



Scottish Council
on Deafness (SCoD)

Mental Health and Wellbeing for all people affected by deafness

Past, Present and Future

31 March 2018

Mandy Reid

Business Development Manager



“A society where deaf people have equal access, rights and citizenship.”

Summary

The Scottish Council on Deafness (SCoD) started to campaign for inclusive mental health services for people with a hearing loss in Scotland in 1927, the year the organisation was set up. Today it continues to campaign for mental health and wellbeing services and information to be fully inclusive for everyone, including people who are deaf across the four pillars of deafness.

In the last ten years, there have been a lot of developments in the field of mental health which have made services more accessible to Deaf and Deafblind BSL users, but more needs to be done to ensure all people with a hearing loss have equality of access to the information and services that they need to maintain good quality mental health and wellbeing.

SCoD has six priorities that it would like to see developed:

1. **DCAMHS:** The business case for a Scottish DCAMHS service is re-visited and every effort is made to ensure equity of service for children and young people in Scotland who have a hearing loss and mental health issues.
2. **Deaf awareness training:** SCoD would like to see the Scottish Government, working with colleges and universities, setting standards for training in deaf awareness and mental health in all health/social care professions, and annual deaf awareness training as part of the CPD of all mental health professionals in Scotland.
3. **Deaf awareness in Scotland:** SCoD would like to see the Scottish Government taking the lead on an awareness-raising campaign across Scotland to tell people in Scotland what it means to lose your hearing and what steps to take to prevent this loss. This would mean that fewer people who lose their hearing would be isolated from their communities, friends and families and help to reduce mental ill-health.
4. **Scottish Mental Health First Aid:** This should be available to all staff who work with or support people with a hearing loss across

Mental Health and Wellbeing across the four pillars of deafness

the four pillars of deafness in Scotland. At the present time, it is cost-prohibitive to too many organisations.

5. **Mental Health Awareness training:** All Language Support Professionals should have access to mental health awareness training, not just BSL/English Interpreters.
6. **Breathing Space and other support:** While Breathing Space is accessible for Deaf BSL users through contact SCOTLAND-BSL, it is not accessible for people who are Deafened or who are Hard of Hearing and cannot use a telephone. Textphones are no longer being used by people with a hearing loss; they are following the rest of the population and using mobile phones and SMS or email and messaging. Breathing Space and other support organisations need to look at how to incorporate inclusive communication into their services.



Mental Health and Wellbeing for all people affected by deafness

Scottish Council on Deafness

The [Scottish Council on Deafness \(SCoD\)](#) is the lead membership organisation for deaf issues in Scotland. We aim to ensure that people across the four pillars of deafness in Scotland can access services and information across all sectors of society from their local communities to what comes from government departments. We represent organisations, agencies and companies from the Third, Public and Private sectors working with and on behalf of people who are deaf.

We take a person-centred, rights based approach to our work and use the social model of disability, which shows that people who have a hearing loss do not have equity with their hearing peers due to the barriers they face on a daily basis. People in Scotland who have a hearing loss cannot be active citizens due to these barriers.

The four pillars of deafness

We use the term the “four pillars of deafness” to describe people who are Deaf/Deaf Sign Language Users, Deafblind, Deafened and Hard of Hearing, as people with different levels of deafness have different barriers to overcome and have different language and communication support needs.

There are over one million people in Scotland, that’s 20% of the population, adversely affected by hearing loss of some sort. It is age related so age over forty about 40% are affected, over sixty it is 60% and over seventy five it is 90%. There is evidence that a significantly higher than average number of people with a hearing loss experience mental health problems. People with a hearing loss also have greater challenges accessing health and well-being messages, training and development opportunities.

People who have a hearing loss are more likely to become socially isolated and separated from their geographical communities, families and friends that their hearing peers due to the lack of understanding of

what it means to have a hearing loss in Scotland. This isolation is often the trigger into more severe and enduring mental health issues for the person.

