Childhood Deafness Research Network

Research Priorities in Childhood Deafness and Hearing Loss

What research matters most to people with lived experience and those caring for deaf children

James Lind Alliance
Priority Setting Partnerships

IN PARTNERSHIP WITH
National Deaf Children's Society

Aston University
BIRMINGHAM UK

Lancaster University

MANCHESTER
1824
The University of Manchester

Contents

A note on language:

Throughout this booklet, we use the term 'deaf' to refer to all types of hearing loss from mild to profound. This includes deafness in one ear or temporary hearing loss such as glue ear.

Foreword

Advances in our understanding of childhood deafness including technologies and interventions that support deaf children have helped to ensure deaf children achieve their full potential. This is evidenced by the closing educational attainment gap between deaf children and hearing children over recent years. This is evidenced by the closing educational attainment gap between deaf children and those with normal hearing over recent years. However, deaf children still face unique challenges and there is more to do to make sure deaf children do not face barriers compared to their peers.

Knowing the value of high-quality research on outcomes, we wanted to understand what particular research topics are important to people with experience of childhood deafness, to make sure that we, and other researchers in the future, are addressing the questions that really matter.

The James Lind Alliance (JLA) provides a clear and transparent framework to do this, consulting with a wide range of stakeholders from across the UK in an equitable and collaborative manner. Working with our steering group, comprising young people, parents, and a wide range of clinical and education professionals has been a fantastic experience. We have all learnt so much from each other and we now have a thoroughly considered list of Top 10 research priorities from both our adult and child contributors. We are now going to get to work to try to make sure these important research topics are addressed.

Anisa Visram

Co-Lead, The University of Manchester

Amanda Hall

Co-Lead, Aston University

Why a Priority Setting Partnership on Childhood Deafness and Hearing Loss?

> "We were absolutely thrilled to involve deaf children and young people throughout this project. Their insights were invaluable. From co-designing many elements of the project to helping us shape and rank the top 10 research priorities, their voices guided every step. It was a privilege to work with them, not just for them"

Hannah Stewart
Focus Group Lead,
Lancaster University

Previous successful priority setting partnerships have been undertaken in topics about adult hearing, including:

- Mild-to-moderate hearing loss
- Tinnitus (ringing or other noise in the ears)
- Hyperacusis (increased sensitivity to sound)

These partnerships demonstrated the value of running such an initiative. A better understanding of what research priorities matter to people with real experience gives researchers a hint about what areas they should be focussing on and gives funders extra confidence to decide which areas of research they should be supporting.

We already know that early support is crucial for good outcomes. By talking to children, young people, parents, and professionals about what research they would prioritise we can get a better understanding of how to improve this support and ultimately improve the lives of deaf children.

Including Children in Setting Research Priorities

Since this topic is all about children, we knew from the start that we wanted to make every effort to make sure children's voices were represented and that we used methods that helped children feel comfortable to express themselves.

Children were consulted at all stages of the process. We developed two child-friendly questionnaires and ran several children's workshops to encourage them to share what's important to them. We were also the first James Lind Alliance Priority Setting Partnership to include a children's workshop at the end of the process, giving us a unique 'Top 10' research priorities that mattered to children, as well as the 'Top 10' list compiled by adult stakeholders.

"This project has brought together and empowered deaf children and young people, parents and professionals from across the UK; using their valuable lived experiences to provide them with a strong voice to guide researchers towards addressing what is most needed to improve deaf children's educational, health, social and emotional outcomes."

Juliet Viney
Parent partner, Dorset

"It was important to fund this work because it provides the impetus and direction for future research into childhood hearing loss. This is a critically under-researched topic that is needed if children with hearing loss are to be provided with the best opportunities in life."

Kevin Munro
Researcher with childhood deafness and one of the project's funders, The University of Manchester

See what they said

"We're proud to have supported this research partnership. We believe in a world where anything is possible for deaf children and we're determined to make sure nothing holds them back. This partnership and the opportunity it has given parents and deaf children to guide future research priorities on the issues that matter most for them will be crucial in helping us to achieve this goal. We're excited to see how researchers tackle the issues and questions generated by the top 10 lists."

Ian Noon

Representing the project funder National Deaf Children's Society

"<I learnt> that others feel like me. That I can help other children like me."

