

Hearing Impairment Network for Children and Young People (HINCYP)

Annual Report 2024/25

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Introduction

The Hearing Impairment Network for Children & Young People (HINCYP) was established in 2019. Its aim is to support services and families to achieve the best possible outcomes for children and young people in Scotland with bilateral severe, or profound hearing loss, through better access to high quality specialist care and support.

HINCYP aims to work through a partnership of patients from 0 to 18 years, their families and friends, health and social care professionals.

Current Position

An Independent Review of Audiology was announced in January 2022 following the publication of an Independent Review into the Paediatric Audiology Service in NHS Lothian. This was carried out by the British Academy of Audiology (BAA) in response to a complaint upheld by the Scottish Public Services Ombudsman.

In March 2022 the Cabinet Secretary for Health and Social Care appointed Professor Jacqueline Taylor to the role of an Independent Chair to provide leadership to the National Audiology Review (NAR) Group. The purpose of the Review Group was to establish the current level of assurance within existing audiology services, to review this within scope of the Review and to make recommendations to improve the assurance of audiology services within NHS Scotland.

In February 2024, Scottish Government accepted in principle the 55 recommendations from the NAR, published in August 2023 and then established a National Implementation Delivery Group (NIDG) to take the recommendations forward. Members of HINCYP have continued engaging with Scottish Government to help define the role that HINCYP has within this framework

Further work to explore the implementation and addressing of the recommendations highlighted in the NAR was completed by Scottish Government in December 2024. All ongoing actions would be transferred to plans with timescales for completion. The three workstreams covered in the report were leadership/governance, quality and education. A communication had been sent to NHS Education for Scotland around the education framework for health care sciences focusing on Audiology (Bands five – nine and then two – four).

Concern, disappointment and frustrations were noted around delayed progression of the review work. Points raised included lack of change/involvement of key colleagues from HINCYP and the amount of responsibility for Heads of Service colleagues progressing work around the recommendations when services were experiencing workforce issues. It was also noted that children and young people were concerned about their care and collaboration with lived experience had not happened.

The review report from the NIDG was currently awaiting final approval prior to publication but was expected to be made available soon.

Due to the NAR, the reduced capacity of HINCYP members while they supported the NAR and for avoidance of duplication of work, HINCYP's workplan for 2024/25 reflected this with many objectives being paused.

Highlights

Network Structure

The network has continued to identify and engage with stakeholders through two steering group meetings in June and February, with a further one planned for May 2025.

Data Subgroup/LRDC

Continuing to improve the quality of data collated that informs the Local Record of Deaf Children (LRDC) report has again been another key focus. The lack of data and accuracy of this data has been a significant concern over recent years.

Through engagement with health board colleagues, HINCYP previously developed a detailed standard operating procedure (SOP) to aid board staff to extract information from their existing patient management system. This process involved a unified single process where data was submitted to a Data Analyst within the Information Management Service for analysing with a view to reducing variation in data collation, extraction and analysis. The network acknowledged that 3 out of 14 health boards did not use this patient management system and would not be able to submit data either at all or in the same format.

Health boards were advised of this new process via the Audiology Heads of Service Group, starting 1 April 2024.

However, over the year concerns were consistently raised around discrepancies in LRDC data reporting in a few Health Board areas. A high-level overview of the 2024/25 Quarter 3 and 4 LRDC data found variation in data reporting due to some data fields being incomplete, inconsistency between boards on data fields being populated and some Boards experiencing technical difficulties. Further work was required to analyse the data as clarification was required in some areas such as double counting of patients, age bandings, reporting consistency etc. It was thought that education around data reporting would help with the inconsistencies, although support had been provided previously.

In a recent steering group meeting, the network decided that despite the challenges in collecting data, it was imperative that some form of data was collected for many reasons. These included, providing evidence that services were under resourced across Scotland, that there was inequity of quality of services across boards and that board governance and safety levels for children and young people with a hearing impairment may be at risk. The consensus of the steering group was that progress had been made in data collection and that extracting high level data would be explored going forward as a way of gathering more useful robust data.

