

Cross Party Group on Deafness

Tuesday 1 November at 6.15pm to 7.40pm

Via Zoom (an online video conferencing platform)

Minutes

Present

MSPs

Convenor – Colin Beattie (Scottish National Party)

Mark Griffin (Labour)

Annabelle Ewing (Scottish National Party)

Karen Adams (Scottish National Party)

Invited guests

Scottish Government – Gillian Heavie

Scottish Government – Susan Shippey

Scottish Government – Lee Sherrin

Scottish Government – Stephanie Yip

The Scottish Sensory Hub, the ALLIANCE – Hazel McFarlane

DataFakts – Andrena McMenemy, Social Researcher

Sense Scotland - Angela Bonomy Representing National Audiology

Review, Reference Group

Kirsten Abioye – Lived Experience Family member

Non-MSP Group Members

Secretariat – Janis McDonald (the ALLIANCE)

Assistant Secretariat – Laura Miller (The ALLIANCE)

Association of Teachers of Lipreading to Adults Scotland (ATLA Scotland) – Jill Bradshaw

British Deaf Association Scotland (BDA Scotland) – Avril Hepner

Deafblind Scotland (DbS) – Isabella Goldie and John Whitfield

Forth Valley Sensory Centre – Jacquie Winning

Hearing Link – Nicholas Orpin

National Deaf Children's Society Scotland (NDCS Scotland) – Lois

Drake and Mark Ballard

Edinburgh University – Rachel O'Neil

North East Sensory Services (NESS) – Graham Findlay

Queen Margaret University (QMU) – Rachel Mapson

Royal National Institute for Deaf People (RNID) – Teri Devine

Scottish Register of Language Professionals with the Deaf Community (SRLPDC) – Leona Glennie
Scottish Sensory Centre – Teresa Quail
Sensory Impaired Support Group Ayrshire (SISG Ayrshire) – Denise McClung
West Scotland Deaf Children’s Society (WSDCS) – Charlene Dolan
Caithness Sensory Services/Hearing and Sight Care – Dierdre Aitken
Gary Quinn – Heriot Watt University
Dumfries and Galloway Hard of Hearing Group – Sian Bertram
Sense Scotland – Joanne O’Donnell

Individuals

Donald Richards

Language Service Professionals

BSL / English Interpreter – Mark Cross
BSL / English Interpreter – Gill Wood
Electronic Notetaker – Gail Richardson
Electronic Notetaker – Melanie Coulter

APOLOGIES

MSPs

Paul O’Kane (Scottish Labour Party)
Douglas Lumsden (Scottish Conservative)

Invited guests

Scottish Government – Maxwell Barber

Non-MSP Group Members

Association of Sign Language Interpreters Scotland (ASLI Scotland) – Tessa Slaughter
Deaf Equality and Accessibility Forum South Lanarkshire (D.E.A.F. South Lanarkshire) – Enrique Canton
Deaf Links – Alana Harper
Deaf Action – Philip Gerrard
Donaldson’s – Kath Cooper
Deaf Links – Alana Harper
NHS Highland Deaf Services – Amanda Wilson
Highland Sensory – Gillian Mitchell
Royal College of Speech and Language Therapists Scotland (RCSLT Scotland) – Glenn Carter

Agenda item 1

Welcome and Introductions.

The Convenor, Colin Beattie MSP, opened the meeting and reminded everyone to say who they were prior to speaking.

Agenda item 2

Attendance and Apologies.

Apologies were noted and listed in this record. It was also noted that Professor Jackie Taylor who is leading the National Audiology Review, was scheduled to speak in September. Angela Bonomy is representing the Audiology Review update and Professor Taylor will join us in December.

Membership

Ideas For Ears. No longer operational and to be removed from the mailing list.

Carol Thomson has retired from BATOD and we thank her for all her contributions to deaf children's education the group over the years.

New Members.

We welcomed Scottish Mental Health Service for Deaf People to the membership. Dr Deborah Innes, briefly introduced herself, is the Psychiatrist running the service which has been in existence some 11 years now.

Agenda item 3

Minutes of last meeting held on Wednesday 12 January 2022 were approved as accurate by the Convenor and unanimously agreed by the group.