Child who took part in the children's workshop

"As a parent of a deaf child, the opportunity to be a steering group member for the JLA PSP into Childhood Deafness and Hearing Loss was a significant opportunity. It enabled me to represent the voice of parents of deaf children throughout the process, from development, engagement stage and outcome. I ensured that the impact on families as a whole was recognised, that all forms of childhood deafness and hearing loss were represented and that inclusive and positive language was used throughout."

Kay Confait

Parent, Bristol

"The adult workshop provided a truly collaborative experience between all (adult) service users of hearing care and education. I'm amazed at how so many original opinions were altered following the contribution from so many different perspectives. It's an experience I'd definitely recommend for all future research."

Ruth Crosby-Stewart

Qualified Teacher of Deaf Children and Young People, Middlesbrough

"I learnt that my voice matters and I can make a difference for me and other deaf children"

Child who took part in the children's workshop

"What he has to say matters; his voice can and will be heard. He can share his opinions with others, learn how to discuss, agree and disagree. Through speaking and educating others, it is going to make a difference."

Parent of a child who took part in the children's workshop

"I have greatly appreciated being involved in this project. It has been a fascinating insight into the way research is designed, the thought that goes into it and the consultation that is involved. Working with a such a wide range of professionals has been wonderful! Hopefully, the project will bring results that can benefit all children with a hearing loss."

Sheila Lundberg

Qualified Teacher of Deaf Children and Young People, Highlands

"I had a really welcoming experience attending the JLA workshop. As an older young person I got to hear what the professionals and parents thought and shared my experiences of being deaf with them. It was lovely to see that parents believed that their children could succeed after meeting me and seeing what I have achieved. Since attending this workshop, I have fostered my passion for deaf advocacy even more and have since joined advisory boards where I can make an impact on the barriers Deaf young people face, for example in education!"

Yazz Hansford

Young person, Dorset

"<I learnt that> lots of people have different experiences with hearing, and that everyone is unique in a good way."

Child who took part in the children's workshop

What we did

Following the established James Lind Alliance process, we used surveys and workshops to consult stakeholders about what research priorities they would like to see addressed, and which of these topics were most important to them.

June 2023

Project registered with the James Lind Alliance

July - November 2023

Preliminary recruitment of partner organisations and steering group members

December 2023

First steering group meeting, comprising deaf young people, parents, health and educational professionals to oversee the whole project.

April – July 2024

First survey live. Children's workshops run in Lancaster and Bristol to gather suggested research questions

August – December 2024

Evidence checking: submitted research questions checked and collated into 'summary questions'

453 parents, professionals, children and young people responded to the surveys

1,252 research questions submitted

Collated into **59** summary questions

February – April 2025

Second survey live:

Respondents chose their own 'Top 10' out of the **59** summary questions

395 parents, professionals, children and young people responded to the survey

The top **21** questions went forward to the final prioritisation workshops

June 2025

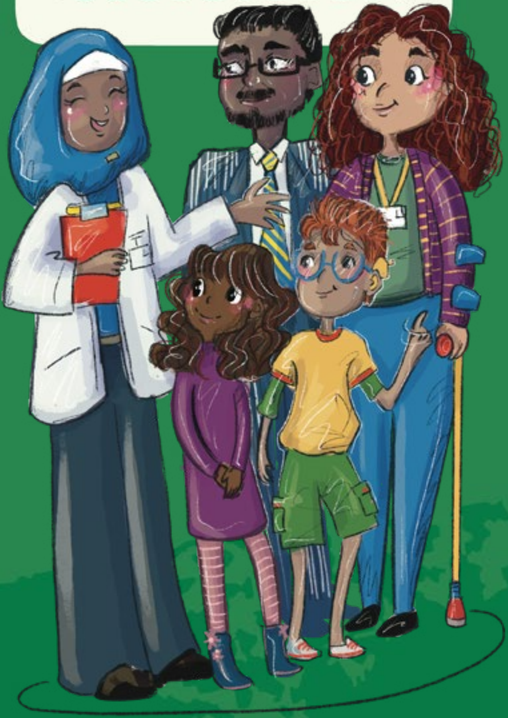
Adult final prioritisation workshop

The face-to-face workshop in Birmingham had **22** participants including young people, parents, and a range of professionals

July 2025

Children's final prioritisation workshop

The face-to-face workshop in London had **10** children aged 7-16 taking part.



Hearing children's voices

All our workshop children and young people were invaluable research assistants! Together we created the top 10 research priorities, but also several tools to be used in our future research network. Our favourite is the collection of beautiful illustrations of deaf children we used in our final workshop.

