

20 April 2025

The First 1000 Days: a renewed focus

Dear Health and Social Care Committee,

This is a submission from The British Association for Deaf Children and Young People (BATOD). BATOD is the only professional association for Qualified Teachers of Deaf Children and Young People (QToDs) in the UK. The Association represents the interests of QToDs and the children and young people they teach with a range of governments and other agencies. The Association supports QToDs and organises continued professional development (CPD) courses and national and regional meetings to provide relevant up-to-date information and to disseminate good practice. Strong links are maintained between BATOD and the UK governments, as well as voluntary bodies, especially the National Deaf Children's Society (NDCS), in order to contribute to policy development in this field.

1. What progress has been made since the previous Committee's 2019 *First 1000 days of life* report in terms of outcomes for children and young people in delivering integrated early years through Family Hubs a) In particular what progress has been made on the calls in the Committee's 2019 report for a) Proportionate universalism and b) Greater integration and multi-agency working?

For a deaf child identified through newborn hearing screening, the child and family are introduced to a wide range of professionals from health and education. QToDs, experienced teachers with an additional qualification in childhood deafness, play a key professional role in supporting families to interact confidently and effectively with their deaf baby from the point of identification. The QToDs support the families in using evidenced based strategies to create rich language environments and make informed choices about which language and communication choices are right for them and their deaf child. The multi-agency working with audiology, health visitors, and if involved portage, early years, British Sign Language (BSL) tutor, deaf role models, speech and language therapist is vital as the home learning environment (HLE) is one of the strongest predictors of a child's development in the early years. The HLE influences outcomes at five years, over and above factors such as socio-economic status, maternal education, and family income. The multi-agency team can support families to create a stimulating and rich HLE through everyday routines, appropriate experiences and play which meets the individual needs of their child and their family.

BATOD supports the previous 2019 report recommendation that checks should be conducted by a health visitor. However, BATOD recommends that QToDs are also involved with 2-year-old checks due to the unique nature of the QToD role input from point of identification.

QToDs are crucial in effectively delivering governments' commitments to supporting deaf children and upholding their rights under legislation, policy and the international conventions. This includes ensuring deaf children's rights under the UN Convention on the Rights of the Child including Article 23 (support for disabled children), Article 28 (right to education) and Article 30 (minority language rights, including BSL/ISL) are upheld in the teaching of deaf children. QToDs are also central to ensuring that deaf

children's rights under Article 24 of the UN Convention on the Rights of People with a Disability (UNCRPD), which commits governments to recognise the right of persons with disabilities to education, are realised.

BATOD members report that budget cuts or freezes impact the specialist service's ability to make long-term investment in QToDs required to effectively meet the needs of the low incidence, high need deaf cohort. QToDs are not BSL tutors. There insufficient provision meet demand for sign language for families. The postcode lottery may unfairly impact families from socio-economic deprived areas. Newborn hearing screening (NBHS) is universal in England. The screening enables families early access to aetiology clinics to understand if the cause of deafness can be identified.

The Association for Improvements in the Maternity Services (AIMS) journal (Dec 2024) highlights examples from parents of their experiences of deafness, both as a deaf parent and/or as parent of a deaf baby.

The aetiology for some children means other additional needs may co-occur with the deafness. Common examples include Usher (deaf and vision impairment), congenital cytomegalovirus (cCMV) (autism, cerebral palsy, vestibular dysfunction,) CHARGE (coloboma and cranial nerve anomalies; heart anomalies; atresia of the choanae; delayed development; genital underdevelopment; and ear anomalies)

Congenital CMV is one of the few childhood conditions where early identification allows timely treatment which may prevent progression of sensorineural deafness. NHS England has uniquely delivered an East of England cCMV programme since 2017. The programme is not universal.

<https://eooneonatalpccsicnetwork.nhs.uk/neonatal/downloads/congenital-cytomegalovirus-guideline/>

Deaf children have a right to specialist input from a QToD from identification. Not all deaf children are identified through the NBHS. Sensory Support Services indicate through the Consortium for Research into Deaf Education (CRIDE) 2024 report that "the proportion of referrals through the newborn hearing screening programme has decreased from 18% to 14%". Whilst newborn hearing screening is universal, there is no universal school screening programme. There is a gap in provision for identifying children missed by limitations of the NBHS ie some children with mild levels of deafness, unilateral deafness, progressive deafness, auditory neuropathy spectrum disorder (ANSO), as well as those children who have late onset deafness due to a condition or environmental factor. Therefore, a number of children have unidentified need and therefore unmet need for a significant time during the crucial period for language and communication development.

