

Childhood deafness: whose experience is it anyway!

Anda Bayliss PhD and Molly Dibble Browne PhD, Research and Insights, National Deaf Children's Society
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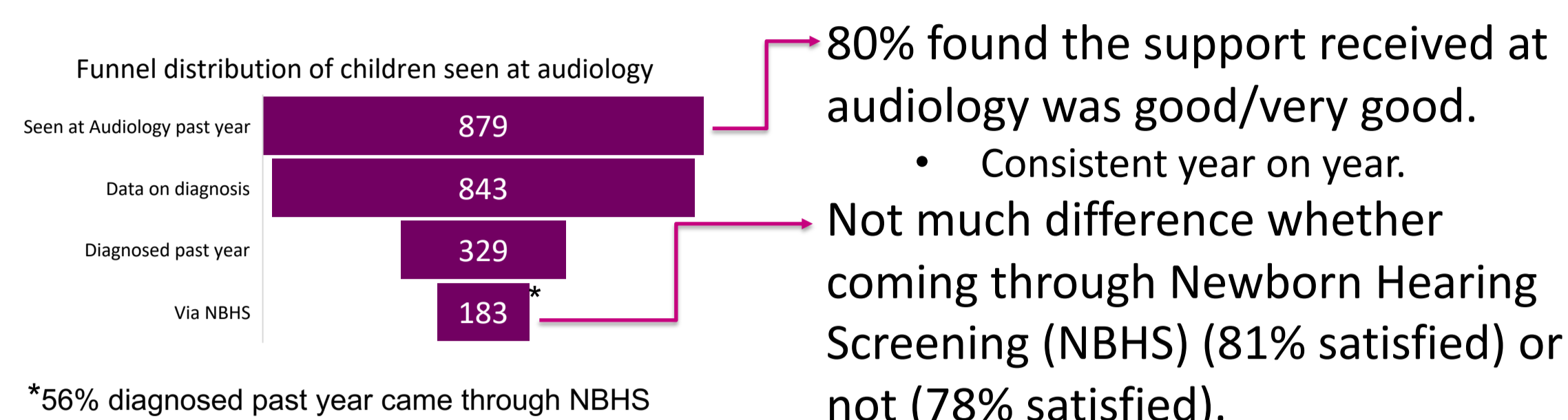


This report brings together three surveys of parents and carers of deaf children, professionals and audiology services, run by the National Deaf Children's Society. We summarise key perspectives and challenges and welcome the opportunity to discuss ways to work collectively for system improvement.

