Development of parent experience-based information resources for families of children aged 0-4 years with mild and unilateral deafness

Children with mild deafness (in both ears) and unilateral deafness (in one ear) are now being identified early through the NHS Newborn Hearing Screening Programme. However, there are lots of uncertainties about the impact of mild or unilateral deafness on a child's development and little guidance for health professionals to advise families on how to best to support their child.

Aims of the research

The aims of this project were to:

- Understand the challenges faced by parents of young children with mild and unilateral deafness
- Develop resources for parents to address their key concerns and information needs and help them to make decisions with health professionals about their child

What did the study involve?

Seventeen parents of children aged 0-4 years with mild or unilateral deafness were interviewed. Parents were invited to share different aspects of their experiences of having a young child with mild or unilateral deafness, including their diagnosis, decision making, use of hearing devices and technology and any advice they would offer to other parents.

Parents' experiences were compared to help us to develop a theory (idea) to explain the experience of parents making decisions about their child's mild or unilateral deafness.

Key findings

Parents faced a great deal of uncertainty when trying to understand and manage their child's mild or unilateral deafness. Their feelings of uncertainty were influenced by several factors, such as whether they trusted the medical advice they received, felt confident in finding information themselves, or if their child used a hearing device or received educational support.

Parents became attuned to changes in their child's behaviour or speech, which sometimes led them to question the diagnosis or, reinforced their understanding of their child's deafness. While some parents chose to introduce a hearing device early, others preferred to adopt a 'wait and see' approach to see how their child developed. As time went on, parents and

children faced new challenges, such as starting at nursery or experiencing a decline in hearing levels.

Resources for families (podcasts and videos)

The findings from the parent interviews helped to inform the development of podcasts and videos to support other families of children with mild or unilateral deafness.

The Little Ears, Big Challenges podcast series, produced by the University College London, talks to parents about their children and their experiences of mild or unilateral deafness, and young people and adults who have grown up with mild or unilateral deafness.

The National Deaf Children's Society created a series of videos featuring the families of children with unilateral deafness who share their personal stories and experiences.

Future directions for research

Future efforts should be focused on developing clinical guidelines to help health professionals to identify and support children with mild and unilateral deafness.

Better explanations of mild and unilateral deafness are needed, including tools such as hearing simulation to help others understand how these children experience sound.

The time and efforts parents invest in managing their child's deafness needs to be recognised, and their preferences prioritised and valued.

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