The history of holistic and linguistically inclusive mental health services for people with a hearing loss in Scotland

Prior to the launch by NHS Lothian of the [Lothian Community Mental Health Service for Deaf people](#) in 2007 and the [Scottish Mental Health Service for Deaf People](#), which was commissioned by NHS National Services Scotland (NSS) on behalf of all 14 NHS Boards in Scotland in 2011 and hosted by NHS Lothian, people who are Deaf, Deafblind and Deafened and who needed support and/or treatment in a holistic and linguistically accessible environment had to be referred to an outreach team from the John Denmark Unit, which is part of the [NHS Greater Manchester Mental Health Foundation Trust's National Centre for Mental Health and Deafness](#). This outreach team held surgeries in Glasgow and Edinburgh (occasionally in Dundee) on a monthly basis, which were personnel dependent – two members of staff formed the outreach team, with little or no cover for leave. The outreach team could refer people who are Deaf or Deafblind BSL users or people who are Deafened to the John Denmark Unit for inpatient treatment, and many people who are Deaf, Deafblind or Deafened were treated over the years. This service, including inpatient treatment at the John Denmark Unit, was paid for by NHS NSS.

Although the treatment received by these inpatients was very good, being treated outside Scotland meant that individuals were isolated from their families, friends and community, and from the Scottish organisations and services that provide ongoing support in the community.

There have been fewer developments specifically for **people who are Hard of Hearing**. It was felt that provided mainstream services made sure their staff had deaf awareness training and places had hearing loops, their needs would be met.

Campaign for a Scottish Mental Health Service

SCoD and its members had campaigned for a long time for accessible and inclusive services for people with a hearing loss across Scotland. **SCoD** had a **Mental Health and Deaf People Task Group** that met on a quarterly basis to look at mental health services for people across the four pillars of deafness throughout Scotland.

In 2005, SCoD lodged Petition PE 808 in the Scottish Parliament and then in 2008, published a research paper - “Making the Case for Specialist Mental Health Services for Deaf People”, which laid out the rights-based need for a specialist service.

In 2009, RNID, now Action on Hearing Loss, received funding from the Scottish Government to commission a piece of research from Glasgow Caledonian University. The two aims of the research were to

“estimate the size of the Scottish population of deaf/deafblind individuals using mental health services and to identify the priority areas for future development. A mixed methods approach was used combining survey techniques with in depth qualitative case studies. A postal survey across three Health Boards was used to estimate the number of deaf/deaf blind people currently using mental health services within Scotland. Telephone interviews were completed with 12 out of 14 Scottish NHS Health Boards to map current and specialist services for people who are deaf /deafblind. Interviews were completed with 4 service users and their trusted associates to build an in depth picture of their care experiences and preferences.”

(Report is available from Action on Hearing Loss Scotland:

Teri.Devine@hearingloss.org.uk)

The **Scottish Parliament’s Health and Sports Committee** held several evidence gathering sessions based on the petition and SCoD and its members were invited to give evidence at these sessions.

SCoD worked in partnership with NHS National Services Scotland, the Scottish Government’s Mental Health Division and Dr Deborah Innes (the consultant psychiatrist who is now the lead for the Scottish Mental

Mental Health and Wellbeing across the four pillars of deafness

Health Service for Deaf People) to put together the business case for a specialist service.

In 2011, SCoD's Mental Health and Deaf People Task Group commissioned NDCS Scotland to carry out a piece of research into what mental health services are available for deaf children and young people in Scotland.

“Research has shown that, in general, deaf people find it very difficult to effectively access primary health services and, as a result, deaf people's health (including mental health) problems are often not effectively addressed at the earliest opportunity by primary services. Those whose health then subsequently deteriorates are later picked up by secondary or tertiary tier services, possibly at a stage where the issue(s) are much worse than they would have been had they been addressed at an earlier time. Specialist services for deaf people are also invariably positioned at the tertiary tier due to their relatively highly specialist nature, which in itself also creates some difficulty, say in terms of ease of access and intervention strategies, amongst others. Because of this, preventative strategies and approaches must also be considered alongside actual service provision.”

(A copy of the report is available from NDCS Scotland:
Alasdair.O'Hara@ndcs.org.uk)

The findings of this research report became the basis for putting together a business case for a **Deaf Children and Adolescent Mental Health (DCAMH) Service** in Scotland. The business case came to a premature halt as there are no specialist mental health professionals in Scotland who could provide the lead role for such a service.

