

Minister for Children, Young People and The Promise
Ministear airson Clann, Daoine Òga is An Gealladh
Natalie Don-Innes MSP
Natalie Don-Innes BPA



T: 0300 244 4000
E: scottish.ministers@gov.scot

Jeremy Balfour MSP
The Scottish Parliament
EH99 1SP

Via Email to:
Jeremy.Balfour.msp@parliament.scot

Copied to Lothian List MSPs

24 April 2025

Dear Jeremy, Lothian MSPs,

Late-diagnosed Deaf Children (Lothian)

Thank you for your time on 5 February 2025 to discuss the issues raised by your constituents regarding their access to support following NHS Lothian's Paediatric Audiology Service failings. Please accept our apologies for the delay in writing to you.

As we outlined in the meeting, we were sorry to hear that some of your constituents continue to face difficulties in accessing support. We were grateful for the opportunity to discuss these concerns and, as agreed, we have enclosed the update provided on each of the issues you raised and have included advice on where your constituents can access support.

We hope this is helpful and, as we discussed, we would be happy to keep in contact about any specific constituency issues that remain. Any specific details you can share would enable the Scottish Government to consider where further action may be required.

Yours sincerely,

Natalie Don-Innes MSP
Minister for Children, Young People
and The Promise

Jenni Minto MSP
Minister for Public Health and
Women's Health

Scottish Ministers, special advisers and the Permanent Secretary are covered by the terms of the Lobbying (Scotland) Act 2016. See www.lobbying.scot

St Andrew's House, Regent Road, Edinburgh EH1 3DG
www.gov.scot

INVESTORS IN PEOPLE
We invest in people Silver



UPDATES ON MATTERS RAISED ON 5 FEBRUARY 2025

A PRO-ACTIVE MULTI-AGENCY RESPONSE FOR THE IDENTIFIED CHILDREN

The Scottish Government has had assurance from NHS Lothian that information was widely disseminated through professional staff groups working directly with children and their families, with clear mechanisms for children to be referred to NHS Lothian's Audiology department where there are concerns about their hearing. These professionals include Speech and Language Therapists, Health Visitors, General Practice, Ear Nose and Throat clinicians, Community Paediatricians, CAMHS and teaching staff, with further communication to Local Authority Directors of Education.

In addition, NHS Lothian provided a specific helpline for a 2 year period for anyone with concerns to contact them. Any concerns can now be raised via NHS Lothian's general enquiry line.

There are monthly meetings in place with key partners as part of the Lothian Children's Hearing Services Working Group, which includes wide representation from paediatric audiology staff, teachers of the deaf, speech and language therapists and the National Deaf Children's Society (NDCS) as well as other stakeholders.

NHS Lothian met with the NDCS 8 August 2024 where the ongoing commitment to work collaboratively with NDCS was discussed along with continued support for open dialogue and engagement with parents of children affected. NHS Lothian has asked NDCS to be actively involved in their BSL action plan for Children's Services.

Referrals to the Service

Ministers advised that there are clear processes in place for referrals to NHS Lothian's Paediatric Audiology service.

NHS Lothian has offered assurances to the Scottish Government about the extensive nature of the engagement they have carried out to inform a variety of stakeholders of the Ombudsman's report and subsequent review by the British Academy of Audiology (BAA) and to reach potentially affected families.

Members asked whether the Scottish Government could summarise what is being done differently by NHS Lothian to find solutions to the problems that affected families have faced. The Scottish Government confirmed that following their whole system review, NHS Lothian has substantially reshaped their service to focus on families' needs and the best way to meet them both now and in the future.

AUDIOLOGY SERVICES

One of the recommendations to NHS Lothian of the BAA was to review the structure of the department. NHS Lothian have revised the structure through engagement with their Quality Improvement Team to ensure that the new structure supports the changes and reflects the key governance and professional issues identified through the audit. There were some administrative challenges due to long term sickness, but they have realigned staff, and they have assured that they always had the service covered.

Scottish Ministers, special advisers and the Permanent Secretary are covered by the terms of the Lobbying (Scotland) Act 2016. See www.lobbying.scot



The Scottish Government confirmed that they would publish its response to the NHS National Audiology Review shortly.

MISSED/UNDIAGNOSED CASES

The British Academy of Audiology (BAA) provided advice that not all of the 23,000 children seen during the period 2009-18 should be reviewed. They selected the different cohort of patients and the number of patients to be reviewed in each of the cohort groups, which was based on an increased likelihood of risk of missed hearing loss and cohorts were stratified in this way by the BAA to maximise detection of missed or delayed cases of hearing loss and poor-quality testing.

NHS Lothian have confirmed to the Scottish Government that all children who have been identified through the original audit have had their care clinically reviewed and, where appropriate, have been recalled for review to ensure these children are receiving the right support and treatment.

BAA Audit Missed Children

NHS Lothian have provided assurances to the Scottish Government on the process that they have in place to respond to patients who were not part of the original BAA audits but who, on review, have a pattern of care that reflects the issues highlighted by the BAA. Families are being directly contacted and offered a meeting with the Senior Management Team to discuss the findings and to agree an appropriate care plan, with a focus on ensuring the right support is in place.

Ministers asked Members whether they were aware of any of their constituents having been missed and where this is the case, whether the families themselves or their MSPs could advise the Scottish Government to enable cases to be followed up appropriately.