Education

HINCYP had explored the possibility of an in-person education day, however due to uncertainty surrounding the network's future it was decided that this would perhaps be revisited at a later date once a clearer picture of the network's future was known.

British Association of Teachers of Deaf Children and Young People (BATOD) and Scottish Sensory Centre (SSC) were noted to be hosting an online, evening event in March/April 2025 but as the Scottish Government report was awaited, it was felt that HINCYP could not currently commit to any dates

Genetic testing pathway

The application had been submitted by Dr Juan Mora, Consultant in Audiovestibular Medicine, NHS GGC, on behalf of HINCYP via the Scottish Genomic Test Advisory Group (SG-TAG). The aim was for a new genetic protocol for testing babies diagnosed with hearing loss at Newborn Screening, giving children and families in Scotland access to the full gene panel test for hearing loss. The form was now in Form B phase, which was being completed by the NHS Tayside lab. Dr Mora would be notified of the outcome of the submission after full SG-TAG assessment was completed. This testing in Scotland would mean that children and young people across the UK would have access to the same level of testing.

HINCYP Name Change

It was noted that the name of the network should be changed to reflect more positive vocabulary with deafness as advised by BATOD. Deaf, hard of hearing and hearing loss being proposed for use. Colleagues were asked to consider the name change, forward suggestions to nss.hincyp@nhs.scot and this would be progressed in 2025/26.

National Deaf Children’s Society (NDCS)/HINCYP Informed Choice Project

Although most network activity had stalled due to uncertainty about its future, work had continued the NDCS /Gwen Carr work package which had been given valuable participation and support by HINCYP. This work had been completed in September 2024, with the report disseminated in May 2025 to all members of HINCYP and the Scottish Government and other relevant colleagues. The project highlighted good practice in Scotland and some useful points from families for consideration and progression via the HINCYP Quality Improvement Group. Evaluation of the project would be conducted at a future date.

Communication & Engagement Planning

Work around communication and engagement had been paused until a clearer picture HINCYP’s direction was known following the National Audiology and Network Reviews.

Website/Newsletter

The network has continued to monitor content to ensure it is kept updated with relevant and appropriate content for network stakeholders relevant to NNMS website guidance.

The website had 3,356 visitors (18,200 views) to the home page and 11,962 visitors (26,044 views) to the more detailed pages. Analysis of the details below evidences the continued requirement for this resource especially when accessing the Service Map and Professional Resources.

HINCYP stats 01/04/2024 - 31/03/2025		
Content	Visitors	Views
Home	3,356	18,200
Service Map	5,842	12,592
Newsletters	719	1,591
News and Events	161	247
Professional Resources	2,726	5,752
Parents, Children and Young People	975	2,404

About Us	682	1,475
Contact Us	857	1,983

Services Delivery Quality Improvement

Work for the above group had been difficult with many variables in play due to the Audiology and Network Review. Communication was required around these areas before progressing work. This would be addressed at the May 2025 Steering Group meeting as it was hoped that a clearer picture of the network's direction would be known.

Waiting Times

A draft dataset was available for use, but approval was awaited from Scottish Government colleagues for this data collection. Reporting would be clear, simple and completed monthly. If no approval from Scottish Government was obtained, the Steering Group were asked to consider HINCYP progressing this work. Key Performance Indicators were split into Adult and Paediatric.

NDCS Survey Update

The NDCS Listen Up 2024 Report for Scotland had been discussed by the network. The main issues were highlighted in the report, and it linked to recommendations documented in the NAR Report.

Looking forward – 2025/26

The network's priority for 2025/26 will be to continue to support the NAR Implementation group through provision of subject matter expertise (SME). This will include providing paediatric subject matter expertise and clinical leadership.

The other priority will be to look to providing robust high level LRDC data set of children and young people in Scotland.

In light of the ongoing Scottish Government review of national networks, planning has been adapted to focus on core priorities and ensure continuity of essential services. We await further guidance to inform future strategic development.

Finance

The network did not spend any of its allocated £5,000 budget during the reporting period.

Risks & Issues

There is a risk that members of HINCYP will become disengaged due to conflicting resource pressures and the need to avoid duplication of effort while the NAR Implementation Group is agreeing future priorities.