NDCS Scotland produced a briefing on childhood deafness prevention/early intervention which states

“at any given time 50.3% of deaf children will experience some mental health problems , 3.4% will require highly specialist services (Hindley et al, 2004). Deaf children are vulnerable to developmental delays, behavioural difficulties and lower

achievement academically. This is largely due to issues arising from communication difficulties and can in turn lead to emotional distress caused by bullying, feelings of isolation, and lack of support. The use of specialist communication support strategies within medical, social and academic services is often below acceptable levels, this can lead to further isolation from the very systems deaf children and young people should be able to rely on for help. Deaf children and their families require a focus on early intervention with positive approach at the point of diagnosis and offer of support for the child and family through childhood and throughout the transition to adulthood.”

Historical developments

In 2009, NHS GGC and Glasgow City Council worked with Hayfield Support Services with Deaf People and Dr Deborah Innes to provide deaf awareness, working with people across the four pillars of deafness who have mental health issues and working with Language Support Professionals training to all the **Mental Health Officers** in the NHS GGC area. Specialist training was also provided to Language Support Professionals, especially **BSL/English Interpreters**, working in mental health settings so that they would have a better understanding of the medical terms used.

The **University of Stirling** working in partnership with Dr Deborah Innes and her training team, provided specialist training to students studying for a mental health nursing qualification.

Scotland's Mental Health First Aid programme worked with Deaf Connections and Glasgow Association for Mental Health's Deaf Project to make the First Aider course accessible for Deaf BSL users. Several Deaf sign language users went through the course, but ScoD does not have any data on who attended and how many went on to train others.

The **Choose Life suicide prevention** training covering awareness and exploration to suicide first aid skills was made fully accessible for Deaf

Mental Health and Wellbeing across the four pillars of deafness

BSL users. SCoD has no data on how many Deaf BSL users received the training.

Glasgow Association for Mental Health (GAMH) has supported initiatives to include people across the four pillars of deafness differing amounts of success. GAMH and Deaf Connections provided a specialist peer support group for people with a hearing loss in Glasgow.

The **Scottish Independent Advocacy Alliance (SIAA)** has, for many years, argued that more mainstream advocacy services across Scotland who are supporting people with mental health issues, should have dedicated budgets for language/communication support to ensure people with a hearing loss who have mental health issues can access independent advocacy support. There have only been three advocacy services that work or have worked directly with people across the four pillars of deafness and who provide advocacy in BSL. Only one provides independent advocacy under the definition of the Mental Health (Care and Treatment) (Scotland) Act 2003.

Breathing Space employed two BSL users to provide a service for Deaf BSL users who could not access the service via the telephone. This provided a face-to-face service which was not widely used as it didn't give Deaf BSL users the same anonymity as hearing people phoning in. People who are Deafened or very Hard of Hearing could use a textphone and TextRelay to contact Breathing Space.

Deafblindness and Mental Health: Psychological distress and unmet need among adults with dual sensory impairment

“Using materials adapted for each member, a self-report survey to examine psychological distress and unmet need was sent to the membership of a third sector organization, Deafblind UK. High rates of psychological distress were reported: 61 percent ($n = 439$) of the respondents obtained a score of two or more (from a maximum of 12) on the GHQ-12 (Goldberg and Williams, 1988), while 45.8 percent obtained a more stringent score of four or more. The findings also suggested high levels of unmet need: more than

one in four respondents (26.9%, $n = 504$) reported that they received no formal support. Surprisingly, given the important role of primary health care practitioners, both in providing treatment and in accessing other services, only a third (32.1%, $n = 504$) of respondents reported receiving regular support from a General Practitioner or community nurse. The implications for the development of service provision and practice, particularly within the health service, are discussed.

Assessing mental health in people with deafblindness

The psychological assessment of individuals with deafblindness has been described as an 'awesome task' (Vernon and Green, 1980, p. 229). The problems in communication, the dearth of appropriate standardized measures, and the lack of specialist skills among health service practitioners may, in part, explain the lack of attention to mental health issues."

(Study in the British Journal of Visual Impairment: 2011 January)

<http://journals.sagepub.com/doi/pdf/10.1177/0264619610387495>

Current support for people with a hearing loss and mental health issues

NHS Greater Glasgow and Clyde hosted a forum on Mental Health and Deaf People for a number of years. This forum was open to all frontline staff working in mental health services in the community and in hospital and deaf organisations supporting people with a hearing loss. The forum shared best practice, training and was an arena for discussion on how best to work with people who are deaf and who have mental health issues.

