

Navigating Language Support for Late Diagnosed Deaf Children

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Summary of MSc Language Education dissertation.

This study explores the personal experiences of families whose children were diagnosed late or misdiagnosed in the NHS Lothian region, uncovering the many difficulties they experienced in accessing language support. Five parents were interviewed who live in 3 of the 6 local authorities affected by the NHS Paediatric Audiology failings (British Academy of Audiology, 2021).

The findings reveal how interactions with various professionals, including audiologists, speech and language therapists (SLTs), teachers of deaf children (ToDs), and British Sign Language (BSL) teachers, influenced these families' efforts to secure support for their children's languages development.

Impact of late diagnosis and professional interactions

1. Audiologists and referral procedures

- **Delayed interventions:** Many audiologists focused primarily on medical aspects, such as fitting hearing aids, and often adopted a 'wait-and-see' approach. This led to delayed language support and increased the risk of language deprivation for children.
- **Lack of comprehensive guidance:** Parents frequently felt lost due to minimal direction from audiologists regarding language support. There was little focus on broader language development needs, leaving families to navigate complex systems late with inadequate support.

And then when we did meet them, there was so much information it was too overwhelming. It was apologies, we diagnosed your child four years too late. But we're going to tell you in 20 minutes. Parent 5 from Council A

- **Emotional insensitivity:** Some audiologists seemed unaware of the emotional struggles parents were going through and often dismissed their concerns. This lack of empathy eroded trust. It also left many parents feeling frustrated and unsupported, making it even more difficult for parents to make well-informed decisions about their child's care.

They just were like, oh, we'll see what happens. Parent 3 from Council B

2. Teachers of deaf children and young people (ToDs) and Speech and Language Therapists (SLTs)

- **Inconsistent experiences:** Families reported varied experiences with ToDs, influenced by local authority practices. Some received timely support, while others

faced delays of over a week for initial contact, adding to stress and uncertainty during a critical period following the late diagnosis.

So, the teacher of the deaf was brilliant, very supportive from straight away. Explained everything to us. What kind of support we're going to get. And how our child is going to be looked after both at the nursery and at home. Parent 2 from Council A

- **Confusion about professional roles:** Parents often found themselves confused by the distinct roles of ToDs and SLTs, particularly when contacted unexpectedly. Misunderstandings about responsibilities, such as a ToD refusing to work with a deaf autistic child, further complicated efforts to obtain language support.

I contacted the teacher of the deaf, but they hung up the phone on me. Then they told me they are a teacher for deaf children and not a teacher for autistic children.
Parent 6 from Council C

- **Resource limitations and delays:** Irregular contact and slow response times from SLTs were common concerns, highlighting the limited resources available for language support services. Some therapists lacked expertise in working with deaf children, focusing primarily on speech development rather than holistic language development.

3. BSL Teachers and language support

- **Valuable, tailored support:** BSL teachers provided essential support by offering flexible and personalised instruction tailored to families' needs. This direct approach helped integrate BSL into daily life, ensuring effective communication within the family.
- **Access challenges:** Despite the value of BSL teachers, some parents faced difficulties in accessing these services due to limited availability or funding. Voluntary organisations offered free online courses, but these were often short-term and less suitable for young children needing hands-on, 3D visual learning.

I think it would have been more beneficial to have some face-to-face tuition. I've purely done it through textbooks and online learning because there are four children in the household all together. And I'm working as well and it's just, it's been too much.
Parent 4 from Council C

4. Language support services

- **Inconsistent service provision:** The quality of deaf education services varied widely across councils, with differing views on sign language and bilingual education.

Yeah, things have changed a lot because she's developed more with her speech and language and having the hearing aids, but also now the world of the language of BSL has been introduced and this is opening up her world more and it's really a huge thing that she is clearly understanding BSL a lot more and it's very clear how easy it is for her. She doesn't have to work hard to listen and that comes with so much emotional stuff for her, and she gets really tired, and with BSL that she doesn't have to work hard.
Parent 5 from Council A

- Some parents felt supported in choosing between spoken language and sign language, while others felt pressured to prioritise speech over BSL.

