

Scottish Council on Deafness Human Rights Paper Equal Opportunities Committee – September 2016

Beyond the BSL Act

Equality, Access and Citizenship for deaf people in Scotland

The Scottish Council on Deafness (SCoD) is the lead for all matters concerning deaf people and their issues in Scotland, representing organisations working with and on behalf of deaf¹ people: Deaf /Sign Language users, Deafblind, Deafened, and Hard of Hearing people. SCoD's membership provides an effective working partnership between the Third, Public and Private Sectors (the Deaf Sector²) and the Scottish Government.

SCoD sees a society where deaf people have equal access, equal rights and equal citizenship with their hearing peers. Deaf people have the right to be included, involved and active citizens in Scotland. SCoD believes this is a human rights issue. While some progress has been made in this regard, there is still a way to go before deaf people's rights to equality of access to goods, services and information in their own language and/or in a manner that they fully understand is the same as their hearing peers. <http://www.scod.org.uk/#> Being involved is the gateway to enjoying and asserting human rights such as Article 10 of the ECHR, which is the right to receive and impart information and then form an opinion.

SCoD uses the social model of disability and recognises that the language/communication support needs of deaf people across the “four pillars of deafness: Deaf/Sign Language users, Deafblind people, Deafened people and Hard of Hearing people” are all different although some of the barriers that people face may be the same.

For example, the hearing world does not always recognise that there are differences in linguistic access depending on the level of deafness the person has and when they lost their hearing. This means that deaf people's access to their rights is breached in different ways.

SCoD supports the work that the Scottish Government Equality Unit has been doing on the UN Convention on the Rights of Persons with Disabilities (UNCRPD). We supported our members to respond to the consultation on the Delivery Plan 2016 to 2020 and eagerly await the final version of the Delivery Plan. The Deaf Sector Partnership³, which is working with the Scottish Government to support the implementation of the BSL (Scotland) Act 2005, translated the summary of the Delivery Plan consultation document into BSL so that the consultation was accessible for people whose first or preferred language is BSL⁴.

The UNCRPD

Article 5 – Equality and non-discrimination: “States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities

¹ The term “deaf” is used to refer to all people with a hearing loss. The term “four pillars of deafness: Deaf/Sign Language users, Deafblind, Deafened and Hard of Hearing people” is used to differentiate between the different levels of deafness and the different language/communication support needs people have.

² The term “Deaf Sector” refers to Public, Third and Private Sector bodies, organisations and businesses that have an interest in and/or support/provide services to deaf people, their families and carers.

³ <http://deafsectorpartnership.net/about-2/>

⁴ <https://www.youtube.com/watch?v=lmimnC35BDw>

equal and effective legal protection against discrimination on all grounds.”⁵ Deaf people continue to be discriminated against due to their lack of hearing in a hearing world. For example, how many public buildings have flashing lights in areas where their fire alarm can be heard but where deaf people may be alone –toilets, stairwells?

Article 8 – Awareness-raising: “States Parties undertake to adopt immediate, effective and appropriate measures:

a) To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities; b) To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life; c) To promote awareness of the capabilities and contributions of persons with disabilities”.⁶

Deafness remains the “hidden” disability. The majority of people in Scotland do not realise how isolating hearing loss can be until it happens to them or a member of their family or in their circle of friends. Phrases such as “deaf as a post”, “deaf and dumb”, “stone deaf” continue to be used in the media on a regular basis, whereas other phrases which are derogatory to other disabled people are frowned upon and action is taken when they are used. There are few famous deaf people and few deaf role models. Access to TV and film is very hit and miss with limited subtitles in English and even less in BSL.

Article 26 – Habilitation and rehabilitation: “States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes.”⁷

This is an area where deaf people are let down and why the See Hear: Joint Sensory Impairment Strategy⁸ is so important, especially for those who lose their hearing after they develop a spoken language. Lip reading courses, in many postcodes, are seen not as rehabilitation, but as an adult education or vocational course.