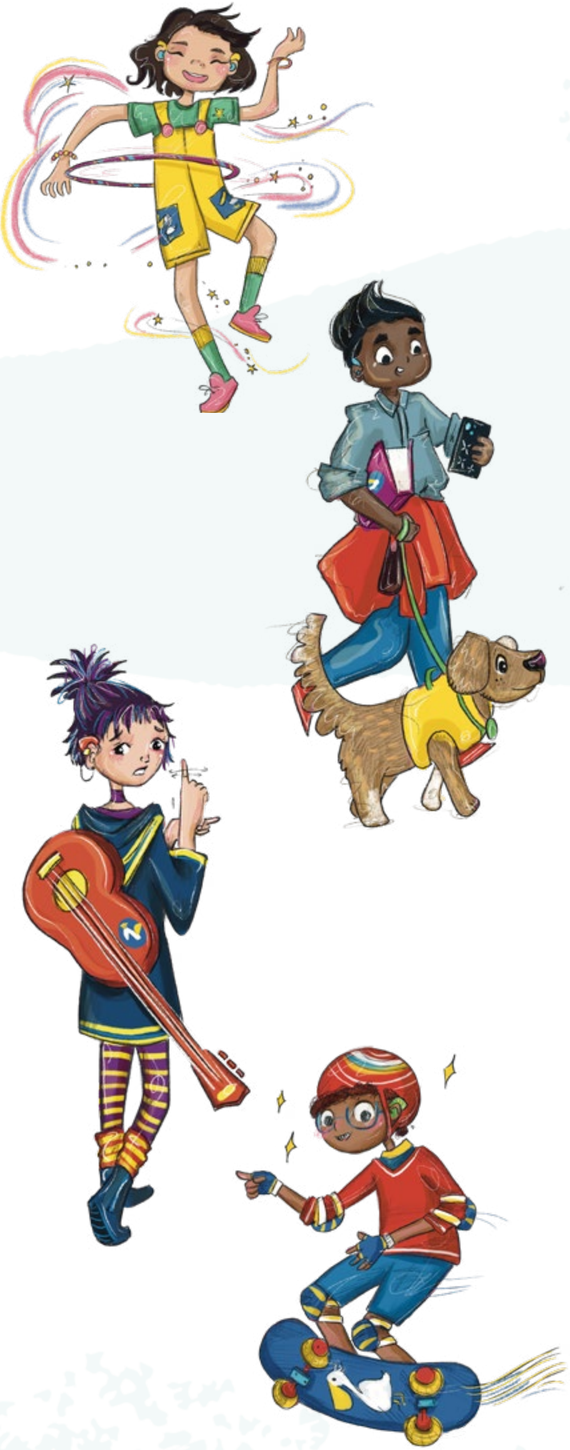
In the very first workshop held in the summer of 2024, we asked the children to draw around each other on giant sheets of paper. They then added stickers and drew and wrote all over their paper people to help introduce themselves to the group. By doing this we started to hear about what it's like growing up deaf in the UK.

In our next series of workshops our paper people shrunk to colourful post-its. This gave us more time to chat and go deeper with our conversations. We covered *many* areas of their lives. From seeing their audiologists to what it's like on the school bus with their friends to playing sport to going to the dentist and the hairdresser.

Working with deaf illustrator Emma Clements, we combined the huge range of hobbies, frustrations and wishes of our workshop children to create our final paper people – the illustrations. These illustrations were the key to the final priority setting workshop, where we were asking the children to think about themselves, *and* other deaf children. This can be very difficult to do, especially for the younger children!

The children and young people in our final children's prioritisation workshop used the illustrations to create characters and invent life stories for them. We loved how intricate the illustrations' new lives were! With this final step, our terrific children and young people ranked our final top 10 – not just for them, but for all deaf children. For today, and for the future.

We would like to say a **HUGE** thank you to all our workshop children, young people and their families. Also, to our team of amazing BSL interpreters, pack of research assistants who organized the workshops, typed up and analysed *hundreds* of pages of transcript; our facilitators Dee and Lesedi; and of course, Emma Clements for her gorgeous illustrations.



Top 10 Research Priorities (according to deaf children)

The children who attended the workshop debated and ranked the 21 most popular questions from the online surveys. To make them easier for children to understand and discuss, the wording of the questions was adapted accordingly. The questions surrounded by a border also appeared in the adult Top 10.

