

Communication for All:
inclusion for people affected by deafness
Impact of Covid-19 Emergency and working towards a better
recovery

**Submission from deafscotland
to the
Equalities and Human Rights Committee COVID-19 Inquiry**

I therefore want to be clear with the Committee that, as a matter of fundamental principle, all lives matter. No-one is somehow of lesser value. Every policy must “see the individual” and must focus on respecting, protecting and fulfilling the rights of everyone, without discrimination.

Shirley-Anne Sommerville MSP, the Cabinet Secretary for Social Security and Older People¹

Overview

deafscotland welcomes this statement from the Minister and appreciates the opportunity to inform the **inquiry** of the **Equality and Human Rights Committee** into the ‘**Impact of the Covid-19 pandemic on equalities and human rights**’. In drafting this submission, we report on deaf people’s experiences across Scotland, the majority feel they don’t have a ‘voice’ because of the communication barriers in place which negatively impact on all aspects of their lives. As their voices and opinions are not heard, they are excluded, and their needs are unmet. This is a human rights issue: communication is a human right and a gateway to the equal enjoyment of all other rights. The remedy is to establish Scotland as an Inclusive Communication Nation – a world first!

In addition to this written submission, deafscotland will furnish the Committee within individual stories of people affected by deafness from across Scotland, and we are happy to provide oral evidence.

Role

deafscotland is Scotland’s national specialist organisation promoting equality, access and citizenship for those affected by deafness. We support the social model of disability, promote a rights - based, person-centred approach and describe a spectrum of deafness with four key pillars which evidence how diverse our population is: Deaf/Deaf Sign Language users (12,500); Deafened (355,000); Deafblind (4,000); and Hard of Hearing (700,000). In total over 1 million people are affected by

¹ Correspondence to the Committee on 15th April 2020

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deafness in Scotland and that is a significant proportion of the population whose needs need to be considered, planned for and met.

We believe people affected by deafness have been particularly badly hit by the actions taken to mitigate Covid-19. While not intentional and some of it was unforeseen, the impact is the same and has happened because inclusive communication is not yet understood as a mainstream activity in Scotland. Our work, research, evidence-led policy, practice and remedies can usefully inform the inquiry remit so that Scotland can recover better from this health emergency.

Question 1 -What groups and individuals are disproportionately impacted by COVID 19?

People affected by deafness.

There are a number of barriers to the equal enjoyment of rights to emergency services and routine actions that negatively impact on the lives of people affected by deafness. Through a human rights lens, we need to examine the impact on Rights Holders and the role in service design and delivery by Duty Bearers. Examples include:

Right Holders

- A person's hearing aid breaks. They find it very hard to get it fixed as they need to find out if their Audiology service is still working, then they have to find out how they get their hearing aid to Audiology safely and securely. Some of this information is available online, but it is not clear and not all deaf people are online at home.
- The majority of people affected by deafness are older. Many older people and especially those on low incomes use their library computers to access online services but this option is not available to them just now. Older people may also be in the vulnerable and shielding groups which stops them posting equipment for repair and accessing other options of assistance.
- The person needs new batteries for their hearing aid(s), but the voluntary service/the libraries and drop-ins where they usually pick them up are no longer available to them. Even if they can access information online, people need to email Audiology to order batteries, which then are posted out. If a person cannot access information online, they are left with an aid they cannot use.

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- The telephone helplines that have been set up to support people through the pandemic are not accessible to those with a hearing loss and most do not offer another method of access apart from an email address which does not work in “real time”. Again this is particularly significant for older adults. SMS works better for most people affected by deafness. Relay UK is less popular and requires improved promotion.
- The use of PPE in pharmacies and other services means that people affected by deafness lose the ability to lip read which supplements what they can hear and/or their understanding of what is being said. This leads to people not having the information they need to make informed choices and give informed consent. It can also lead to misunderstandings.
- Little information is available in BSL although this is improving. What information there is appears to be duplicated by several organisations/bodies which is unhelpful and a waste to the public purse.

