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Assessment of children with complex needs: when can we safely discharge?

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Overview of session

- Why is it important to assess the hearing of children with complex needs?
- When to stop trying for behavioural testing
- Objective tests and limitations
- Informed choice/ shared decision making
- Case examples /discussion

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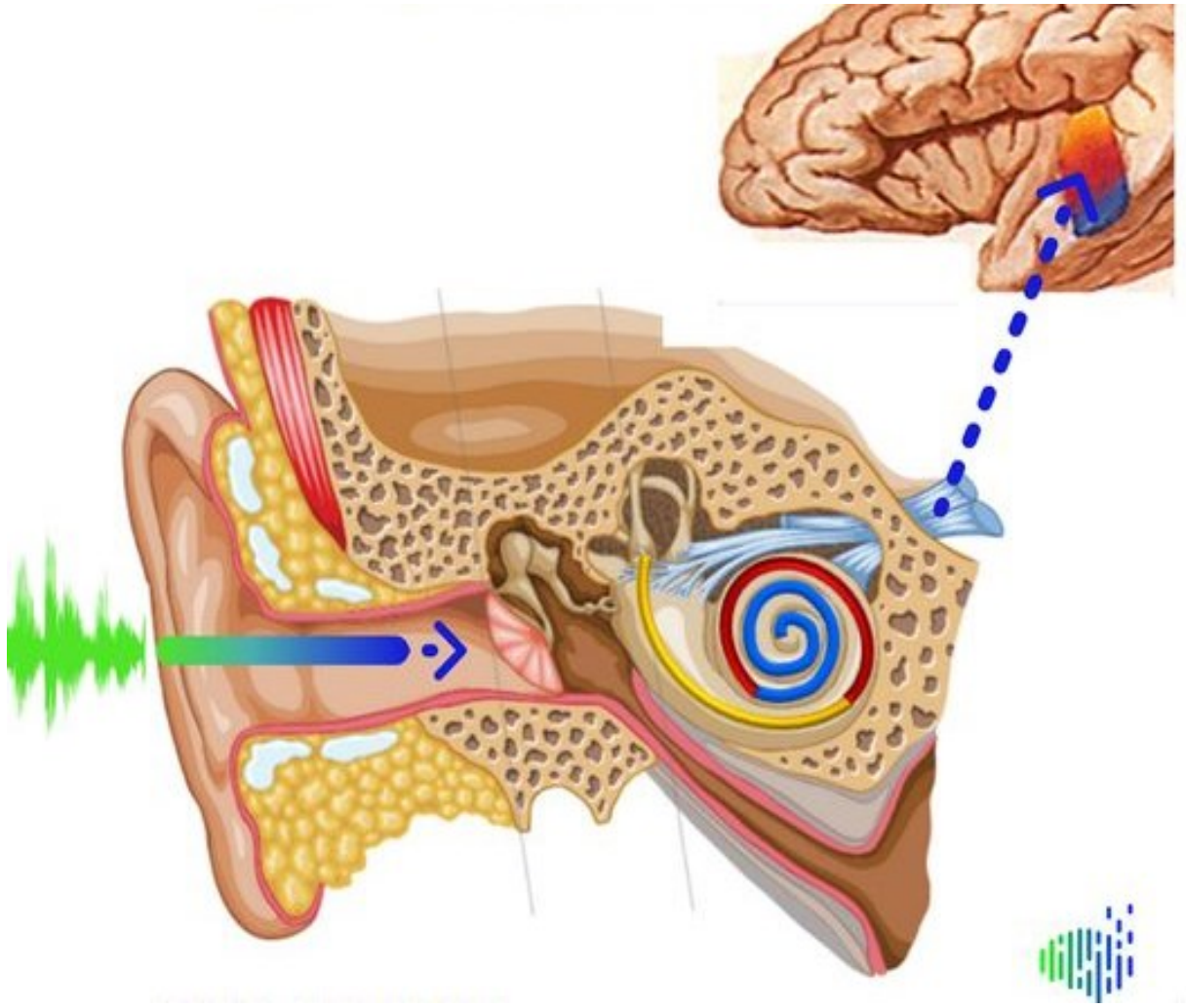
The gateway to the brain