Context

The Scottish Government and SCoD recognised the need to look at British Sign Language (BSL) and Linguistic Access for deaf people in 2000 when the BSL and Linguistic Access Working Group was set up. This working group with a project manager financed by the Scottish Government Equality Unit put together a report which was published in 2009 –“The Long and Winding Road - A Roadmap to British Sign Language & Linguistic Access in Scotland⁹.” This report was “developed to contribute to the knowledge the Scottish Government requires in making informed

⁵ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-5-equality-and-non-discrimination.html>

⁶ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-8-awareness-raising.html>

⁷ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-26-habilitation-and-rehabilitation.html>

⁸ <http://www.gov.scot/Publications/2014/04/7863>

⁹ <http://www.gov.scot/Publications/2009/07/01102537/0>

judgements about linguistic access when it is formulating, revising, or implementing policy. It is intended to be a resource for government and whilst it is primarily aimed at central government officials, it should also be of use to other bodies, such as local authorities.”¹⁰ At the same time, the Cross Party Group on Deafness was looking at the issues surrounding BSL as a language used by Deaf and Deafblind people and the reasons that so many people in Scotland did not recognise BSL as a language in its own right like Gaelic or English. As many of you will be aware, in 2015, the BSL (Scotland) Act¹¹ became law and the BSL National Advisory Group is working towards the first BSL National Plan¹². This is a first for the UK.

The implementation of the BSL (Scotland) Act through the first BSL National and Local Plans along with their review should lead to better access to information, goods and services for people whose first or preferred language is BSL – Deaf and Deafblind people. It should also make more people aware of deafness in general as more people in public bodies become Deaf, Deafblind and BSL aware. This awareness should help to ensure that the rights of deaf people to upheld and not abused.

Data Collection: How many deaf people are there in Scotland?

The BSL (Scotland) Act will only apply to some deaf people, as according to the 2011 Census¹³,

- 350,492 of the Scottish population aged 3 and over listed deafness or partial hearing loss as a long-term health condition.
- There are 12,533 people who use BSL at home.

SCoD members do not believe the Census gives the true numbers of deaf people in Scotland because of the way that the “long term conditions” question was framed. The phrasing of this question and the explanatory notes need to be revisited if accurate information is to be compiled. SCoD believes that the figure is more likely to be nearer **to one million people** in Scotland who have some level of hearing loss. This figure represents the biggest single minority group under the auspices of the Scottish Parliament.

“There are estimated to be around 850,000 people with hearing loss in Scotland...of those, 70% are over 70. It is projected that this figure will increase by 50% in the next 20 years.” See Hear: A strategic framework for meeting the needs of people with a sensory impairment in Scotland¹⁴.

The fact that there is no hard data on the numbers of deaf people in Scotland and where they live makes it difficult for public bodies to take a proactive stance when looking at language/communication support needs, access to information and access to goods and services. What this means in practice is that deaf people’s rights are breached on a daily basis and for Deaf and Deafblind BSL users, they often do not realise that their rights have been breached as they do not actually know what their rights are. Why? There is no published information about the Human Rights Act 1998

¹⁰ <http://www.gov.scot/Topics/People/Equality/remit/Access-Working-Group>

¹¹ <http://www.parliament.scot/parliamentarybusiness/CurrentCommittees/83760.aspx>

¹² <http://deafsectorpartnership.net/nag/>

¹³ <http://www.scotlandscensus.gov.uk/ods-analyser/jsf/tableView/tableView.xhtml>

¹⁴ <http://www.gov.scot/Resource/0041/00417992.pdf>

in BSL and the only BSL version of the Universal Declaration of Human Rights was created by Signworld as part of a performance art work called *Anniversary – an act of memory* by artist Monica Ross¹⁵.

When deaf people's human rights are breached

The Human Rights Act 1998 gives some domestic effect to the European convention on Human Rights (EHRC). Human rights are not being equally enjoyed in Scotland.

