

Family centred intervention in Wales

Meg Shepherd outlines supporting families through the pathway from screening through to early intervention (the Welsh Perspective)

Welcome to Wales

Newborn Hearing Screening Wales (NBHSW) was introduced in 2003 with completion of roll-out of the programme to all areas in Wales in 2004. There are 50 screeners working in three regions (South-East Wales, Mid and West Wales and North Wales). NBHSW works with the seven Welsh Health Boards, with 16 Audiologists providing assessment and follow-up of babies referred from the screen.

There are roughly 38000 births nationally per year. Approximately 40 deaf babies are identified annually with greater than 40 dB HL bilateral permanent hearing loss.

NBHSW is part of Public Health Wales and is commissioned at a national level. Newborn Hearing Screeners are employed directly by NBHSW.

NBHSW has Service Level Agreements (SLAs) with the Health Boards. Under the SLAs Audiology Departments are funded for diagnostic hearing assessments, hearing-aid fitting and ongoing management. Funding is allocated for the medical leads working with Audiologists to oversee support for the baby and family through the pathway. The SLAs explicitly allocate funding for multi-disciplinary planning and review. Audiologists work together with the medical leads and with colleagues in Education to provide co-ordinated multi-disciplinary input to children and their families.

The relatively small numbers of babies and personnel involved make ensuring equity of provision across the country a feasible proposition.

What works well? An all-Wales approach

NBHSW was established as an all-Wales programme with protocols that apply nationally across the pathway.

Screeners are trained to all-Wales standards based on UK and international best practice to ensure safe, accurate and high quality screening.

All Audiologists take part in peer-review, with every assessment reviewed against UK guidance to provide a uniformly high level of input to babies and their families.

CHSWG's were set up in every Health Board as part of the implementation of the programme.

The SLAs with the Health Boards require key tools for multi-agency planning, coordination and review to be in place and routinely audited:

- Individual Management Plans (IMPs) which outline plans for Audiological management and assessment – agreed with parents and shared with Education and the wider team – must be set up when the baby's deafness is identified and updated at each appointment.

- Multi-Agency Support Plans (MASPs) provide a mechanism for reviewing the baby's and family's needs and for whole-team forward planning in collaboration with the family.
- The first Multi-Agency Planning meeting must be held within three months of diagnosis and then every six months until the child reaches the age of 3 when multi-agency planning transitions to Education.

What works well? Externally accrediting our training to ensure parents receive the best service

The Health Care Support Worker (HCSW) Framework was introduced by the Welsh Government to provide a set of all-Wales Education requirements for all HCSW staff in Agenda for Change Bands 2-4 (Screeners in Wales are employed at Bands 2 and 3). Following a workforce review in 2016, NBHSW has used the Framework to create a career progression pathway for Screeners. This has included the introduction of a new Senior Screener role at a Band 4 and external accreditation of the skills and knowledge required throughout the progression route at Education Levels 2, 3 and 4.

External recognition of underpinning training and experience helps to keep the quality of screening high and ensure appropriate care and support for parents.

What works well? Re-thinking how we monitor screener performance

Screener competency checks have traditionally been undertaken as an annual review via direct observation on the day. Systematic evaluation of the effectiveness of this process and feedback from staff and parents have shown the limitations of summative reviews in showing how the role is carried out on a daily basis. As an alternative we are currently piloting peer-review with a focus on ongoing assessment.

Capturing how well a screener carries out the role on a day-to-day basis will provide a more accurate picture of the service provided to parents and allow for a more responsive approach to improvements where needed.

What works well? Involving parents in Quality-Assuring the Pathway

NBHSW routinely collects data on the performance of the screening and assessment process for reporting at local, national and Welsh-government level.

In addition, NBHSW undertakes twice-yearly parent satisfaction surveys which include feedback on information provision and overall satisfaction with the service. More detailed parental surveys of specific populations are undertaken at regular intervals.

- Parent feedback is incorporated into training and guidance updates.

