

National Review of Audiology Services

Engagement insights

June 2023



Summary report



ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre



Contents

1. Background	2
2. Methodology	2
3. Findings	3
Accessibility	4
Communication	6
Relationships	7
Person centred care	8
Collaboration	10
Technology	11
Gaps in services	12
4. Conclusion	14
About the ALLIANCE	15

Note

For the purposes of this report, we use the terms hearing loss, deafness and people affected by deafness to cover a range of terms that include definitions of people that may identify as Deaf or Deaf Community members; deafened, deafblind and hard of hearing and family members and/or carers.

1. Background

A report published in December 2021 described errors in treatment provided to children by Paediatric Audiology in NHS Lothian (British Academy of Audiology, 2021).

In response to that report, the then Cabinet Secretary for Health and Social Care set up a National Audiology Review to look at Audiological Services for children and adults in health boards across Scotland. As part of this, a Reference Group was established to ensure the voice of lived experience was central to the review.

The Health and Social Care Alliance Scotland (the ALLIANCE) worked with the Reference Group to engage with people who had accessed audiology services. The engagement was designed to be inclusive and aimed to capture people's experiences and views in ways that were convenient and accessible to them. The aim of the engagement was to help inform what services would look like in the future.

This is a summary of the full insights report submitted to the Chair of the National Audiology Review Group.

2. Methodology

The ALLIANCE adopted a mixed methods approach consisting of online surveys, focus groups, one to one interviews and the option for people to share their experience by email or letter. The aim was to engage with people or their families who had accessed audiology services within the past five years. Participation was entirely voluntary and saw people from across Scotland share their experiences.

The surveys, designed in collaboration with the Reference Group, consisted of both quantitative and qualitative questions. These were available in both written and BSL formats.

Four surveys were designed to take account of the different groups of people who access audiology services:

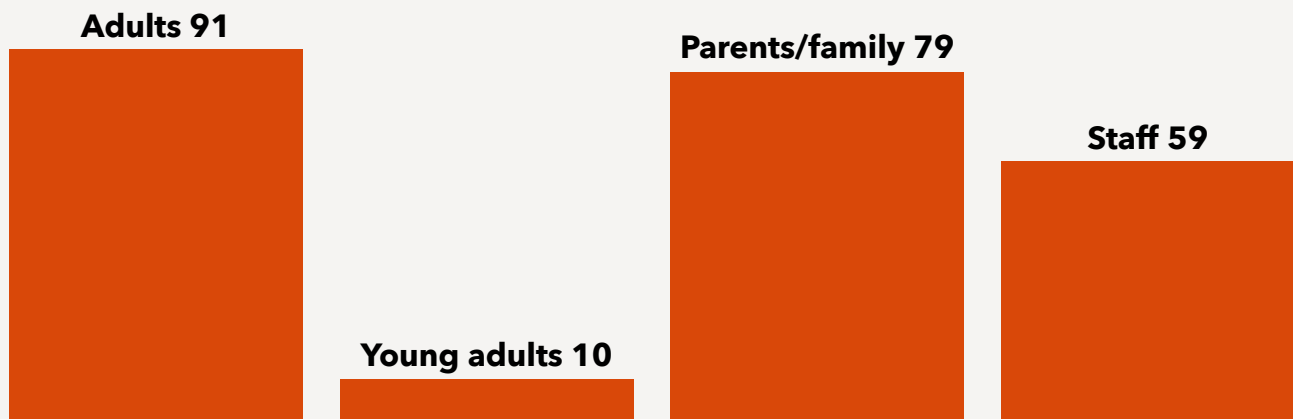
Adults (aged over 18)

Young adults (aged 12 - 18)

Parents / families of younger children accessing audiology services

Healthcare professionals working with audiologists and/or audiology services

The surveys were promoted during December 2022 and January 2023. 239 people completed the survey most relevant to them:



Two focus groups were held in February 2023. The first one had six adults attend and the second saw three young adults participate. In addition, individual interviews were undertaken with two adults. All 11 people who spoke to us had first-hand experience of accessing audiology services.

A graphic illustrator captured the discussions at the focus group for young adults. This is appendix 1.

3. Findings

Analysis found common themes across all four surveys. These were:

- **accessibility**
- **communication**
- **relationships**
- **person centred care**
- **collaboration**
- **technology**
- **gaps in service.**

Accessibility

Many people told us about their long wait before they received initial and subsequent appointments and the impact this had on their quality of life.



Had to wait 12 months with profound hearing loss and no hearing aids over COVID, meant I couldn't understand lectures or go to work.