Duty Bearers

- NHS Boards have made general statements about service provision during the crisis, but there is little information available to inform people affected by deafness how to access new batteries, hearing aid repairs or adjustments to their hearing aids or for those to be seen as essential in support packs for those vulnerable and shielding. However unintentional, this leaves rights holders feeling anxious and more isolated than what they are usually.
- NHS Boards have sent information about hearing aid batteries, repairs and contacts to deaf organisations and See Hear Leads across Scotland. The majority of people with a hearing loss in Scotland are not in touch with a deaf organisation or any other support organisation and they would not think to contact social work or a Health and Social Care Partnership for information about their hearing aids.
- There does not appear to be anything in the funding agreements between Scottish Government, public funding bodies and other funders about accessibility and inclusion of “helplines”. The majority of telephone helplines in Scotland are not accessible for the majority of people affected by deafness who do not use BSL (12,500 of the population) as they do not provide an alternative

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such as SMS or webchat. Email addresses are often provided but they are not “real time” information services.

- PPE is needed for health and social care providers, as well as some other essential service providers, to ensure staff are kept safe and well. However, buying PPE that covers the lower face means that people with a hearing loss who lip read lose their right to communication, to informed choice and to informed consent.

Conclusion

We believe that people affected by deafness have been particularly badly hit by the actions taken to mitigate COVID-19 and believe the Inquiry needs to focus on what human rights duty bearers could have delivered better; how resources could have more inclusively delivered the agreed outcomes; and what rights need to be better respected, protected and fulfilled.

Some actions of the duty bearers, under the Human Rights Act 1998, have intensified existing barriers, which should have been addressed before and will need to be addressed in the future in order that the right holders, in this case, people affected by deafness and others with communication support needs, have parity of access to the services used by those who are hearing and do not identify with any communication support needs.

The ripple effect of failure to communicate effectively is significant. For example, there are currently approximately 140,000 staff who work across 14 territorial NHS Boards, seven special NHS Boards and one public health body. Their joint partnership working should be a catalyst for better communication but conversely, if they do not have the awareness, training, skills and resources to communicate inclusively, then there is a communication deficit across the integrated services and many service users will continue to suffer from communication poverty.²

During the crisis, we recognise that a number of issues have been due to the lack of deaf awareness in UK Government departments. We will raise these in other appropriate places. We believe the Committee needs to adopt ‘a whole person approach’ and would suggest you

² For more information on communication deficit and poverty see <https://deafscotland.org/support-communication-for-all/>

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undertake a session with the Joint Committee on Human Rights as both Committees are undertaking inquiries on the impact of COVID-19.

deafscotland does not believe the repeated failure to follow the Principles of Inclusive Communication³ - is deliberate, rather it is a list of successive actions and decisions of omission. However, the impact on people affected by deafness including their carers and families is the same. Exclusive communication limits the effectiveness of any government strategy.

We have identified a number of barriers to inclusion and will suggest possible solutions to breaking these barriers in the short term and on the road to recovery. This should lead to better recovery outcomes for Scotland as a whole.

Question 2. What equality and human rights impacts have there been?

We feel a better recovery should “close the gap” between communication barriers, disability and sensory issues and how society views them.

The Scotland Act 1998 and the Human Rights Act 1998 are now over 20 years old and their ambition for Scotland is well rehearsed and echoed in the work of the Committee as well as the First Minister’s Taskforce on Human Rights Leadership. Were human rights to be more evidently mainstreamed in Scotland, some of the problems could have been avoided.

Human Rights engaged by the process of managing the response to the COVID-19 pandemic cut across domestic, European and international ratified, human rights treaties including:

- Article 8 of the European Convention on Human Rights - right to respect for private and family life, home and correspondence.
- Article 13 of the UN Convention on the Rights of the Child - the right to freedom of expression including freedom to seek, receive and impart information and ideas of all kinds, either orally, in

³ See <https://www.gov.scot/publications/principles-inclusive-communication-information-self-assessment-tool-public-authorities/pages/9/>

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writing or in print, in the form of art, or through any other media of the child's choice

- Article 25 of the International Covenant on Civil and Political Rights – the right and the opportunity, without unreasonable restrictions, to take part in the conduct of public affairs.

In addition, there have been aggravating factors, to the inclusive and equal enjoyment of human rights especially to technology. The imbalance in the use of online services and smart technology have amplified problems and limited the impact of chosen approaches in Scotland to deal with COVID-19.