For example,

Article 3 – prohibition of torture, inhuman or degrading treatment or punishment

Article 8 - right to respect for private & family life, home & correspondence

Article 9 - right to respect for freedom of thought, conscience & religion

Jim, an 84 year old man with only one son who has mental health issues, lived in a dementia unit in a care home in Glasgow. He had been there for two years since being found lying in his garden by neighbours who called an ambulance. While in hospital, the medical doctors brought in a psychiatrist to examine him as Jim's answers to questions seemed "off" and he seemed to be confused. The psychiatrist and colleagues decided that Jim had dementia and arranged for him to go into the care home. In the meantime, the Council emptied Jim's house and put some of his belongings in storage. His furniture was recycled. (Article 8)

Jim was losing weight and seemed to be "drawing into himself" more and more. It was listed on his care plan that he was a Catholic (Article 9). A care review was arranged and an independent advocate was brought in to represent Jim's views as he couldn't do this himself. After spending time with Jim, the advocate asked if Jim was deaf. The care home staff told the advocate that no, Jim had come to them without hearing aids and that he doesn't sign. The advocate decided to visit Jim's son for more background and historical information and was told that Jim had worn hearing aids all his adult life after losing most of his hearing in an accident. Jim is vegetarian and a Quaker. The advocate arranged for Jim to go to for a hearing test. Jim was given two new hearing aids. Following another care review, it was decided that the psychiatric service would be brought in to re-assess Jim. (Article 3) After the psychiatric review, Jim was asked if he wanted to move out of the dementia unit. Jim asked to go home and was told that his house had been re-let and all his furniture had been recycled. The rest of his belongings had disappeared from storage. (Article 5). Jim, with legal service support, sued the council for loss of possessions and won his case. He received an apology from the health board for his treatment when he put in a complaint.

Article 3 – prohibition of torture, inhuman or degrading treatment or punishment

Article 6 - right to a fair and public hearing

Article 8 - right to respect for private & family life, home & correspondence

Tom lives in rural Aberdeenshire. He is in his 30s and he has to drive to his work every day. He works in forestry. Tom is hard of hearing and has tinnitus. Tom has been stopped eight times in the last year by the police. Each time he has been

¹⁵ <http://www.youtube.com/actofmemory>

stopped, he has been on his way home from his work and he has taken his hearing aids out to try to cut down the “noise” of his tinnitus.

When the police stop him, he has trouble understanding what the police say to him as he cannot lipread unless the light is good. The police do not believe that he is deaf and do believe that he has been drinking or taking drugs. His car is routinely searched and he is patted down at the roadside. (Articles 3, 8) As this is a rural area, his neighbours often see him with the police. After the last time he was stopped, his girlfriend overheard people in the local shop speaking about Tom and they had come to the conclusion that he is selling illegal drugs and that they should get a petition together to get him out of the village. (Article 6) Tom’s girlfriend contacted a deaf organisation for advice and Tom put in a complaint to the police with a suggestion that the police who work in traffic go on deaf awareness training.

Progress made so far

Scotland is leading the way in the UK in relation to upholding the some rights for deaf people. For example:

- contact-SCOTLAND-BSL ¹⁶ is the first national online BSL/English Interpreter service that covers all public bodies and third sector organisations in Scotland. This allow Deaf and Deafblind BSL users the opportunity to contact so many more public bodies, their departments, and support organisations than they have in the past. (Article 8 of the European Convention on Human Rights¹⁷). Before contactSCOTLAND was available in this way, and since deaf people, have in the main, moved away from using textphones (Minicom ©) to using mobile phones/smart phones, just as the hearing population has, Deaf BSL users had to rely on other people to make calls for them. This could be a family member or carer, but it could be a worker from a deaf or other support organisation. This “paternalistic service” meant that, in many cases, the Deaf/Deafblind person’s “right to respect for his private and family life, his home and his correspondence” was breached on a regular basis. Emergency contact: – contactSCOTLAND cannot be used for emergency contact as it is not a 24 hour service, i.e 999 calls. Therefore emergency calls are currently ourwith the scope. There are also some technical compatibility issues. The calls to 101 number have steadily increased and that is expected to continue.
- The See Hear: Joint Sensory Impairment Strategy¹⁸ has been in place since 2014. This strategy has seen a more uniform access to specialist services across Scotland.
- In the last session of Parliament, the Education and Culture Committee held a short inquiry to consider how the attainment levels of school pupils with a hearing and/or a visual impairment¹⁹ can be improved. The Committee recognised that children with a sensory impairment may have other disabilities, which may have a significant effect on education and can require complex additional support. Therefore, the Committee’s inquiry focussed solely on children with a sensory impairment and no other disabilities. (Article