Professionals also discussed the “backlog” of cases and the impact of other changes made during or after COVID pandemic restrictions.



During COVID they posted out spare parts and batteries to people but complained of the cost so no longer send out spares.

People also told us they don't always receive notifications or reminders about appointments and tests from the Audiology Department. Many felt that it was left to the individual to chase their own care.



Once I received my hearing aids I have had no more communication with the audiology dept. Perhaps I am supposed to contact them again but I have had no reminders or info. As there was a great deal to take in at my fitting appointment I think that there should be some follow up info.

However, other people told us about good practice, where appointments were given quickly when needed.



Review appointments are slow in coming through due to current issues within the NHS however when we needed to get new impressions taken for replacement moulds, our son got an appointment quite quickly.

Some people told us that Audiology Services should be easier to contact. Many people had no alternative but to phone audiology, which was frustrating for those who find calls problematic due to their hearing loss.



Having to leave a message on an answer machine is challenging for me in terms of my hearing.

Others praised Audiology Departments for using email correspondence and called for this to be implemented across the country as a more accessible option.

People also told us they wanted Audiology Services to be more flexible and easier to access across the country.



Providing Audiology Services at local health centres would cut our carbon footprint and reduce inconvenience for a mainly elderly client base.

Many people told us they felt frustrated that minor repairs, fittings or extra batteries were not easier to access. Lengthy waiting times were felt to be unnecessary for these types of services. Many people called for drop-in and local services to support their technology and equipment concerns.



I believe that there should be a better way of getting batteries and hearing aid tubing...you have to post your audiology book into the hospital and wait for it to be returned along with batteries. It would be useful if you could either collect batteries on the day from the hospital or from your local GP surgery without having to post the book.

Professionals who work closely with Audiology Services also shared their views about how easy it is for them to get in touch with Audiology Services.



It can be difficult getting someone on the phone...emailing is usually the most effective way but their email address isn't on their voicemail or widely publicised.



Audiologist takes weeks to respond to emails and this is frustrating.

Communication

The need for staff to better understand D/deaf culture was highlighted by many people.

Several people told us about communication styles that were not accessible for people with hearing loss. This included staff talking to people while wearing a mask making lip-reading impossible; speaking to individuals after asking them to take off their aids; and shouting names in the waiting room where people struggle to hear.



Electronic signs [needed] to notify patient when the doctor or audiologist is ready to see them (it's unbelievable that staff shout out patients' names in an audiology department!)

Professionals working with Audiologists also identified inappropriate methods of communicating.



Telephone review of adults...often don't make sense for deaf people.



Some patients have stated that audiologists have spoken to patients when not facing them or when they don't have their aids in.

Some people told us how their information needs were not met.



First experience was that they didn't have time to explain things, we weren't told what the testing process is, how or why certain tests were done.



Overwhelmingly a lot of terminology we were not familiar with was used.

Others were satisfied with the way Audiology Services communicated with them.



They were extremely helpful and explained what was happening and what tests would be carried out.

With regards to written communication, even though information had been provided, it was not always in an accessible format, nor did it tell them everything people needed to know.



The audiology results were only printed and explained to us once in all the tests that my daughter has taken. I recall having to ask “what is normal range of hearing” as it was so difficult to interpret what the results showed.

Some people also expressed a desire to see their management plan so they could be more proactive about their own self management.

One young person at a focus group also spoke about having to be accompanied by their mother whenever attending appointments. They told us about their desire to become more independent in life, sharing that having to have someone there to interpret was a barrier to their independence.

Relationships

People told us they often see a different Audiologist every time they attend an appointment. This makes it difficult to build relationships and harder for the Audiologist to gain good insight into each person’s specific needs and interests.



I would have liked to have more consistent audiologists. I feel this would have helped avoid confusion and make me feel a bit more comfortable when going to appointments.

There were many positive comments about the relationship between Audiologists and families. Some respondents named their Audiologist and rated them very highly, including recommending them to family and friends.



We have always, as a family, been fully supported and everyone involved in service provision has been outstanding. Overall, the quality of service has made a profoundly positive difference to our child's life.

Other people described problematic relationships with staff.



Consultant spoke over my deaf child and virtually ignored her talking about implant which confused and upset my child.



They should talk directly to me instead of talking directly to my parents.

Relationships between professionals working with audiologists were also shared and seemed to be positively or negatively influenced by:

- appropriateness of referrals**
- access to audiology staff**
- response time to queries**
- degree of collaboration**



We have an excellent relationship with audiology in our area; communication has been excellent and two-way dialogue is open and trusting.