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Essential early opportunities

- Every day counts in the first years of a child's life.
- Hearing function is present even before birth, and neural connections are forming constantly
- Language starts to develop along with higher cognitive functions.
- Children with hearing loss require 3x the exposure to learn new words and concepts (Pittman, 2008)
- Not being given the opportunity to develop language early (spoken or sign) will have lasting impact on a child's achievement and mental wellbeing

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Children with complex needs also need the opportunity to access language

The importance of access to language for ALL children- be INCLUSIVE!

The incidence of deafness amongst individuals with learning disabilities is recognised as being significantly higher than amongst the general population (Neumann et al., 2006; Evenhuis et al., 1997)

According to some estimates, approximately 25% to 42% of children with hearing loss have at least one additional needs and about 20% of these children have two additional needs.

Yet, evidence that hearing loss remains hidden in children with multiple disabilities

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Difficulties reaching audiological uncertainty in children with complex needs

There are some children whose hearing ***cannot*** be assessed through through a standardised approach (Andersson et al, 2000).

Range of reasons which may including the audiologist's lack of experience, the child's abilities, and limitations in the test battery available (Stein et al., 1995)

It "*may be a reflection on and training in working with individuals who have learning disabilities within audiology personnel*" (McCracken et al, 2008)

There is evidence that individuals with learning disabilities characteristically do not have access to audiological care or where it is available, it is less than optimal (Neumann et al., 2006)

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Why not just "*wait and try again when they are a bit older..*"?

- Children need to be constantly exposed to language -consistent exposure the biggest predictor of a good outcome
- Evidence that children with hearing loss do not "catch up" and in children with hearing loss ***and*** complex needs this gap is even wider
- Very important ***not*** to assume that lack of responsiveness to sound/language delay/ lack of communication is due to other issues (eg ASD).
- A study of 20 children with recognised hearing loss and learning disabilities reported that audiological certainty had actually only been established for two individuals

(McCracken 2008)

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Moving on to sedated ABR

Considerations:

- Have there been at least 2 attempts at behavioural testing with experienced testers?
- Is the child able to respond clearly and ***repeatably*** to any sound stimuli?
- Are there any previous definitive test results that contribute to the picture? E.g. OAEs, Acoustic reflexes, speech testing?
- Is there a suspicion of a hearing loss?
- How old is the child now?
- Is the child medically fit for sedation or anaethestic?

Explain to parents <u>why</u> it is important to establish what hearing levels are, so that a joint decision can be made.

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Sedated ABR & ABR under GA

NB. ABR can be attempted without sedation for some children!

- Variable approaches to ABR under sedation/GA and access to this nationally.

  In the NDCS *Listen Up survey* 2022, 58% of services said they had access to sedated ABR, and 82% to ABR under anaesthetic.

- New sedatives such as intranasal Dexmedetomidine present a lower risk option than previously used sedatives, reducing the need for ABRs to be performed under GA

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2021- Sedated ABR at Sheffield Children's

RESULTS	Number of children
unable to obtain results	1
Normal / Discharged	18
Bilateral CHL	2
Fixed CHL / Atresia	1
Bilateral mixed loss	1
Bilateral mild SNHL	1
unilateral HF mixed HL	1
Mild SN unilateral HL	1
Unilateral CHL	1
Unilateral / dead ear	1

32% of the children who had sedated ABR had a hearing loss (n=9)

(Of those, 2 were known to have a HL previously, but we couldn't monitor the HL behaviourally)

The other 7 children would not have been picked up without sedated ABR in a timely manner, as we could not test them behaviourally.