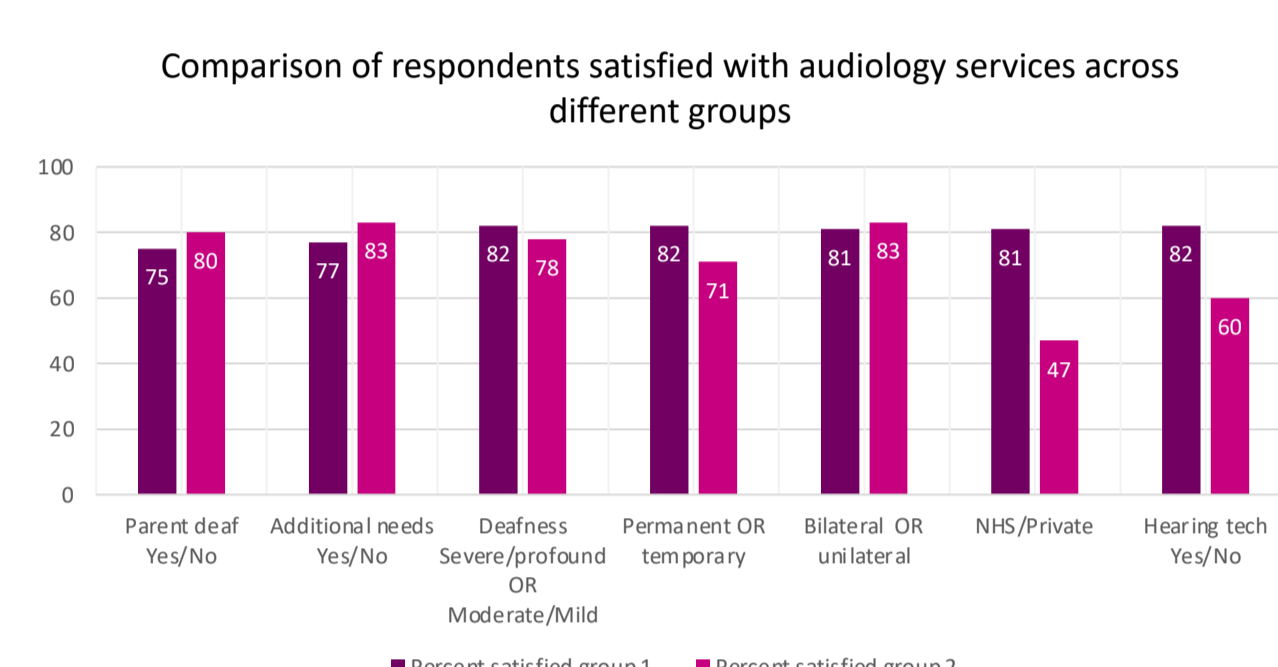
1. Deaf Children Today 2023

Annual survey of parents and carers of deaf children

- UK-wide.
- Running since 2018
- Experiences, reflections, beliefs, attitudes.
- Embedded British Sign Language (BSL).



Experiences of audiology services



Differences according to whether children had **permanent** or **temporary deafness** (82% v 71%), use **hearing technology** (only 60% of non-users found services good) and having used NHS (81%) or private (47%) audiology services.

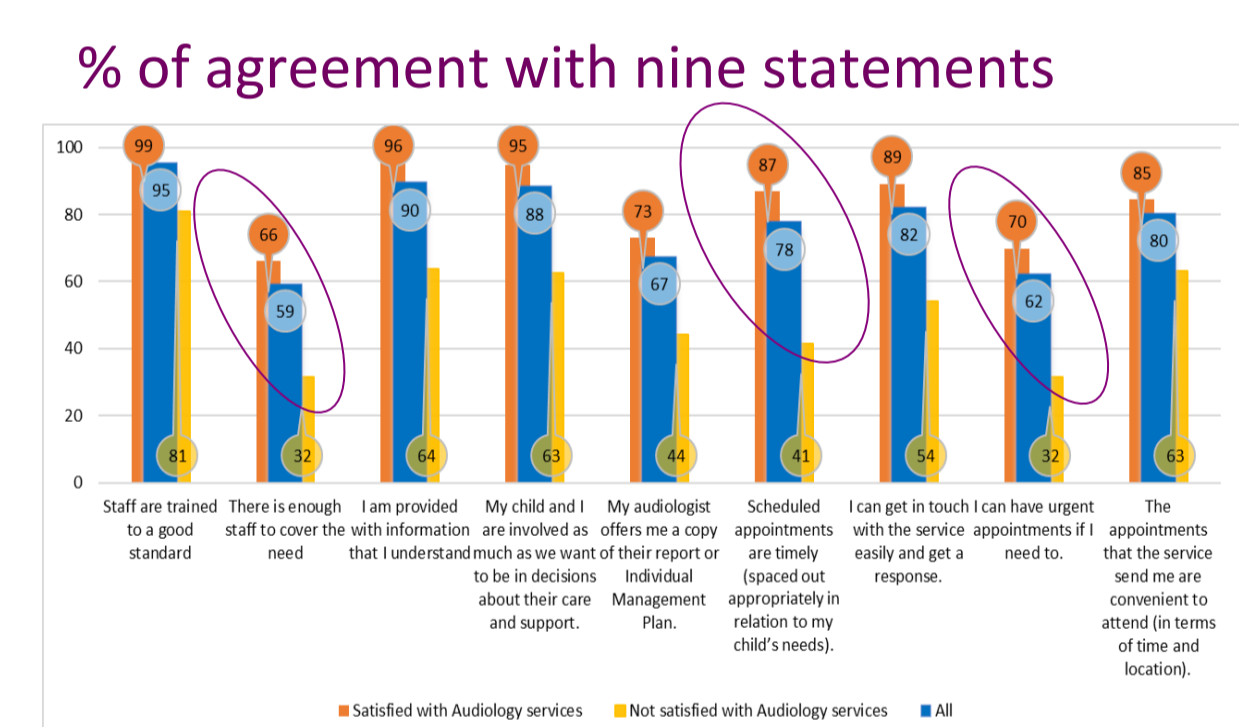
Referrals to audiology outside NBHS

- GP or direct route equally likely.
- Nearly half were satisfied overall.
- The rest reported their concerns not taken seriously or acted upon; took too long to get appointment.