- 12.6 million UK adults lack basic digital skills and 5.3m of have never been online.
- 25% of disabled adults have never used the internet, compared to 10.2% of the entire UK population.
- Disabled adults make up 50% of the 0.9 million lapsed internet users (those who last used the internet over 3 months ago).
- Disabled people are significantly less likely than non-disabled people to have internet access (65% compared to 88%).
- Employers report that 92% of the positions they recruit for require at least basic level IT skills, making it unsurprising that 46.7% of disabled people are employed compared to 80.3% of non-disabled people.
- Disabled people spend on average £550 a month on disability related expenditure although we do not know how this relates to those affected by deafness.
- 23% of disabled people say they are quite or very lonely on a typical day.^{1 4} People with hearing loss can be lonely in a busy room as they cannot participate easily and their voice is not heard.
- Poor or non-existent internet signals magnify the frustration and misery of some people in rural areas of Scotland.

Short term

- A. Lack of inclusive communication and accessible information to make informed choices

⁴ 'Doing Digital Inclusion: disability handbook' published by The Good Things Foundation https://www.goodthingsfoundation.org/sites/default/files/research-publications/disability_handbook-with_links-final.pdf

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The emergency compounded this by the fact that the Scottish Government did not have:

- A clear, co-ordinated communications plan across Inclusive Communication activity: performance varied considerably depending on the knowledge of people working in each directorate and public body; and
- Information was not available in a timely manner that was fully accessible across all communication needs. For example, there has been a BSL/English Interpreter for all the First Minister's broadcasts, but there is no requirement to broadcast with subtitles and the BSL/English Interpreter was not visible on all shots. The film crew initially did not understand the need to keep the Interpreter in frame at all times. Many public bodies have provided information on their position on Covid-19 and what they can and cannot do during the emergency. We feel it is better that information communication is as integrated as possible including BSL, voice and subtitles as a minimum.
- Even though public bodies all have BSL Plans, few have included information in BSL during the pandemic.
- Information also needs to be available in a way that Deafblind people understand, which may mean tactile BSL or Deafblind Manual or Moon or Braille; and again videos with voice over need to be captioned.

B. Lack of planning and co-ordination to reduce existing and additional barriers to communication and reducing exclusion and isolation.

- The emergency compounded this by the fact that the Scottish Government may actually have several communications strategies, but not one overall "Communication For All" strategy that covers all communications from government, public bodies and those Third Sector and Private Sector organisations and services paid from the public purse.
- For example, the Digital Strategy includes mention of the Digital First Standard: which in turn mentions - "Understand user needs.⁵ Research to develop a deep knowledge of who the service users are and what that means for the design of

⁵ See <https://resources.mygov.scot/standards/digital-first/>

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the service.”⁶ And “Create a service that is usable, accessible and intuitive enough that users succeed first time.” On the list of resources for people using this standard, there is a reading list of 52 books that are recommended for ideas on how to understand user needs and make the service user-centred.

- Nowhere is there a list of organisations that can help in this; and there is no Scottish Government guidance on how to involve users, even though the Scottish Government has guidance built up over years, including the National Standards for Community Engagement⁷ and the Principles of Inclusive Communication.

Conclusion

The inability of people affected by deafness across the four key pillars, to influence the way services are designed and funded to cope with COVID-19 emergency is a matter of concern. Had their voices been heard, the same amount of resource would have been spent but the impact would have been more inclusive for society as well as the individuals.

of work done during the pandemic. Also, has there been any significant The ability of the Committee to focus on solutions may first require taking evidence as to how many human rights impact assessments were undertaken by public authorities in the planning, delivery and evaluation and sustained human rights training for staff which they could draw on to inform their decision-making processes? In its deliberations, the Committee needs to be aware that if the Scottish Government and public bodies’ commitment to Inclusive Communication is reliant on the marginalised and excluded having access to technology then success will be limited.

3. What the Scottish Government can change or improve to mitigate against these impacts?

It is not just the Scottish Government that needs to act. Yes, it has a leadership role but in many cases the problems arose because existing commitments, plans and strategies were set aside by publicly funded

⁶ See <https://resources.mygov.scot/criterion/user-centred/>

⁷ See <https://www.scdc.org.uk/what/national-standards>

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services. Awareness and an acceptance of the issues on delivering Inclusive Communication is key to recovering better.

Road to recovery

A. Learning from early issues – inclusive communication and accessible information to make informed choices.

The emergency compounded this by the fact that although the Scottish Government supported the British Sign Language (Scotland) Act 2015 with its requirement of BSL National and Local Plans, it could have gone further with a “BSL+”. BSL users, like the rest of the population, have other communication support and language access needs on occasion. For example, if they are Polish or if they have a stroke or a brain injury that causes aphasia or if someone has a Learning Disability then they may sign but also use other methods of communication. “BSL+” as a concept could have taken an Inclusive Communication approach which would have looked at guidance to making communication more inclusive to everyone **before** the pandemic crisis hit.