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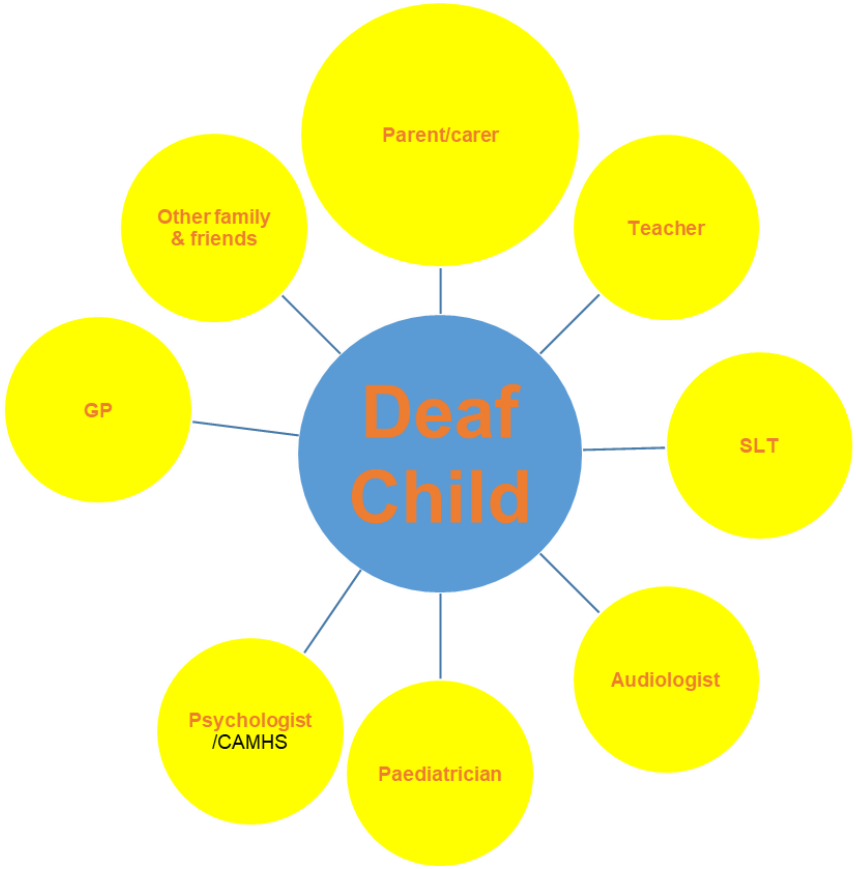
What else can we do? - multi-disciplinary working

Teachers of the Deaf (ToD) can provide valuable support and positively input to the assessment

Along with other professionals and the parents/carers

Reports of behavioural responses?
Questionnaire responses



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Putting it all together- is it safe to discharge?

- It is not ethical to have “lesser” discharge criteria for children with complex needs. All children should be treated equitably

- It is only audiologically “***safe***” to discharge when audiological certainty has been achieved

- Consider all audiological results obtained and reports from the family/ professionals - are they coherent? It is important not to view a lack of lack of congruence between results as the typical result of an individual with learning disabilities (Gravel, 2001)

- ***However…..*** sometimes we are just unable to get to audiological certainty. So when deciding whether to keep testing or discharge, the family and other professionals ***must*** be involved in decision making in the interests of the child. Audiologists need to be clear about what *is* known and what *isn’t,* and the potential impact of an undiagnosed HL on the child

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What is “Informed Choice”?

- Shift from “*medical model*” to shared-decision making

- **Informed Choice** means that families can make knowledgeable decisions, which reflect their own culture, values and views. It is based on access to comprehensive, unbiased and evidence-based information, about the full range of options

- Use phrases such as ‘***in my experience***’ and ‘***everyone is different***’. You can share your experience and what worked for families you have supported but just make sure that it’s clear that other options are available too and different things can work for different people.