They seem to keep themselves to themselves, protecting their territory and appear to see any work being done by other professionals or services with the patient as a threat rather than a support.

Person centred care

Many people told us that Audiologists do not ask them about their lifestyle or provide relevant wellbeing advice.



Audiology Services should have a holistic approach to their patients. They should recognise that hearing aids (while they work very well for many and I would not be without mine) are not the final and total answer. Every individual should be treated as such - how they manage their hearing loss is unique to them and this should be acknowledged and supported.

Many people told us that Audiologists do not ask them about their lifestyle or provide relevant wellbeing advice.



Maybe parents should have a separate appointment to be given guidance, cleaning aids, understanding what I am going through, why my moods are different, why I needed time out.

Parents and guardians often spoke about the time when their child's deafness/ hearing loss was diagnosed. Many felt there was a lack of person centred care at that time. Three main reasons were given for negative experiences.

1

Parental concerns dismissed or ignored by professionals:



I noticed early on my child had hearing loss. The hospital always said his ears were blocked but I knew different. He got aids in P1.



I feel they should listen more to parents, we know our children best and hopefully they will pick up on hearing loss quicker so no more children have to wait 10 years for help.

2

Appointment delays:



She failed Newborn Screening test and 2 follow up tests but then due to "COVID" was not seen or diagnosed with permanent hearing loss until age 2 and a half!!!



I am more concerned about the 2 year waiting times for children who are clearly deaf but have to wait to be assessed while their crucial opportunities for language development and perhaps even cochlear implants are missed.

3

Not enough emotional support for parents/guardians:



It could have been dealt with in a much more sympathetic way. It's a huge shock and it could have been dealt with better. When making a diagnosis they really need to think about the words they use. I was handed a leaflet and given an appointment in a few weeks time.

Collaboration

People wanted Audiology and other services to work better together. Particularly, communication problems between Audiology and Ear, Nose and Throat (ENT) services were raised several times.



There was a disconnect between audiology and ENT - for example attending a hearing exam and being told her hearing isn't where it needs to be or hasn't improved since the grommets operation but not explaining the issues/next steps and being told "the specialist will discuss this with you" - and you just wait for a letter that never comes.



They need to be better coordinated with ENT and other departments.

One person shared their concerns about services for people with dual sensory loss. They told us services need to be better aligned to make sure the person is treated as a whole person and not eyes and ears as separate entities.

Experiences of communication between audiology and education also varied.



Better communication between audiology and schools would be amazing. We had to contact teachers many times to say our child can't hear.

Some people also told us about challenges they experienced when moving from child to adult services.



Transitioning to adult clinic was very messy, I am not sure if I have transitioned yet or when it started. I can't remember anyone explaining this. It wasn't bad, it was just very confusing.

Professionals called for greater collaboration, increased joint working, and an overall greater sense of connectedness.



It appears from the outside that there is a complete disconnect (between audiology and other services).



They (Audiology Services) keep themselves in a bubble and don't interact very well with other services.

However, many other people shared positive examples of Audiology Services collaborating well with other services.



We even had a follow up call from the consultant a week or 2 later to make sure we had digested the diagnosis and to check if we had any more questions. The Audiologists...have also put us in contact with the NDCS, Speech and Language as well as our Teacher of the Deaf.

Technology

Most people told us they wear hearing aids and knew how to use, clean and keep their hearing aid or other device working. However, several people told us of their frustrations about the unfair variation in technology available. People felt that certain health boards provided better devices than others. This "postcode lottery" was raised frequently. As a result, several people were considering buying their own up-to-date devices in high street stores.



My department is so outdated, that the hearing aids are useless. I'd like Bluetooth hearing-aids (can get in other departments except mines) to be able to connect with the world easier and make my life more accessible.

Young people also hoped that improvements in medical technology would better support their hearing in future and be more accessible to them.

There was similar frustration regarding variance in the level of information provided by audiology staff on the device's fitting. For some, device information was given and explained clearly; for others they were provided with the device but not properly shown how to use it.

Dual sensory loss was highlighted as being especially important when looking at the quality of equipment and technology available as it can be life changing.

People also told us about being left to cope with faulty, broken or outdated devices.



The plastic hoop at the top had a crack after 6 years so I was getting feedback. I made an appointment and was told if they can't fix it in the moment they would make a new pair. The audiologist realised in the appointment they don't have the parts as too old and tried to fix with Sellotape, which hurt my ear and fell off.