So, we've often felt like we have to push to decide whether we want Herbert to become verbal or we want him to be a signer. And we very much want him to have access and resources for both so that he can decide.

Parent 3 from Council B

- **Biases and discriminatory practices:** In some council areas, professionals exhibited biases towards oralism, withdrawing sign language support based on the mistaken belief that spoken language should take precedence. This left families without comprehensive support during the critical period of language acquisition after a late start.
- **Impact of funding cuts:** Budget reductions exacerbated disparities in support services, reducing the number of ToDs available and causing instability in service provision. Families sometimes had to work with multiple ToDs due to frequent staff changes, complicating continuity of support.

5. Private language education

- **Supplementing public services:** Many families turned to private services to fill gaps in the limited services provided by local authorities and the Health Board. However, this often created a financial burden, particularly for those seeking specialised instruction, such as private BSL lessons or speech therapy.

So, we were in a good position because we had a private tutor come to the house and teach us real life communication. So, talking about things like health or falling and hurting my knee, you know, things that are relatable and useful for a young child. And so that is what needs to be available for every family. Because when you start your level one course, you're learning really useful language basics. But when you're talking to a four-year-old, you need to be able to have communication about things that they're interested in. And actually, they don't care about the weather and about holidays or shopping, those kinds of things. So, it's really tricky because you want to have the language, but you just don't have the right skill... it's not the right sort of language.

Parent 1 from Council A

- **Financial strain and inequality:** The cost of private tuition highlighted disparities in access to resources, with some families able to afford additional help while others struggled. Parents often spent significant time seeking funding or resources to provide the necessary language support for their children.

6. Suitable language support

- **Challenges in finding appropriate support:** Parents faced significant difficulties in securing language support tailored to their child's daily life, both at home and at school. Online courses were often unsuitable for young children due to the limitations of two-dimensional screens, which cannot capture three-dimensional aspects of sign language, although they offered flexibility for families dealing with childcare or travel issues.

- **Need for specialised BSL education:** The study emphasised the need for more targeted and regular BSL education that aligns with the daily lives of these late diagnosed deaf children. Existing courses were often designed for adult learners conversing with deaf adults and did not address the specific needs of young children.

Noticing that if he can't think of a word, if he's speaking, he will automatically just sign what he's meaning.

Parent 1 from Council A

- **Shortage of comprehensive support:** Despite advancements in hearing technology, there remains a lack of specialised speech and language support for deaf children, forcing many parents to seek private therapists. The absence of well-rounded, interactionist-based therapy that promotes natural language development further highlights the need for improved support systems.