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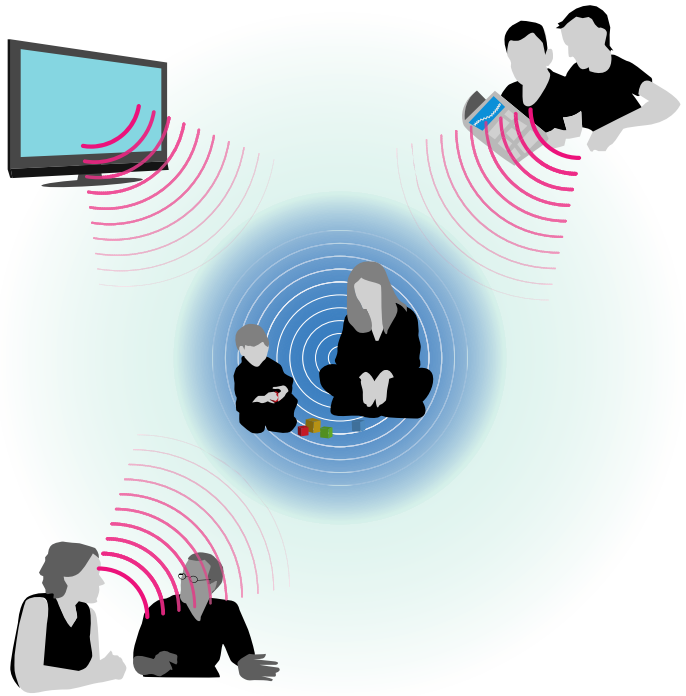
What do parents need to make an informed choice?

- Clear information: no jargon, check they understand, answer questions
- To make an informed choice, options must be explained clearly and with as much information given as possible.
- Families need to know things like the what will happen if their child has a hearing loss e.g. missed opportunities to benefit from incidental learning - important in language and social development.
- Families need to know there are different choices available



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Some examples of good and bad uses of Informed Choice

Hearing aids

- ***Good practice for Informed Choice****: 'I specialise in hearing aids and can tell you about how they may benefit your child. There are other options in addition to hearing aids too which you might want to find out more about to decide what is best for your child.'*
- ***Poor practice for Informed Choice:*** *'Hearing aids are a much better choice than Cochlear Implants because they are less invasive and don't have the same risks as an implant*

Language and communication

- ***Good practice for Informed Choice:*** *'Helping your child improve their speech and listening skills are very important to their language development. Using as many different methods as you can will help them grow and learn. You can introduce some signs and non-verbal communication as well as using speech and sounds to give them a full range options.'*
- ***Poor practice for Informed Choice:*** *'If your child uses speech then you should never use any signs or non-verbal communication with them.'*

Not able to reach audiological certainty for a child with complex needs

- *"TEOAEs were recorded for each ear, so your child's hearing is normal".*

Discuss whether this is good practice for *informed choice*

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Case study: A

- Dob: July 2019
- Born 39 weeks, respiratory distress- tracheostomy at 2 days
- SCBU for several weeks
- NHSP: passed TEOAE Right ear & AABR Left ear only
- ABR at 4kHz “mild SNHL” at 4 months
- Multiple issues: tracheostomy, constant respiratory infections, severe developmental delay, asthma, allergies, chromosome 18 deletion
- Decision made to fit HAs at a few months (just prior to pandemic)
- Wearing aids 5-6 hours a day over lockdown- kept pulling them out but parents used a soft head band to hold in place
- Needs frequent suction of trache.
- Always congested with flat tymps, so likelihood of conductive overlay?
- Not medically appropriate for sedated ABR, and no planned GA (not appropriate to do for ABR)
- Mum reports a difference with hearing aids but cannot test behaviourally, until 2 years. Then still “not ready for VRA” , but some turns on distraction to moderately raised levels