There were two matters arising. The first was the definition of Deafblindness. Isabella Goldie from Deafblind Scotland apologised as she was losing her voice. She reminded the group that there is no legal or clinical definition in Scotland. Currently, the World Health Organisation definition is very similar to the Nordic one and we would like to see it adopted. She felt a legal definition would support clinical development.

Actions – the discussion identified three actions:

Creation of a CPGD working group to take forward a definition. Isabella offered to lead.

Isabella offered to compose a short, focussed paper encompassing relevant detail to take to the Scottish Government and to have it formed before the March meeting.

Janis will explore if this work can be incorporated into the next iteration of the See Hear Strategy and identify relevant Scottish Government Officers.

The other matter arising was Educational Attainment for deaf children.

Action

It will be on the agenda for December meeting and Janis will invite a relevant Scottish Government officer to participate.

Agenda item 4

The National Audiology Review first there were remarks from the Convenor. Colin Beattie MSP reminded the group of the origins of the review and noted we had a parent observing the meeting. He noted the connections between the Review and poor attainment. The issues are very interdependent.

Then as a spokesperson for the National Audiology Review, Angela Bonomy spoke. She also apologised for voice difficulties and is no stranger to the group as the CEO of Sense Scotland. She is the current Chair of the HINCYP (Hearing Impaired Network for Children and Young People) and Chair of the Reference group which is one of four sub groups of the National Audiology Review structure. [National Audiology Review Group – gov.scot \(www.gov.scot\)](http://www.gov.scot)

Angela said:

“Rather than assume you all know about the National Audiology Review, I will give a brief introduction to it. Issues arose from an NHS Lothian report regarding diagnoses, mis diagnoses and late diagnoses. In January, the Cabinet Secretary for health and social care announced a review of audiology services for children and adults to ensure public confidence in quality and effectiveness of current service provision.

The Review group will provide recommendations for national plan. Timescale is February 2023 though there is debate in various groups associated with the review about requesting a short extension period, thus not dragging this out. The Review group has a steering group and several organisations or people on this zoom call are represented on that group. Also, there are other subgroups looking at governance and

leadership and quality and improvement and a reference group, which I chair, was established a few months ago. The purpose of the reference group is to support, encourage and facilitate the participation of stakeholders in engaging with the review. It supports the review being supported by lived experience as part of its fact finding into what is going on in audiology and what the recommendations may be.

As a principal of the reference group is to have people who use audiology, not those who deliver. Any audiologists on the group as users. Users: could be people with hearing loss or deafness or family members of people with hearing impairment, medics, GPs, a universal newborn hearing screening manager, a speech and language therapist, Third Sector, education etc. It is not just people who use audiology and go and have hearing tested. It is also the other agencies that link in with audiology and use that too. There have been 2 or 3 meetings airing and sharing and thrashing out what we are and what we are not, what we can and /cannot do.

We have engaged the ALLIANCE as the experts in the field of gathering lived experience and the ALLIANCE are supporting the design of appropriate sets of questions that will be used.

We recognise there is a need for 2 or more sets of questions. As a set of questions will apply to those who use adult audiology services and a set of questions for paediatric audiology services. These questions are not academic research they support prompting people to share what they want from audiology.

The questions give some structure and will be prompts for people to share their experiences of audiology services to date and what they would want from future audiology services. The question sets, once developed, will be shared reference group members and those on the call today for them to share with their constituency group as we want to encourage as wide involvement as resources allow.

The questions will allow a structured approach to any events that people and or organisations wish to hold to gain views from different stakeholders. Event facilitation packs can be sent to organisations to support their consultation events.

The ALLIANCE will, also, distribute the packs and surveys through their large membership There will also be a dedicated e-mail address so that if anyone wants to share a view and not necessarily fill in a questionnaire they can simply e-mail their feedback.

We are trying to make it as easy as we can for people to engage and give us their views. We are trying to help people that hold events and want to encourage members to participate and give them as many tools as we can. Also we are trying ultimately to get that real lived experience in ordinary language and understand what people are telling us about.

One of the concerns levelled at us was surely if you wait till the end of the review and then feed in the findings of the reference group that will be too late. What is happening is at the moment the chairs of subgroups, chair or review group and myself meet monthly. As themes come through, we will be feeding them into the Chair and make sure it resonates with what other subgroups are hearing or thinking or recommendations they make.