¹⁶ <http://contactscotland-bsl.org/>

¹⁷ http://www.echr.coe.int/Documents/Convention_ENG.pdf

¹⁸ <http://www.gov.scot/Resource/0044/00448444.pdf>

¹⁹ <http://www.parliament.scot/parliamentarybusiness/CurrentCommittees/87932.aspx>

2 of the UNCRC²⁰). The report stated that “on average, school leavers with a visual or hearing impairment achieve fewer qualifications at school than those who do not have any additional support needs.²¹”

The majority of deaf children receive a mainstream education with input from a teacher of the deaf.

“There is a national shortage and aging profile of qualified Teachers of the Deaf... These teachers have a deep knowledge and understanding of a child or young person’s level of deafness and the implications for their social and emotional wellbeing and educational needs. They provide vital support to children and families from diagnosis to school leaving age and assist parents to manage equipment and develop good communication skills with their children from the earliest stages. In order to raise attainment we must increase the number of qualified staff in all areas of Scotland to ensure equity for deaf children and young people across the country.” BATOD’s response to the call for evidence.²²

If the Education and Culture Committee had used the context of the UN Convention of the Rights on the Child and the UN Convention on the Rights of Persons with Disabilities to look at the attainment of deaf children then the resulting report could have been richer and more relevant as a result.

- The Scottish Legal Aid Board (SLAB)²³ is currently carrying out a piece of research exploring access to civil legal services for Deaf, Hard of Hearing, Deafened and Deafblind people. The findings from this research will be used to help improve access to civil legal services for people with hearing loss. The Crown Office and Procurators Fiscal has a working group looking at how the Scottish Court system could use technology so that deaf people can do jury service. (Article 6)
- NHS Greater Glasgow and Clyde and NHS Lanarkshire have actively involved deaf people in the development of their policies and services. When NHS GGC were planning and developing the new Southern General hospital (now the Queen Elizabeth University Hospital), the “Better Access to Health (BATH)” team asked SCoD to find them two deaf people to sit on their team. In the end, the BATH team had 3 deaf people – one person who is Deafened, a Deaf BSL user and a Deafblind person. NHS Lanarkshire has a focus group of deaf people who meet regularly with the Equality and Diversity Manager to look at service development. Both Forth Valley and Tayside NHS have made good progress recently. (Article 14)

What else needs to be done?

²⁰ States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status. <http://www.ohchr.org/en/professionalinterest/pages/crc.aspx>

²¹ <http://www.parliament.scot/parliamentarybusiness/CurrentCommittees/92452.aspx#top>

²² http://www.parliament.scot/S4_EducationandCultureCommittee/Attainment%20-%20sensory%20impairments/BATOD_response.pdf

²³ <http://www.scod.org.uk/about/bsl/>

Inclusive Communication for deaf people

Empowerment is a central pillar to the human rights based approach outlined in the Scottish National Action Plan (SNAP)²⁴. In respect to the participation of people in decisions that affect them, “there is a need for greater consistency to ensure meaningful participation of people in decisions that affect their lives.”

National strategies and plans emphasise the need for services to be person centred, rights and developed using an asset based approach and a co-production model. To be effective, they all require to have inclusive communication as their starting point, because without inclusive communication, a person does not understand their rights and service providers do not include all those that should be.