As BSL National and Local Plans are being reviewed, a more inclusive approach to communication, language and communication support needs should be considered.

B. Support to enhance communication –

- a. between service providers and service users
- b. between people in lockdown
- c. between colleagues

to ensure health and wellbeing.

Funding to organisations to provide “helplines” should include a section on how that organisation will ensure their service is available to all citizens in Scotland who need that service. If the public purse is being used to fund the work, then the public need access.

State funding for meeting communication support needs should be considered. Not everyone is eligible for Access to Work – volunteers, people on work placements, those who do not fit the criteria; and not everyone who has a communication support need can access Personal Independence Payment/Attendance Allowance. Under the social model of disability it is actually often the environment that creates the difficulty to hear. We know that

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the majority of funders do not ask what a project or organisation's communication strategy is or what is being done to provide access and meet communication support needs.

There also needs to be increased access to

- Resources to support improved acoustics and environments;
- Equipment such as hearing loops and speech to text apps;
- Communication support workers;
- BSL/English Interpreters, Translators, and Electronic Notetakers; and
- Training on how to make better environments; access and use communication support; work with communication and language professionals; for policy makers, finance staff and frontline staff so that policy, budgets and services know the benefit of Inclusive Communication.

A national commitment to 'Inclusive Communication/Communication For All', would in turn ensure a reduction in social isolation for many people in Scotland, not just those with a hearing loss, but those who are older, who have long-term health conditions, have disabilities and who are living in poverty. A reduction in social isolation also helps with the public purse spend on mental health services and social care.

More needs to be done to bring together the unco-ordinated but exemplar pockets of good practice and on effectively using technology and symbols.

Conclusion - human rights impacts

The Human Rights Act 1998 gives domestic effect to most of the Rights contained in the European Convention on Human Rights (ECHR), so we have confined our observations on the impact of exclusive communication and its consequences, on this domestic law.

Article 2: right to life - It means the Government should take appropriate measures to safeguard life by making laws to protect you and, in some

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circumstances, by taking steps to protect you if your life is at risk. Public authorities should also consider your right to life when making decisions that might put you in danger or that affect your life expectancy.

People affected by deafness are not receiving the same messages at the same time as their hearing peers due to the lack of clarity about what it means to provide Inclusive Communication.

People who are Deafblind are particularly at risk as most of the information they need to make informed choices and give informed consent needs to be delivered by another person in the form of tactile BSL or Deafblind Manual or in Moon or Braille. This is so much more difficult with “social distancing” taking place.

ECHR Article 3: Freedom from torture and inhuman or degrading treatment

Audiology has not been identified as an essential service and yet communication and language are human rights. Indeed, sustained sensory deprivation is a form of torture. Daily heightened anxiety compounded by lack of information, use of masks and other barriers, and lack of alternative communication supports and resources increase this deprivation. This in turn means that mental health services will need to look at their own accessibility and inclusiveness once lockdown is over.

ECHR Article 10: Freedom of expression - protects your freedom to receive information from other people but it must be in a format that you can understand, and they must be able to receive and understand your response.

ECHR Article 14: Protection from discrimination

We prefer the term “physical distancing” rather than social distancing. Why? The term social distancing is something that happens between many people affected by deafness and their family/friends as their hearing loss gets greater. It is not something “new” to do during the pandemic.

All distancing measures affect people who use hearing aids as they only work, on average, within a 1 metre radius, of the person who is wearing them. Most people with a hearing aid do not have a personal, portable

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loop system as they are expensive. Buildings, including those that provide health and social care, do not all have hearing loops fitted and working as standard. deafscotland would like to see hearing loops fitted in the same way that accessible toilets and ramps are required.

Mitigating actions such as masks added to everyday stressors making speech muffled and lipreading impossible. Full PPE has made communication difficult for everyone but most people affected by deafness have felt the greatest impact.

Next Steps

deafscotland would like Scottish Government to look at PPE for service providers and how to enable informed choice and informed consent by designing clinically safe but accessible transparent masks; and/or providing and using technology for all service providers to enable the provision of visual real time speech to text communication.

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