peer to Peer support for parents of deaf children (particularly on rural areas).
- A forum to speak with parents and teenagers who have cochlear implants.

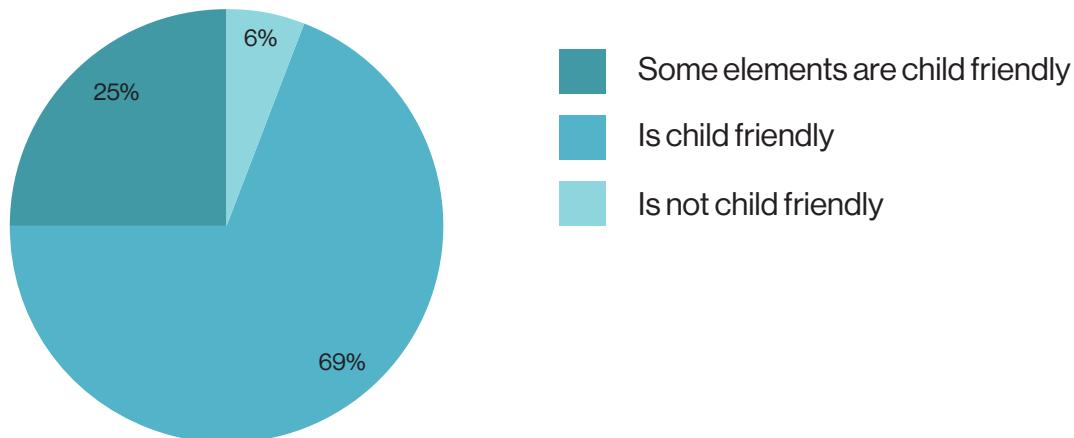
- Vending machine for hearing aid batteries available in public spaces.
- Support in attending clinics such as Car Parking pass or alternative arrangements like a skype call.
- A Regional service - Review of appropriate location of clinics; the opportunity to attend closest clinics in community hospitals regardless of Trust location.
- Email service to engage with the Audiology Team.
- Need for more up to date hearing aids. Review of the available technology within our health services in NI.

4.4 Closed Questions

The final section of the survey asked two closed questions. Question 4 asked "How convenient is your audiology clinic?" 78% of responses identified the clinic to be convenient and accessible. 22% stated the clinic was not accessible. In the narrative of these responses issues highlighted were clinics outside of the trust area would be more local and car parking difficulties causing long delays. These are reflected in 4.3 as areas for improvement

Question 5 explored the environment of the clinic in relation to it being child friendly and is demonstrated in Diagram 18.

Diagram. 18 Responses to Question 5...



Positively 69% identified the environment to be child friendly and reflected upon the use of teddies, toys and games as part of the assessment. They also identified staff who demonstrated an understanding of children and the importance of working with the child at their level. In the small number of responses, which identified the environment as not child friendly, respondents reflected upon out of date premises and need for modernisation of the waiting areas.

5.0 AREAS OF REFLECTION AND LEARNING

The following is a summary of the findings from the Regional data which has been agreed by the Regional Audiology Forum to review as part of the wider development of Paediatric Audiology Standards. Each trust will also review the local trust data to establish areas of development specific to the organisation and integrate the findings into local service improvement work.

- The patient and family experience of Paediatric Audiology services is mainly positive and provides a high standard of care to children attending in line with the Paediatric Audiology Quality Standards.
- Audiology services are recognised as key source of support and guidance for both patient and family during physical, emotional or social concerns.
- Audiology services provide person centred and individualised care, with particular reference to children with complex needs.
- Parents identified a need for more support forums to connect with other families, to provide support and advice and to facilitate children to meet with other children with hearing difficulties.
- Other areas for development are the need to improve communication with patients, for example leaflets to support families (especially for the first appointment to audiology), guidance and advice for youth clubs, sports etc to access training on British Sign Language. Easier access to batteries was also highlighted.
- The data is available for further briefing papers to inform other aspects of healthcare such as transition phase for teenagers to adulthood and services in relation to children with complex needs.

6.0 APPENDICES

Appendix 1 – Project Team

10,000 More Voices

Name	Role	Organisation	Email
Mrs Linda Craig	Project Lead	Public Health Agency	Linda.craig3@hscni.net
Mr David Todd	Project Support	Public Health Agency	David.todd@hscni.net
Mr Barry Murtagh	Patient Client Experience (PCE) Facilitator	Belfast Health & Social Care Trust	Barry.murtagh@belfasttrust.hscni.net
Mrs Sarah Arthur	Patient Client Experience (PCE) Facilitator	Northern Health & Social Care Trust	Sarah.arthur@northerntrust.hscni.net
Mrs Mairead Casey	Patient Client Experience (PCE) Facilitator	Southern Health & Social Care Trust	Mairead.casey@southerntrust.hscni.net
Mr Conor Campbell	Governance and Patient experience manager (in absence of PCE facilitator)	South Eastern Health & Social Care Trust	Conor.campbell@setrust.hscni.net
Mrs Vi Gray	Patient Client Experience (PCE) Facilitator	Western Health & Social Care Trust	vi.gray@westerntrust.hscni.net