This is not an easy process, and we know there will be people who will feel left out or missed but it won't be for the want of trying. We have thought about this from as many different angles as we can. Once the questions are finalised the ALLIANCE will co-design the packs, the surveys and make them well communicated to facilitate, people having support to use the packs and methods available in different formats and accessible languages including BSL.

The questions will be designed around tell us about your experience. Not looking for people to tell us what they believe what solutions or improvements are. It is about asking people to tell us about their experiences so they can look back and think of their most recent experience or experience at the start of their journey and make sure it is conveyed to us.

That is about as much as I have to say just now. I am happy to take questions and comments, as I know this is a very emotive subject. We are trying to be as inclusive or as straightforward as we can be to allow views to be input, feelings expressed and as much as possible taken account of.

Discussion that followed noted Annabelle Ewing MSP praising the speed and quality of what has been achieved to date and supporting the principle of doing a good job rather than a quick one. It seemed a month extension from the original timescale was being sought.

Questions highlighted the need for time in order to be as inclusive as possible, specifically understand issues of single parents of deaf

children, ensure scrutiny and accountability were ongoing, understand links with ancillary services such as speech and language therapy or lip-reading and support education in a more effective way.

Karen Adams MSP specifically mentioned education and issues related to attainment and fulfilling the potential of our deaf children, particularly improving BSL at school.

Action

Professor Taylor should be attending the next meeting to introduce herself and give an update.

New Topic

Dementia

Presentation from Andrena McMenemy, DataFakts.

I am here to speak about findings of recent research about sensory loss in Scotland, the background, why it was necessary, Global research in dual sensory loss and dementia, conclusions and next steps.

It results from a collaboration made up various organisations, Queen Margaret University and DataFakts and is based on the Lancet commission. In 2017, it produced the seminal publication entitled "dementia prevention and care". It identified hearing loss as one key factor in dementia. Age 45-65 identified as one of the main risk factors. They updated their work in 2020, standing by these risk factors, there are 12 now.

The collaboration found funding for a scoping exercise on the prevalence of deafness in Scotland. The work covers the four pillars of deafness. Using population statistics, we modelled prevalence figures across Local Authorities in Scotland. It found there must be better awareness so that health and social care and community support services can meet the needs of those with dual sensory loss. It came as no surprise that when trying to establish prevalence for those with dual sensory loss we found the same lack of data in previous research into hearing loss in dementia.

Dual sensory loss research faces another obstacle, the lack of consensus in the definition. While there is no global consensus, the Nordic definition is widely accepted and recently endorsed by WHO and ICF. It is important to note that to help compensate for combined vision and hearing impairment, tactile sense becomes important. A commonly

adopted definition is loss or function that can't be made up by any of the two senses.

The main themes that come across:

The lack of data and problem with definition.

The problems defining dual sensory loss.

Things can be overlooked in settings because of intellectual differences.

Link between dual sensory loss and dementia.

In 2020 study it was argued that more research was needed to establish connection between dementia and those with dual sensory loss.

Effectiveness of preventative measures.

Studies suggest that further research into the study should be carried out to determine what interventions should be beneficial. Consideration also given to at what age should these be helpful and reduce impact of cognitive impairment and dementia.

The next area that comes up is improved screening and diagnostics.

Dementia can be misdiagnosed or undiagnosed in those with dual sensory loss. People are not always screened for dual sensory loss which leads to under reporting. There is a need to be nuanced so that cases are identified as soon as possible. Dementia diagnostic technology must take into consideration that dual sensory loss may provide skewed results. Research investigating screening has been prominent in the last 5 years at international level. The first international study sought views of health care professionals for care on older people with sensory loss. Findings would inform adaptation of assessments and development of supportive intervention and new provision of services.

The next area is inter-disciplinary health care. In 2021 the management and hearing and vision impairment for people with dementia was published. It was the first set of recommendations to be produced. These recommendations are across disciplines.

Moving on to the dual sensory loss and dementia prevalence estimates and procedure followed, it was evident we needed to build upon learning. Using a combination of databases, the report provided estimates for those with dual sensory loss. You always build upon shoulders of giants and that is where we began our work. The work of Robertson and Emerson started the prevalence estimates for this project. The combination of models made results in the report possible. The bigger the Local Authority the more people are in the cohort and the more people are affected. There are regional variations if you break it

down to a data zone which is the smallest geographical region to analyse and you can get more nuanced data.