This can impact on the well-being of families as "For parents whose deaf child is identified later, decision making can also assume some urgency as they perceive the need to 'make up for lost time' in their child's language and communication development. Although the pathway may differ, the professionals involved can play a significant part in informing them of their options to meet their child's communication needs." NDCS 2025

BATOD believes the review of the hearing screening programmes, due in 2024/2025, must occur. Waiting lists for Ear Nose Throat (ENT) for assessment and referral for subsequent audiology and specialist education interventions are unacceptable in some areas. Untreated glue ear is, for some children, resulting in exclusions due to mis-identified behavioural problems, attention deficit hyperactivity

disorder (ADHD) and auditory processing disorders (APD) conditions as well as increased social and emotional needs.

2. What should the Government prioritise in upcoming funding allocations for early years services?

The Government should prioritise funding allocations for early years services for training staff to identify and support deafness. This requires funding the associated assistive technology, acoustic room treatments and specialist external services, including sign language classes, needed by deaf children to access the environment around them. BATOD supported the Assistive Listening Technology Working Group (ALTWG) recommendation for the need for joint funding between health and education for assistive technology in the early years.

In addition, a number of deaf children will have co-occurring needs and disabilities, therefore early years settings and the wider multi-agency team around a deaf child require training to identify and support the needs of each individual child.

3. How effective have Family Hubs and the introduction of integrated care systems been in improving early childhood outcomes?

A deaf professional, ie lived experience perspective, has highlighted the South West England - Early Years Stronger Practice Hub programme, launched in November 2022 and is supported by the Education Endowment Foundation (EEF) and the National Children's Bureau (NCB), as a positive example of hub improving early childhood outcomes.

4. What are the key barriers to delivering high-quality early years services, particularly in Family Hubs and through neonatal and paediatric services, and how can they be addressed?

Key barriers to delivering high-quality early years services, stem from the Health system. The 2024 NDCS (England) Listen up highlighted these issues:

- "There are regional variations in service provision, particularly in the assessment of children with complex needs and in the management of temporary deafness.
- There are regional variations in service provision, particularly in the assessment of children with complex needs and in the management of temporary deafness.
- Long waiting times for routine first assessments present a significant risk of delayed identification of deafness in children who are not identified at the time of the newborn screening.
- Long waiting times for hearing aid reviews are likely to have a significant impact on the quality of care for deaf children.
- Significant waiting times for Ear, Nose and Throat (ENT) services are likely to have a significant impact on the quality of care for children with temporary and mixed deafness."

The Government needs to learn from the Scottish National Audiology review and address the issues found in the small number of English audiology services that were 'failing' to identify deafness in a timely manner.

6. How can the Government most effectively tackle inequalities in access and infant health outcomes for those from underserved groups including those with disabilities, or from ethnic minority or deprived backgrounds?

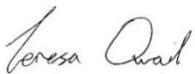
The Government should work with the parent and multi-agency Children Hearing Services Working Group (CHSWG) as local stakeholder voice to feed into the "clear and ambitious plan for their area, which sets how they will improve support for local children, parents and families during the first 1,000 days and how they intend to meet national goals." These working groups can give insights to the problems and potential solutions for the inequalities experienced by ethnic minority, disabled and vulnerable communities.

7. What could the Government learn from examples of best practice that exist in local authorities, NHS Trusts, or internationally?

- There is an international survey currently collecting data about NBHS and school hearing screening that might provide valuable international data about best practice.
- NIHR funded research - Dr Martina Curtin's research is an example of deaf related practice informed with parent partnership <https://fundingawards.nihr.ac.uk/award/NIHR300558>
- Learning from the East of England cCMV project <https://eooneonatalpccsicnetwork.nhs.uk/neonatal/downloads/congenital-cytomegalovirus-guideline/>
- In April 2025, the National Deaf Children's Society (NDCS) published research on how parents of deaf children are supported with choices on language and communication. The research reflects the practice of informed choice and barriers experienced by families and professionals across different sectors. <https://www.ndcs.org.uk/media/9587/investigating-how-families-experience-informed-choice-final-report.pdf>

If you require any other information, please do not hesitate to contact me, the National Executive Officer, on exec@batod.org.uk.

Yours sincerely



Teresa Quail
BATOD National Executive Officer