The Regional Team for 10,000 More Voices can be contacted by

Email: 10000morevoices@hscni.net

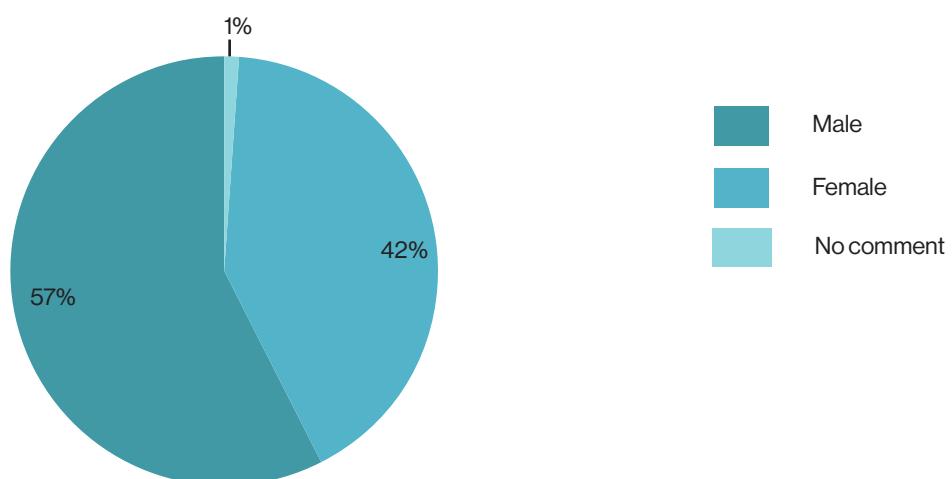
Telephone: 028 95362868 (Monday-Friday 9am-5pm)

Regional Audiology Forum

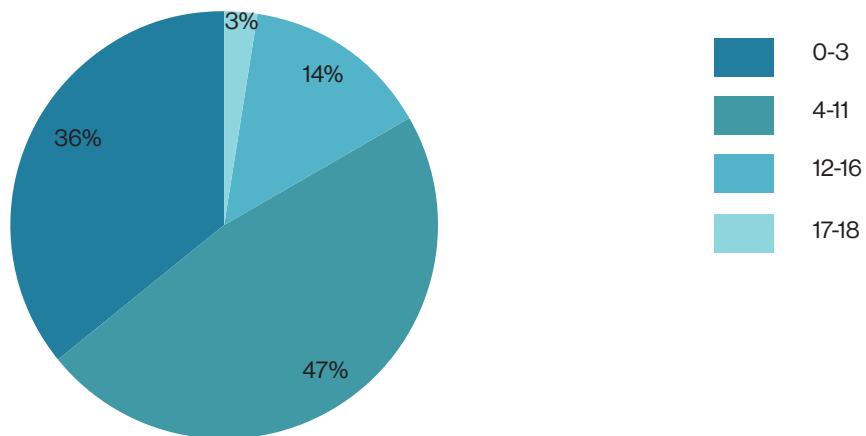
Name	Organisation
Linus McLaughlin	Health and Social Care Board
Siobhan Sawey	Belfast Health & Social Care Trust
Rosemary Boyce	
Lorraine Fentie	
Roberta Campbell	Northern Health & Social Care Trust
Avril Watson	Southern Health & Social Care Trust
Barbara Gregg	South Eastern Health & Social Care Trust
Karyn McMulkin	Western Health & Social Care Trust