Conclusion

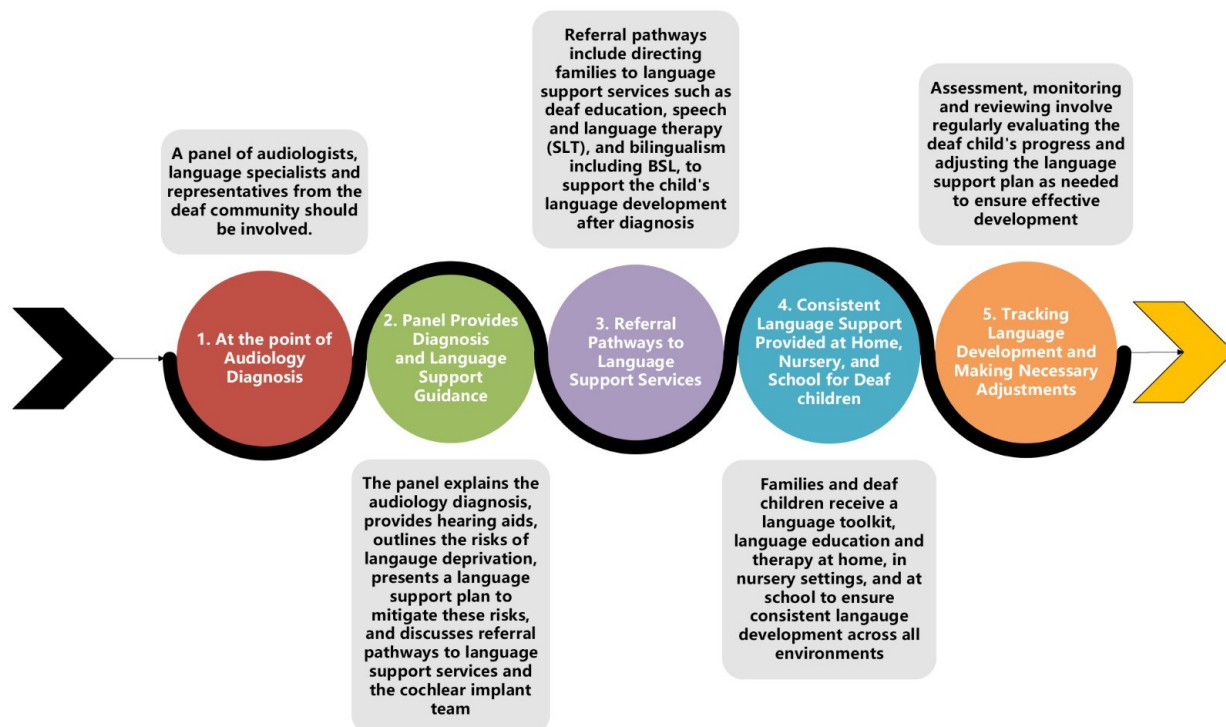
Professionals frequently displayed insensitivity towards parents' emotional experiences following their child's diagnosis, contributing to the stress and confusion families faced. The lack of accessible, clear information about language risks and support options forced many parents to navigate a complex system without proper guidance. Despite recognition of these issues, little progress has been made in improving informed choice and referral processes, leading to continued negative impacts on the cognitive and language development of the deaf children.

Bilingual education for all deaf children in education policy can provide broad protection against language deprivation by integrating BSL teachers and trained deaf mentors into deaf education services, thereby offering tailored support for families, preschools, and schools. Many of these recommendations would also support parents of all deaf children, even those identified as deaf at birth or on time. See the recommendations below.

Recommendations for Language Support Pathway – Table 1

| Step | Recommendations for Language Support Pathway | Details |
|-------------|---|---|
| 1 | At the point of diagnosis | When a child is fitted with hearing aids, a collaborative approach is paramount. A panel of audiologists specialising in language development, Speech and Language Therapists (SLTs), and language specialists from the deaf community should meet with the parents or carers to discuss the child's language support plan. This meeting outlines the roles of key professionals - teachers of deaf children (ToDs), BSL teachers, SLTs, and support staff - and emphasises the importance of bilingual education in BSL and spoken English. They also explain the referral process and connect families with language support services and deaf organisations. |
| 2 | Referral pathways | Within two working days of diagnosis, families should be directed to language support services, including BSL and bilingual education. ToDs and SLTs should receive up-to-date training to reduce bias in language options, adopting a more open-minded approach to multilingualism, and working with BSL teachers to implement a BSL bilingual language policy, ensuring that BSL is integrated into education. |
| 3 | Consistent language support at no cost | Establish bilingual education as the standard in language support services and in preschools and schools. The local authority should provide consistent language support at no cost to families by employing deaf mentors and BSL teachers who offer a language toolkit and education at home, supporting parents, siblings, and the deaf child, as well as in nursery and school settings, including peers. The BSL teachers should ensure that the context of BSL and vocabulary are matched to the appropriate age and stage of the deaf child and provide parents with the relevant contextual BSL needed for everyday life at home and in nursery or school. ToDs should have at least a level 3 qualification in BSL (equivalent to SCQF level 6). BSL teachers, ToDs, and SLTs should focus on interactionist-based and conversational approaches rather than relying on drilling pedagogy. Additionally, they should offer sign language training to teaching and support staff. SLTs should receive updated training to work with deaf children and make regular, consistent visits. |
| 4 | Assessment, monitoring and review | BSL teachers, ToDs, and SLTs should liaise regularly to track the child's language(s) development and ensure they reach the appropriate language milestones. Regular panel review meetings should be established to monitor progress. If the child falls behind, the language education plan should be promptly reviewed and adjusted accordingly to help them achieve the next milestones. |

Figure 1 - This diagram outlines the study's recommendations for language support pathways



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