For example, “If there isn’t Inclusive Communication services can’t be person centred. Without Inclusive Communication and I’m not just talking about face to face communication. Take for example booking a doctor’s appointment or any kind of appointment most time it’s on the phone. For me I can’t do that I’m deaf so I can’t use the phone. A simple thing like an email address to make that appointment would make all the difference. It would allow me to be able to make that appointment without having to actually travel to the surgery or office or whatever I’m going to do. For other people they maybe need speech to text or other ways in which to communicate. Without this range of communication how can it be person centred because they aren’t including that person’s needs so it can’t be person centred..... If people are not allowed to get their thoughts and points across they aren’t being served as they should be. Unless the person offering a service can actually communicate in the way that the other person does that person isn’t going to get anything out of it. Ultimately that could be the difference between them engaging with that person and not and if they don’t engage with that person how is that person going to get the care or services they actually need.”

Bill, co-author of the Inclusive Communication Nation essay²⁵

Health

For many years, there was plenty of anecdotal evidence that deaf people who were inpatients in hospital did not receive the appropriate language/communication support to make informed choices and give informed consent to treatment (Article 3 of the ECHR²⁶).

In March 2013, the SPSO²⁷ published details of a complaint it investigated against NHS Tayside - that it was unacceptable for the Board not to provide a BSL interpreter during Ms A’s 12-day in-patient admission to the Ninewells Hospital in July 2011. In this case, the Ombudsman’s recommendations²⁸ included:

²⁴<http://www.scottishhumanrights.com/actionplan>

²⁵ <http://www.scod.org.uk/scotdeaf/wp-content/uploads/2015/04/Inclusive-Communication-Nation-2015-1.pdf> Page 11

²⁶ Prohibition of torture No one shall be subjected to torture or to inhuman or degrading treatment or punishment. http://www.echr.coe.int/Documents/Convention_ENG.pdf

²⁷

http://www.spsso.org.uk/sites/spsso/files/communications_material/annual_accounts/SPSO_health_complaints_report_2012-13_web.pdf Page 25

²⁸ <http://www.spsso.org.uk/investigation-reports/2013/march/tayside-nhs-board-0>

- NHS Tayside consider amending their Interpretation and Translation Policy to highlight the legal duties staff have and to explain that using families (Article 8), lipreading and pen and paper is not likely to be an adequate or reasonable response to the needs of a BSL user. This should make clear that BSL is a registered language and not simply signed English;
- consider providing further training to staff on deaf culture, language and legal rights; and
- consider seeking input from deaf people on the Board's Interpretation and Translation Operational Group to review the effectiveness of the implementation of the Interpretation and Translation Policy.

In December 2014, it was reported in the press that another Deaf BSL user had been treated in a similar way in Perth Royal Infirmary²⁹, another NHS Tayside hospital.

When services expect family members to translate and interpret for a Deaf or Deafblind person, that person loses their right to a private life, and depending on the reason for their hospital admission and possible diagnosis, can also lose their right to a family life. Conversely, the medical professionals cannot be certain the information being provided by the family member is being accurately interpreted and sometimes, wrong diagnoses and treatments are given.

Mental Health for Children and Young People

In 2008, SCoD published a paper – “Making the case for Specialist Mental Health Services for Deaf People in Scotland” – which highlighted the problems with the mental health services that were being provided for Deaf, Deafblind and Deafened people. At the time, there was no Scottish service for deaf people. Specialist outreach services were provided by the John Denmark Unit³⁰ in Prestwich Hospital in Greater Manchester. If a BSL user required long term in-patient treatment in a linguistically accessible unit, they were admitted to the John Denmark Unit. In 2011, the Scottish Mental Health Service for Deaf People³¹ was set up in St John’s Hospital in Livingston by NHS Lothian. This is an adult service.