1. Incidental hearing and learning

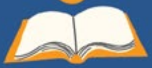
How does it affect deaf children when they miss out on hearing things going on around them? Like during play with their friends.

2. Family relationships

How can families communicate well and have a good relationship with their deaf child?

3. Special educational needs

What kinds of help do deaf children need at school, especially if they have other learning needs too? Are they getting this?



4. Mild and unilateral deafness

If a child is a little bit deaf or deaf in one ear, do they still need help? If so, what works?

5. Language deprivation

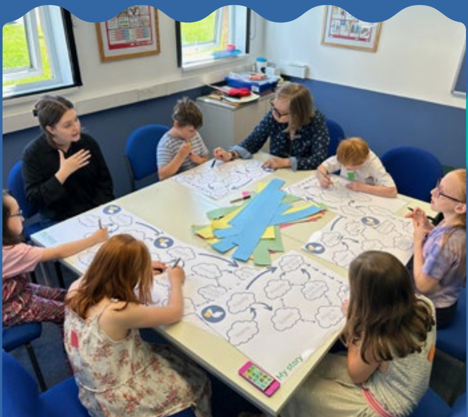
Is it harder for deaf children if they don't learn to communicate early in their lives?

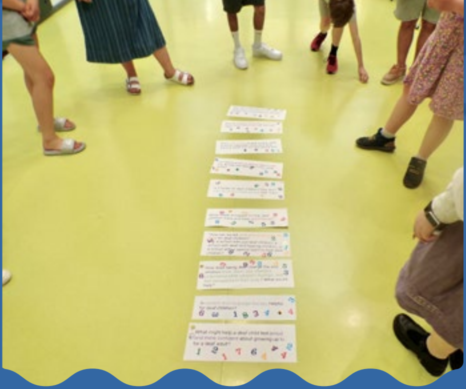
6. Friendships

What needs to happen to help deaf children make and keep good friends?

7. Type of school

How can we tell what sort of schools are best for deaf children? e.g. a school with just deaf children, a school with deaf and hearing children, or a school with a special team to help deaf children?





8. Cognition

How does being deaf change the way children think, learn, pay attention, understand other people's feelings, and feel sensations in their body? What would help?

9. Speech and language therapy

Is speech and language therapy helpful for deaf children?

10. Self-advocacy

What might help a deaf child feel proud and more confident about growing up to be a deaf adult?

Top 10 Research Priorities (according to deaf young people, parents, health and educational professionals)

The adult participants also took part in a fantastic prioritisation workshop held in Birmingham. Everyone was very passionate about sharing their experiences and very respectful and keen to learn from other people. After a day of lively debate, everyone was happy with the final top 10 priorities.

1. Special educational needs

What are the best ways to support the special educational needs of deaf children, including children with multiple special education needs, to improve educational outcomes; what support is being provided currently in different school settings, and how effective is it?

2. Self-advocacy

How can deaf children be empowered to advocate for themselves, understand their deafness, develop confidence and independence, and be prepared for adulthood?

3. Family relationships

How can families be supported to build positive relationships and communicate well with their deaf child, and how does this affect language, cognition and social-emotional development?

4. Mild and unilateral deafness

What is the impact of mild deafness or unilateral deafness on the outcomes of children and young people, and do hearing technology and educational interventions help?

5. Deaf identity

How can deaf children develop a positive Deaf identity/sense of self, feel accepted in both the Deaf and hearing communities, and what is the impact of Deaf culture and role models?

6. Language deprivation

How can language deprivation be identified early, what are its impacts, and what interventions can help?

7. Access to learning BSL

What are the availability, barriers and enablers to learning and using British Sign Language (BSL) for deaf children of all ages, their families and professionals across the UK?

8. Communication choices

How do communication choices, like British Sign Language (BSL), spoken language, or a combination of both, affect deaf children's mental health, education, and well-being, and how can this be communicated to families to ensure informed choice(s)?

9. Glue ear

What are the causes, prevalence and impact of glue ear, and which interventions and clinical pathways are most effective in supporting families and improving outcomes?

10. Speech and language interventions

Which interventions are the most effective in developing speech and/or language skills in deaf children?

Additional research priorities

The workshop participants agreed that all 21 shortlisted questions were important, even if they didn't make the Top 10 list. Here you can see how the adult workshop participants ranked the remaining 11 questions. Child-friendly versions of questions 12, 13, 19, 20 and 21 made it into the children's Top 10.

11.

How can early development of deaf children be supported, and how does early family intervention, type of play, and workforce training affect outcomes?