Conclusions, in summation,

- it is evident that individuals with sensory loss and dementia and those who care for them need to be able to access several health and social care services.
- As has been argued how can this be done effectively if numbers are not known.
- Modelling has been added to obtain robust estimates for those with dual sensory loss and dementia for all 32 Local Authorities in Scotland and it is hoped this will assist in the future.

In terms of next steps

- this could be done at International and local level.
- In terms of international level to ensure patient centred services to meet the needs of the individual and essential to find consensus on definition and promote data sharing in terms of figures and techniques.
- Norway has a definition of deafblindness and identification teams and healthcare system that recognises deaf blindness. Scotland has not. There is potential for strong cross national comparative study.

It is an exciting time for international collaboration and Scotland is in a good place to inform and be informed by this research.

It is argued that future studies include coordinated data collection tools.

Reports will be circulated with meeting papers.

<https://www.datafakts.com/dual-sensory-loss-and-dementia-in-scotland/>

There was limited time for discussion.

Action

Janis will discuss links to the See Hear Strategy Review and other Scottish Government workstreams and report back to the group on connections and any need for further actions.

AOCB:

The Convenor re-organised the agenda to allow Rachel Mapson to go on to another meeting. She informed the group that the four Edinburgh universities, Queen Margaret University, Heriot Watt and University of Edinburgh and Napier have formalised the collaborative work done for BSL. The group has adopted the name EdSign. It has already been used for a joint lecture series and is familiar

to people. There was a launch event on September 23 timed to coincide with the International Day of Sign languages. Next it is hoped to reinstate the EdSign lecture series put off by the pandemic.

See Hear Strategy

The Scottish Government Support for Sensory Loss and Augmentative and Assistive Communication Team were present, and Susan Shippey noted a brief paper circulated with the agenda. Many organisations have registered interest in being involved with the See Hear Strategy Review. The team is now doing a series of “deep dive” reviews with Sensory Leads on a one to one basis.

Action

There will be more time at the next meeting in December to discuss in detail.

BSL National Plan

Update from Avril Hepner, BDA Scotland

With the BSL National Plan, next year we'll be reviewing the five year plan. There is one year left to be working with education and national authorities giving an opportunity to look at what's worked and liaising with the Scottish Government.

We are also thinking about next year for a national meeting looking at services, mental health, well-being. Covid has been an issue.

We can improve services creating more sign language videos and keeping deaf people in the loop.

We are working in schools looking at the national plan involving young people and ensuring people know their rights. Often, they don't know what's going on. They don't have the information or a voice, know they can ask for interpreters or additional time and have communication needs being met in exams, they are becoming more assertive. We worked with Education Scotland on a new plan, that's the BSL toolkit they put together in collaboration with us (BDA Scotland) and the University of Edinburgh, that's in written English and BSL. It is important to talk about bilingualism, deaf pride, and getting parents involved to develop that area.

We responded to the consultation with the Scottish Government and a national care service. There are issues for older people, those living with dementia, and how sign language is a key part of accessing vital

services. We noticed an absence of information for deaf people living with dementia, care homes have fed back to us how sign language is used.

We are thinking about long and short term goals, working with the University of Manchester where there is a deaf Professor there who has specific knowledge and has collated data and collected rich information that can be used well. It adds value to the BSL national plan.

We have responded to Mental health service consultations where issues have come up that will be part of the national review as well. We are looking to raise the experience that we gained from that, think about setting up training, workshops, supporting counsellors and they can have a local influence.

In Scotland, BSL has gone from strength to strength. The 999 BSL service, that is UK wide and Contact Scotland has been heavily influential for developing access for deaf people. We are also setting up a BSL helpline for people having trouble accessing services, that has been very helpful and we supported them. Housing is a common theme, how to raise a dispute. The NHS have been liaising with us, thinking about the lack of interpreters and helping them book interpreters, that has been hard to procure services.

The Report was noted

Agenda item 5

AOCB

No other business.

Agenda item 6

Date of next meetings

Wednesday 07 December 2022 at 6.00pm

Agenda item 7

Closing remarks

The Convenor wished everyone well and looked forward to progressing work between this and the next meeting.