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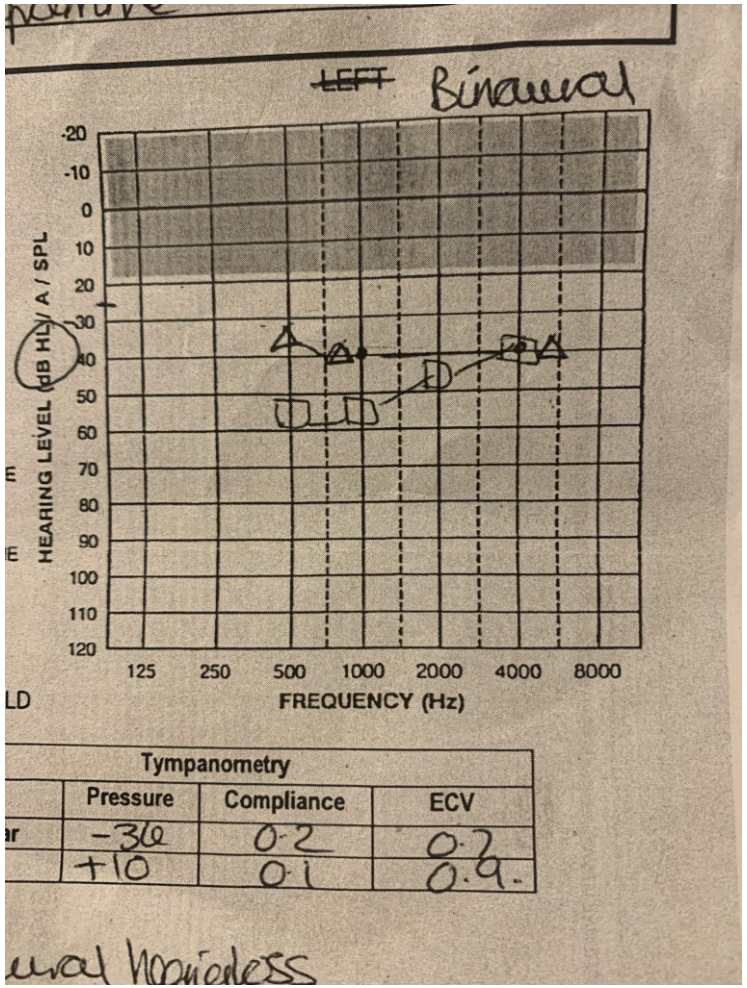
Case study- A



Feb 2022

- Less willing to keep aids in – 3 hours (also pulls trache out up to 9 times/day)
- But normal tymps at last! And a reliable SF VRA
- Very happy & sociable, language developing/ signs and puts her fingers in her trache tube to say words!
- Mum v clear about benefit of HAs and happy with decisions family made

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Conclusion

- Children with complex needs need access to language to reach their full social, educational, and employment potential
- Aim for same audiological certainty as would want for ***all*** children
- Consider whole picture/ congruence between different results and reports of responses before reporting on hearing status
- Decision to discharge *without* audiological uncertainty, or even when there is a known hearing loss or a risk of HL, needs to be an informed joint decision
- Remind parents and other professionals to be vigilant about hearing loss and its impact. Make sure hearing loss doesn't remain invisible amongst other complex needs!

A few useful references

NHS Long Term Plan (2019) Chapter 2: **More NHS action on prevention and health inequalities. Accessed at** NHS Long Term Plan » Stronger NHS action on health inequalities

Dr Paul Johns, Keynote lecture BAA Conference **2022**- available on members area of BAA website

McCracken, W., Ravichandran, A,. Laoide-Kemp, S. (2008) Audiological Certainty in Deaf Children with Learning Disabilities: An Imperative for Inter-agency Working, Deafness & Education International, 10:1, 4-21, DOI: 10.1179/146431508790559841

Godbehere J, Harper S, Loxey T, Kirton C, Verma R, Carr S. (2021). Auditory brainstem response testing using intranasal dexmedetomidine sedation in children: a pilot study. Int J Audiol. 2021 Jul;60(7):549-554. doi: 10.1080/14992027.2020.1852327. Epub 2020 Dec 18. PMID: 33336606.

Young, A., Carr, G., Hunt, R., Skipp, A., Tattersall, H., & Mccracken, W. (2006). Informed Choice, Families and Deaf Children: Professional Handbook. (1 ed.) Department for Education and Skills

Luterman D. (2004) Counseling of families of children with hearing loss and special needs. *Volta Review.* 2004;104(4)[monograph]:215-220.