- Recorded interviews with parents on their experiences of screening, assessment, diagnosis and early support are used with screening and other staff to review and improve provision.
- Parents are also involved in the direct delivery of training to staff to ensure that the parent perspective remains at the heart of what we do.

What works well? Providing multi-disciplinary training for our wider teams

NBHSW commissions annual training for Audiologists and Medical Leads with a focus on multi-disciplinary team working from a range of outside experts.

Training has included the impact of Adverse Childhood Experiences (ACEs) (www.rsph.org.uk/our-work/resources/early-action-together-learning-network.html) on early brain development, attachment and parent-infant interaction and the need for a team approach to address these complex risk factors. Other topics have included Auditory Neuropathy Spectrum Disorder (ANSD) and the importance of an integrated approach to assessment, profiling and management to improve outcomes. Most recently, we have looked at ways of planning for the post-diagnosis journey by building connections between families, clinical and educational professionals to determine common destinations along the route.

What would we like to improve on? Measuring the impact of early identification on communication outcomes

There is ongoing review and analysis at an all-Wales level of the processes which support multi-disciplinary input and follow-up but no collection of data at a corresponding level to measure the impact of early identification on early language and communication.

NBHSW undertook a small-scale study 5 years ago on 63 deaf children identified at birth. This study looked at their expressive vocabulary at 30 months of age and analysed their language scores in relation to level of hearing loss, age at hearing aid fitting, home language, gender and social deprivation (using postcode to allocate children to different quintiles of deprivation).

In the study group language outcomes were found to be influenced by level of hearing loss and age at hearing aid fitting. Interestingly, there was no significant link between social deprivation and language outcomes in the data. As numbers were small, there is insufficient evidence to suggest a protective effect of early intervention.

This was a small-scale study and its focus was on expressive language only.

The database of deaf children maintained by NBHSW and the data on communication outcomes, levels, frequency and type of intervention held by Sensory Support Teams working with 0-3 year olds in Wales represent a rich seam of relatively untapped data. Given the national protocols around assessment and early hearing-aid fitting which introduce a high level of consistency to a number of the factors potentially impacting outcomes, putting these

Health and Education data sources together would provide useful evidence of the effectiveness of different intervention modalities to further support the case for specialist input with deaf children.

What would we like to improve on? Seizing opportunities provided by legislative and policy changes

The Social Services and Well Being (Wales) Act (2014) (socialcare.wales/hub/sswbact) focuses on what needs to be done to improve wellbeing rather than on process measures. It puts the spotlight on service users rather than on the priorities of those delivering the service. From an NBHSW perspective, this provides an opportunity to work with Education to commit to further working with families on the timing and design of early-intervention pathways.

NBHSW sits on the Project Board for the implementation of **The Audiology Framework of Action for Wales (2017-2020): Integrated Framework of Care and Support for People who are D/deaf or living with hearing loss** (gov.wales/sites/default/files/publications/2019-03/integrated-framework-of-care-and-support-for-people-who-are-d-deaf-or-living-with-hearing-loss.pdf).

With a collaborative working brief, the implementation phase provides an opportunity for NBHSW, working with Education, parents, and other statutory and 3rd sector organisations to look at innovative ways of designing and delivering parent information.

SEN reforms in Wales and the phased introduction of the new ALN system in September 2021 (gov.wales/additional-learning-needs-special-educational-needs) provide an opportunity for NBHSW and the Health Boards with which it works to collaborate with Education to further improve integrated pathways of care for deaf children and their families from identification to early support.

Looking forward to the future: What changes would we like to be involved in?

- More joined-up working between Health and Education to allow the impact of early identification to be measured and to inform improvements
- A greater shift towards well-being outcomes for parents and their deaf children rather than process measures as a way of evaluating the effectiveness of provision
- The introduction of longitudinal studies of deaf children joining up early identification, hearing-aid fitting and early intervention data with educational outcomes. ■



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