EDUCATION

Ministers provided the following update:

- The Scottish Government sought reassurance from Lothian area local authorities (City of Edinburgh, East Lothian, West Lothian, Midlothian, and Scottish Borders Councils) in 2024 about the education support they have been putting in place for the children and young people affected. This has confirmed:
 - The Lothian authorities have generally responded well to increases in referrals to their deaf services, particularly in 2022, where referrals peaked.
 - Extra resource in terms of Communication Support Workers, BSL Tutors, and extra Teachers of the Deaf hours have been put in place to support the children and young people affected.
 - There is a newly established deaf education provision in Midlothian at Easthouses Primary School in Dalkeith, which has a deaf base.

This local authority engagement builds upon the previous engagement in 2022 to support inter-agency collaboration on this issue, gather views and concerns regarding the identification of affected children and the provision of support.

BSL Tutoring

Scottish Ministers, special advisers and the Permanent Secretary are covered by the terms of the Lobbying (Scotland) Act 2016. See www.lobbying.scot



Ministers provided the following comments on the issues raised around the access to BSL tutors:

- The Scottish Government recognises the importance of accessing BSL tutoring at an early age and we are sorry that some of your constituents have struggled to access this support. Parents and carers should be able to access BSL tutoring for their children through their education authority where there is an identified need.
- Under the Additional Support for Learning Act 2004, education authorities have duties to identify, provide for and review the additional support needs of their pupils. This includes education support arising from hearing loss.
- If they have not already done so, the Scottish Government continues to advise parents to contact the Enquire service for parents and carers of children with additional support needs for advice on how to access education support. They can contact Enquire's confidential helpline directly on 0345 123 2303. They will be happy to discuss the details of their situation and advise what their rights and options are in more detail. Further information on how to contact them can be found at: [Enquire Helpline - Enquire](#).
- The Scottish Government is exploring ways in which the commitment to provide additional funds for local authorities for free BSL tuition for deaf children from the age of five could be fulfilled, as our aim is to ensure that we are delivering this in a way that will benefit deaf children as much as possible.
- In the BSL National Plan 2023 – 2029, we have a set of actions within Children, Young People and their Families to work with NHS teams and professionals to develop referral pathways for language learning support and ensure there is full understanding of the importance of BSL provision for child and family wellbeing.

Members asked that the Scottish Government consider ways to address delays in accessing BSL tutors, including whether information could be shared by NHS Lothian to enable education authorities to offer BSL tutors more quickly than is currently the case.

Speech and Language Therapy

The Scottish Government is investing in a programme of work to support early intervention in speech, language and communication development for children and their families. This will help to build the confidence and capacity of staff working in early learning and childcare settings and joining up efforts across other key public services, such as health visiting.

Education Scotland's National Early Language and Communication team is working in partnership with local teams and at a national level to support improved outcomes for children in relation to their early language and communication development.

The NHS Scotland speech and language therapist workforce has increased by 6.7% over the last decade, increasing by 65.1 Whole Time Equivalents to 1,035.2 Whole Time Equivalent staff.

CO-ORDINATED SUPPORT PLANS (CSPs)

Ministers were sorry to hear constituents have struggled to access a CSP. Ministers advised that children and young people who meet the criteria for a CSP are legally entitled to one and parents have recourse to the Additional Support Needs Tribunal if one is not provided.

Scottish Ministers, special advisers and the Permanent Secretary are covered by the terms of the Lobbying (Scotland) Act 2016. See www.lobbying.scot



Ministers recognised the concerns that have been raised regarding access to CSPs. Following the review of CSPs, which has already been undertaken, it has been agreed that the statutory guidance on CSPs which forms part of the Additional Support for Learning code of practice will be reviewed and strengthened.

GETTING IT RIGHT FOR EVERY CHILD (GIRFEC)

Ministers confirmed that the GIRFEC Information Sharing Guidance outlines the circumstances in which information can be shared with organisations, the considerations that need to be taken into account to ensure sharing information with another organisation is appropriate and the importance of involving children, young people and families in any decision to share information with other practitioners or professionals.

The Scottish Government continues to work with partners in each local authority and Health Board to understand where there are remaining challenges in the consistent implementation of GIRFEC and what further support the workforce requires to embed a multi-agency GIRFEC approach into everyday practice. The Scottish Government commissioned NHS Education for Scotland to produce two GIRFEC e-learning modules which were published in December 2024, to better support the knowledge and skills of the workforce in GIRFEC implementation across public agencies.

Members advised that constituents have raised specific cases where consent has been given to share information regarding children and young people's paediatric audiology reports, and these were not shared. Ministers encouraged Members to share any details of specific cases to allow appropriate follow up action to be taken.

British Sign Language (BSL)

Ministers confirmed that the BSL National Plan 2023-29 contains 45 cross-government actions aimed at addressing barriers faced by BSL users in their daily lives. The Scottish Government will work with key partners who represent the deaf and deafblind communities in Scotland as part of the Implementation Advisory Group who will provide accountability on the actions in the plan and offer their experience to help strengthen its delivery.

Ministers confirmed that there is an action in the BSL National Plan 2023-29 to capture the learning and share best practice from local activity. The Scottish Government welcomes the Alliance report and its findings. Alongside partners, we are considering the issues raised.

Members stressed the importance of ensuring the BSL National Plan has clear measurable data to allow parliament to scrutinize evidence of improvement, which the Scottish Government will consider.