NDCS supported by SCoD put forward the business case for having a similar service for deaf children and young people. This is still in the planning stages although it is a much needed service. As the Committee members will be aware, the majority of deaf children are born to hearing parents and as they grow up, many struggle with their identity as they do not feel they “fit” in with the hearing world as they cannot hear, but neither do they “fit” with the Deaf Community because their first language is English (or another spoken language and English is their second language) not BSL. This leads to an increased risk of mental ill health in deaf children and young people. Without a sympathetic service that understands their language/communication support needs as well as their identity and cultural needs, deaf children and young people’s rights are not being upheld.

Social Care

²⁹ <http://www.bbc.co.uk/news/uk-scotland-tayside-central-30446838>

³⁰ <https://www.gmw.nhs.uk/search/venue/john-denmark-unit-17>

³¹ <http://www.nhslothian.scot.nhs.uk/Services/A-Z/mhdeafservice/Documents/ScottishDeafMentalHealthLeaflet.pdf>

In a research report published by Action on Hearing Loss in 2012³², looking at adult social work services for people who are deaf in Scotland, nearly 40% said they did not have a social care assessment because they were not aware the services existed. This means that people who are being diagnosed as having a hearing loss in later life especially do not access information and services that can help them continue to be active citizens in Scotland. Many become more dependent on carers and families and lose their right to a private life; and as their deafness increases, carers and family start to lose patience and the deaf person loses their right to family life too.

Justice

When deaf people are detained/arrested, technology could be used by Police Scotland and solicitors to ensure that deaf people's "right to liberty and security" is upheld. (Article 5 of the ECHR³³). Specifically Article 5 offers the following protection: "Everyone who is arrested shall be informed promptly, in a language which he understands, of the reasons for his arrest and of any charge against him."

And Article 6 of the ECHR³⁴ states:

"Everyone charged with a criminal offence has the following minimum rights: (a) to be informed promptly, in a language which he understands and in detail, of the nature and cause of the accusation against him; (d) to examine or have examined witnesses against him and to obtain the attendance and examination of witnesses on his behalf under the same conditions as witnesses against him; (e) to have the free assistance of an interpreter if he cannot understand or speak the language used in court."

Online video relay services as well as online Palantypist/electronic notetaking services can be accessed so that deaf people understand what is being said to them and can ask questions. For a number of years, police in Scotland have been looking at providing information in BSL on a video as well as a written statement on what happens when "you" are detained/arrested. While this gives information to the deaf person, without language/communication support, the police cannot be sure that

- the person understands what the information means; and
- the person has no questions or nothing to say to the officers giving the information

For example, the deaf person is diabetic and needs to inject insulin before food or is epileptic and needs to take medication. Or the deaf person has a pet that needs looking after or a child who is at school.

Active Citizenship

For all deaf people in Scotland, we would like to see the Scottish Government setting the standard in language/communication support provision by providing a national fund and encouraging local funds that organisations can access. For example, deaf people would like to be able to volunteer in their communities, but too often, organisations have no money in their budget for language/communication support so cannot provide the opportunity. Or deaf people would like to be involved in

³²

<https://www.actiononhearingloss.org.uk/search.aspx?gcs=research%2binto%2badult%2bsocial%2bwork%2bse rvices%2bfor%2bpeople%2bwho%2bare%2bdeaf%2bor%2bhard%2bof%2bhearing%2bin%2bScotland>

³³ http://www.echr.coe.int/Documents/Convention_ENG.pdf Page 8

³⁴ http://www.echr.coe.int/Documents/Convention_ENG.pdf Page 9

community events or to involve hearing people in their events, but there is no money available for language/communication support to enable this to happen. (Article 11, 14)

Summary

In terms of human rights for deaf people in Scotland, much has moved on with the progress of technology and the recognition of British Sign Language through the BSL (Scotland) Act, but there is still a way to go.

Without inclusive communication³⁵, deaf people continue to be excluded from many aspects of society in Scotland, which means that many of their rights as citizens are breached. SCoD would like the Scottish Government to take the lead on this matter to ensure that the rights that hearing citizens enjoy on a daily basis as extended to include all deaf people.

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³⁵ <http://www.gov.scot/Resource/Doc/357865/0120931.pdf>