People also highlighted problems with funding for their equipment. Some people told us of occasions where Audiology Services would provide hearing aids but their education department would have to provide other parts of the equipment they need, such as radio aid systems.



The service is not joined up as half the hearing aid comes from the NHS and half from education department which is completely crazy. We were supplied half a hearing aid from the NHS but the education department were not able to supply the radio system which is the bottom half of the same unit. Our consultant agrees. If you attend a school not in the heath board area it gets complicated. We ended up buying the shoe for the hearing aid and providing to NHS audiology.

Gaps in services

When engaging with professionals we were particularly interested in identifying any gaps in services. Professionals described several gaps (perceived or actual) including training, accessibility, delivery of care, the impact of COVID-19, issues with equipment, desire for increased follow-up and a need for greater collaboration.

Many professionals wanted to see more training for Audiologists. This included training in British Sign Language (BSL) to improve communication during appointments, and specialist training to improve delivery of care for individuals who also have learning disabilities.



Making adaptations for testing children with developmental or learning difficulties. Parents report that their children find it difficult to comply with tests and that the audiologist doesn't change their approach.

Some professionals also told us that they would like to see more follow-up appointments for adults to check that aids are in working order, are being used correctly, and meet the needs of the people using them.



Hearing aids would be used much more effectively if patients were re-called 8 weeks or so after being issued with their aids.

Some professionals working with Audiology Services perceive that paediatric services and children are prioritised, creating a hierarchy within the system and delivery of care.



For adults, audiologists tend to tell the person to refer themselves. As a result, people often don't or don't give us the full picture. Referral for children is smooth.



If referral is for a baby, I am contacted by audiology by telephone immediately.

Many professionals mentioned staff shortages, 'overworking' and the impact this had on the service as a whole.



For the last 4 years, the audiology department has been running without a head of audiology.



ongoing years of understaffing in audiology...staff overworked

Staff shortages were linked to long wait times, slow referral speeds and slow response times to queries.

4. Conclusion

Experiences of hearing loss and deafness and people's support needs are unique to each person. Experiences of Audiology Services across Scotland were therefore complex, and often included both positive and negative examples.

Communication is a fundamental aspect of being human. It enables us to connect with others and participate in different aspects of our lives such as socialising, education, and work, to name just a few. People often described being excluded from these aspects of their lives, with many people telling us how this impacted on their wider health and wellbeing.

People emphasised that it was important to consider technical solutions to improve their hearing loss, but also wanted staff to better understand how their lives were impacted by this.

People also told us that when appropriate aids improved their hearing their quality of life automatically improved. But people also told us that timely, skilled and relevant interventions to help improve their quality of life were very important to them.

Most people emphasised the importance of collaboration and partnership working to improve outcomes for deaf people. Effective joint working between services was seen as important to meet people's clinical needs and improve their quality of life and wellbeing.

The importance of communication and relationships with staff was also emphasised. People felt staff need to be more deaf aware, with some easy to implement suggestions around inclusive communication strategies. Other feedback concerned more relational aspects of communication. Parents and guardians identified that when they felt emotionally supported by audiology teams, with appropriate information sharing with other professions and organisations involved in supporting their child, they had more positive experiences in general. Young people valued good communication and relationships, with some also expressing concern about how gaps in these areas impacted on their parents.

Some adults reported a sense of being 'done' and 'ticked off' and even, in some cases, being left for decades. Parental experiences of not being listened to - to a large extent replicated for adults - led to missed opportunities for child development and for adult social inclusion and wellbeing.

It is important to emphasise that although people identified many ways in which they thought Audiology Services could improve, there were also many examples of good practice, and experiences that were highly valued. This tells us that practitioners are at times delivering great person centred and effective practice. They are doing so despite a need for improved staff training and development opportunities and significant resource limitations.

People shared a breadth and depth of experience and valuable perspectives that help us understand the impact of both strengths and gaps in the system and in practice. We can then begin to envisage what works and what needs to become common practice. It is not the role of the reference group to make recommendations – rather to ensure that voices of people who are on the receiving end of Audiology Services are directed into the review. It is essential that those voices continue to shape the next steps and to influence the direction of Audiology Services.

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces, Libraries and Access Panels are also members.

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims. We seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.



ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

References

British Academy of Audiology (2021) Review into NHS Lothian Paediatric Audiology: Audit Report. https://www.baaudiology.org/app/uploads/2021/12/BAA-Audit-Report_NHS-Lothian-Paediatric-Audiology.pdf

Appendix 1.