Appendix 2 - Demographic Profile of Carers

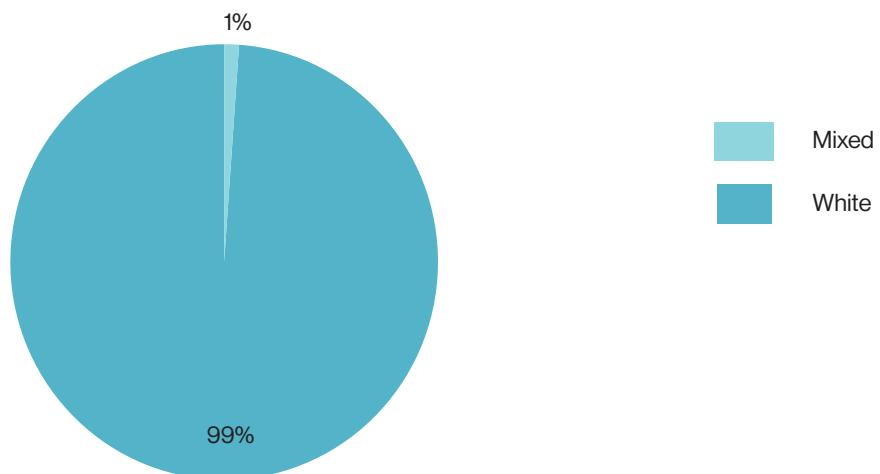
1 - Gender

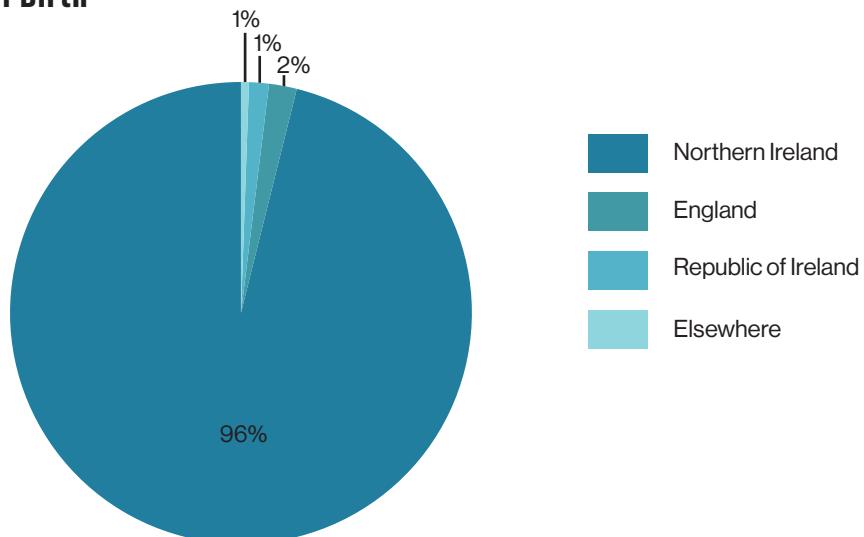
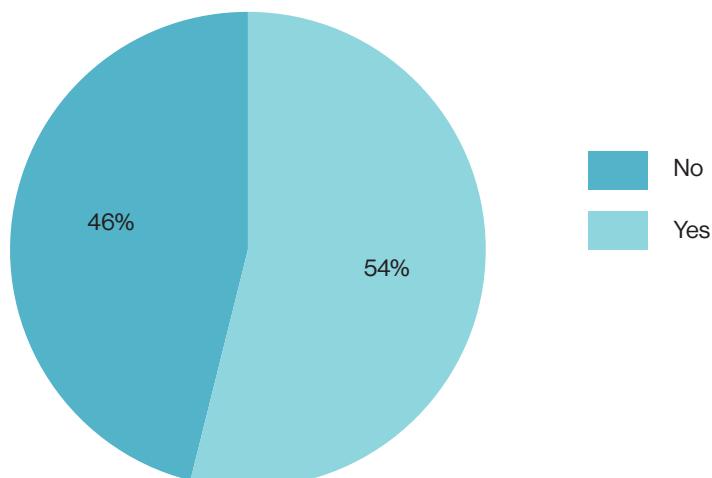
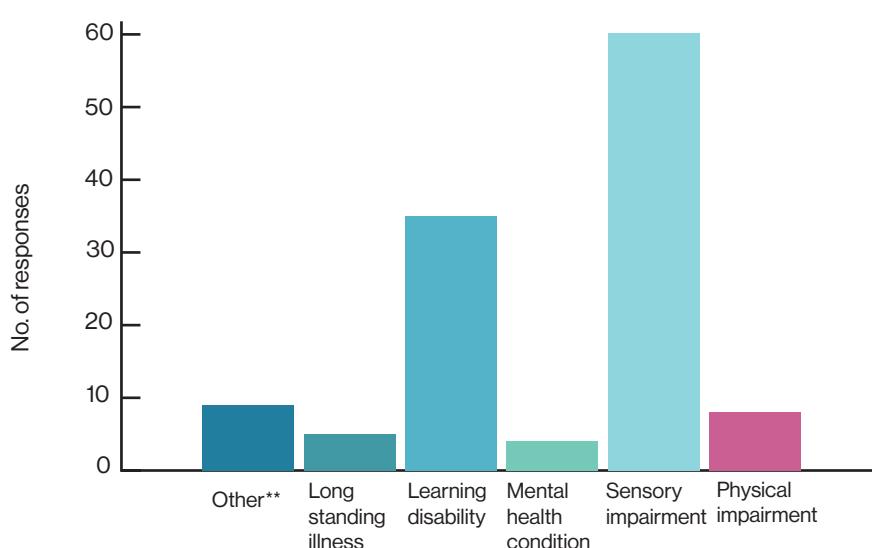


2 - Age



3 - Ethnicity



4 - Country of Birth**5 - Disability****6 - Type of Disability**

** other included Cystic Fibrosis, Autism, Congenital Heart Defect, Williams Syndrome, Dyspraxia, Charge Syndrome



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