12.

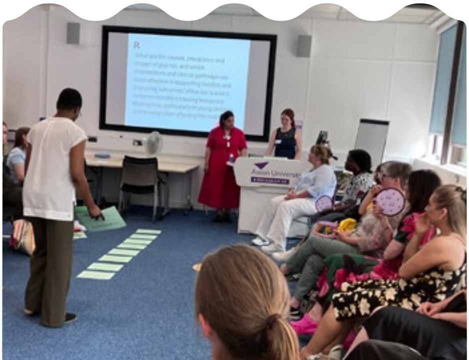
How does childhood deafness affect cognitive functioning and development (such as attention, listening effort, theory of mind, and recognising body sensations) and how can we measure and support this?

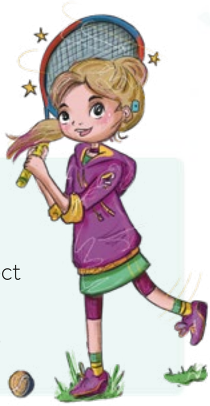
13.

What are the impacts of incidental learning and incidental hearing on deaf children's social, emotional and educational outcomes, including through play?

14.

What is the relationship between childhood deafness and neurodiversity (e.g. autism, Attention-Deficit/Hyperactivity Disorder (ADHD)), and how can we best support children with these combined conditions?





15.

How does deafness affect mental health, and what support is most helpful?

16.

What are the best ways to support deaf children at key transition points throughout their education and into the workplace?

17.

What activities, like sports and music, best support deaf children's development, and how can hearing devices be improved to enable enjoyment of such activities?

18.

How can the school system ensure that the voices of deaf children and their families are heard and acted upon in both mainstream and deaf schools?

19.

What are the measurable outcomes of deaf children educated in different school environments (e.g. schools with or without deaf specialist provision or deaf schools)?

20.

How does deafness affect friendships and how can deaf children be supported to form positive relationships?

21.

How do deaf children benefit from speech and language therapy, and is specialist speech and language therapy better?

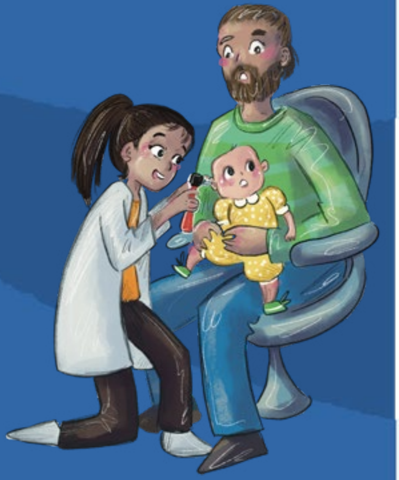
What now?

Now that we know what the research priorities are we have work to do in making sure these priorities get addressed. We will work with researchers, funders, clinicians, educators, families and young people to collaborate on making this work happen.

You too can get involved.

Find out more at:
childdeafnessresearch.co.uk

or contact us at:
childhooddeafness@manchester.ac.uk



Thanks to our amazing team

Our partner organisations

- British Academy of Audiology (BAA)
- British Association of Audiovestibular Physicians (BAAP)
- British Association of Educational Audiologists (BAEA)
- British Association of Teachers of Deaf Children and Young People (BATOD)
- British Society of Audiology (BSA)
- Chloe's and Sophie's Special Ears Fund (CSSEF)
- Ewing Foundation
- Hear Together
- National Sensory Impairment Partnership (NatSIP)
- Royal College of Speech & Language Therapists (RCSLT)

Our management group

- Anisa Visram
- Amanda Hall
- Juliet Viney
- Hannah Stewart
- Jenny Chan

Our steering group

- Lucy Armstrong
- Aliyah Black
- Zain Shukur
- Louise Bowdery
- Kay Confait
- Juliet Viney
- Ruth Crosby-Stewart
- Martina Curtin
- Veronica Kennedy
- Samantha Lear
- Sheila Lundberg
- Martine Monksfield

Our JLA advisor

- Nahid Ahmad

Our research assistants

- Holly Amos
- Lynne Blair
- Maida Bundil
- Rebecca Maguire
- Eeman Patel
- Skye Potts
- El Smith
- Victoria St. Clair
- Daisy Watson

Our children's workshop facilitators

- Dee Hennessy
- Lesedi Vine

Our illustrator

- Emma Clements

Our BSL interpreters

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