Assessment of service quality

Are parents mindful of aspects of service design and delivery?



- Agreement with the quality statements ranged from 95% to 59%.
- Respondents not satisfied with audiology overall were less likely to agree with the quality statements (average 53%).
- The biggest difference was in 'Scheduled appointments are timely' (87% vs 41%).

- Consistency between the two groups about their agreement with 'Staff are trained to a good standard' (both groups agreed) and 'There is enough staff to cover the need' and 'I can have urgent appointments' (both groups were less likely to agree).

Common challenges

- Identified simultaneously by parents, professionals and services.
- Mostly systemic:
 - ⊗ staffing and training
 - ⊗ general capacity/appointments
 - ⊗ pathways for diagnosis outside NBHS
 - ⊗ type of deafness (temporary, mild)
 - ⊗ non-users of hearing technology.

Recent example of partnership work

- Review of audiology services in Scotland and England.

Continuing opportunities as partners in change

- Campaigning and influencing (policy).
- Capacity building (materials to give to parents, signposting for further support, parents' education).
- Capability building (training and resources).

2. Listen Up 2022

Annual survey of NHS paediatric audiology services

- England FOI spring 2022.
- Running since 2017
- Service delivery information, challenges.
- N=114/124 (82%).

Service provision

- **Caseload:** Number of children with permanent childhood hearing impairment (PCHI) ranged from 21 to 1,124 (average 392).
- **Hearing technology for all** dropped from 92% in 2021 to 75% in 2022.
- **Waiting times:** from newborn screening, 98% reported average ≤ 28 days.
 - ⊗ Outside screening: only 61% reported average waiting ≤ 42 days.
 - ⊗ Review of hearing aids: on average 62.5 days later than agreed.
 - ⊗ No hearing aids users: 84% appointments delayed; >91 days than planned.

Staffing

Drop in staffing levels in the past two years

- 6.5 permanent full time equivalent (FTE) average per service (was 7.7 in 2019).
- No increase in vacant posts (1.4 FTE average, was 1.5 in 2019).
- Drop in temporary posts (1.2 FTE average, was 1.5 in 2019).
- Only 19 services (17%) had trainees in post.
- Difficulties recruiting and retaining staff; some staff wanted to reduce their hours.

Quality assurance

Low take up

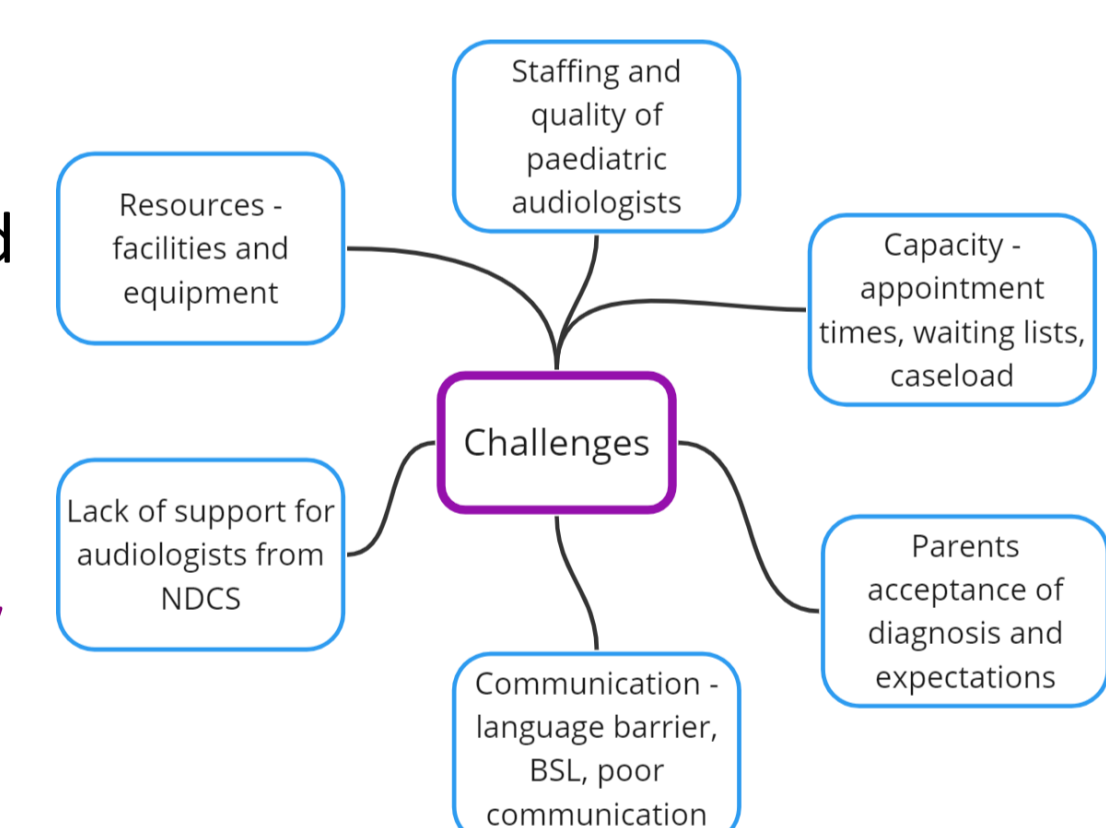
- Only 26 services (23%) currently accredited by Improving Quality in Physiological Services (IQIPs).

3. Professionals questionnaire 2023

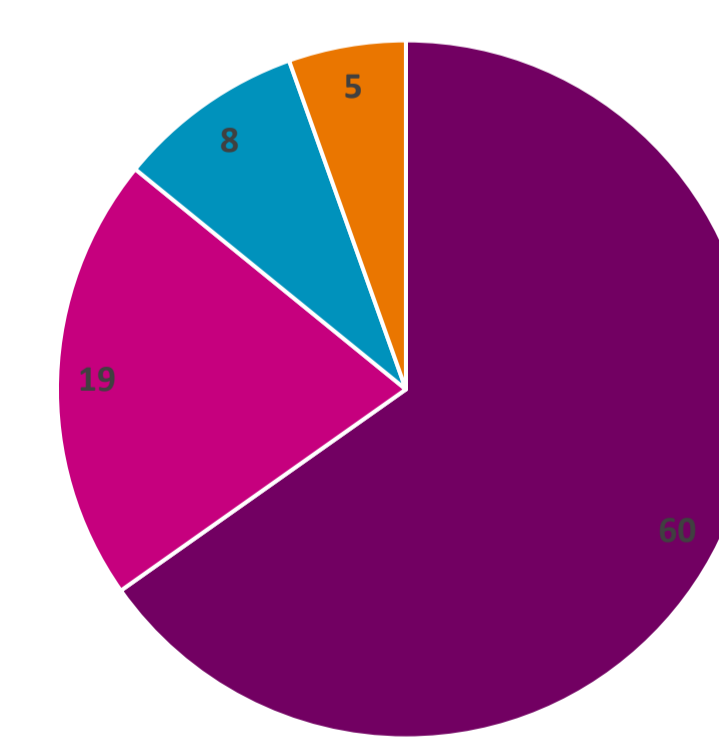
National Deaf Children's Society survey of audiologists

- UK-wide.
- May/June 2023.
- N=97; 35% deaf.
- Working in variety of settings.
- Most working with children aged 0 to 19.

Challenges faced by audiologists



Signposting families to the National Deaf Children's Society



- Many audiologists view the National Deaf Children's Society as a credible source of information and guidance for families.
- Audiologists are using our leaflets to give to families at diagnosis.
- Families are being signposted to the National Deaf Children's Society for further information (via website).
- Audiologists are mindful that they give families a lot of information following diagnosis and do not want to overwhelm them.

Coming up

- Listen Up 2023 out as FOI UK-wide.
- New project activity about improving engagement between audiology and the National Deaf Children's Society.
- Early Years Quality Standards development: set of principles and interdisciplinary practices which clearly identify the best possible family-centred support to the families of deaf babies and children, and what families should expect from the services and organisations who support them