The **Mental Health and Deaf People Task Group** came from this forum and continues today, with its focus moving towards specific support for **Deaf and Deafblind BSL users** and which provides support for the Deaf Health Improvement Practitioner for Mental Health. The Health Improvement Practitioner meets Deaf and Deafblind BSL stakeholders on a regular basis to gather their views of the services provided.

The [Scottish Mental Health Service for Deaf People](#) is the national service hosted by NHS Lothian. The service provides specialist support to people across the four pillars of deafness who have mental health problems across Scotland.

It provides a high quality service for people with a hearing loss who have mental health issues.”

Health and Wellbeing

When looking at mental health issues, it is important to look at the person’s health and wellbeing as well as access to support and accessible information.

See Me Scotland

[See Me Scotland](#) is Scotland’s National Programme to end mental health stigma and discrimination, enabling people who experience mental health problems to live fulfilled lives.

See Me recognise that mental wellbeing is influenced by biological, psychological, social and environmental factors, which interact in complex ways. Environmental factors include inequalities in life circumstances; good living environments, housing, transport, education and a supportive political structure. Community also affects mental wellbeing, such as a sense of belonging, social support, a sense of citizenship and participation in society.

See Me is working with SCoD to tackle mental health stigma and discrimination within the Deaf Community and from a deaf perspective. This work will benefit all people with a hearing loss not just those who are deaf BSL users.

SCoD will adopt the See Me Community Champions approach within communities in Scotland and will develop Community Champions within the Deaf Sector. The first phase of this project is to identify the need to

Mental Health and Wellbeing across the four pillars of deafness

raise awareness and build capacity within the Deaf Community in relation to mental health stigma and discrimination.

Self Management

SCoD is working in partnership with Deaf Links and Deaf Action to produce information that is fully accessible to Deaf BSL users and other people with a hearing loss about [Self Management](#).

Self Management is a way of living and working that means people living with long term conditions feel more in control of their own health and wellbeing. Self management is about people living with long term conditions being in 'the driving seat'. It supports people to live their lives better, on their terms.

Self management supports and encourages people living with long term conditions to access information and to develop skills to find out what's right for their condition and, most importantly, right for them.

The first part of the project is to produce information on what Self Management is; the second part is to train Deaf BSL users to provide peer support across the country.

[Deafblind Scotland](#) have been working in Glasgow developing Self Directed Support and Self Management models with Deafblind BSL users. This has been utilising an enterprise model where individuals have been supported to use personal budgets to develop their enterprise. This has been successful with, for example, one Deafblind BSL member now providing a holistic therapies service for Deaf and Deafblind BSL users. Materials on SDS and Self Management have been made accessible for people in Scotland who are deafblind.

[BSL National Plan](#)

Health, Mental Health and Wellbeing

Mental Health and Wellbeing across the four pillars of deafness

In the BSL National Plan, the Scottish Government has laid out what it will do to ensure “BSL users will have access to the information and services they need to live active, healthy lives, and to make informed choices at every stage of their lives”. For the full list, go to the Appendix at the back of this paper.

Sport in Scotland

Access to sport and leisure classes are important for people with with a hearing loss mental health issues and who are self managing long term conditions.

The Scottish Government’s Physical Activity Implementation Plan, Ministers are implementing measures for greater physical activity and promoting opportunities that have a positive impact on people’s health and wellbeing. The [Active Scotland Outcomes Framework](#) describes Scotland’s ambitions for sport and physical activity.

We support well-being and resilience in communities through physical activity and sport. This outcome is about the development of communities through sport and physical activity, rather than developing sport in communities. Sport and physical activity is often seen as an end in itself, but can also be a means to develop wider social outcomes in communities, for example using sport to address education, employment and crime related issues. (Active Scotland Outcomes Framework)

People with a hearing loss are more likely to need access to language/communication support when using mainstream sports and leisure facilities. This is not always provided for a number of reasons – facility does not realise that they need to make “reasonable adjustment” or does not have a budget to provide this inclusive communication.

SCoD and its members support the need for mainstream facilities that provide sport and leisure opportunities should be fully accessible to all people across the four pillars of deafness.

[Scottish Disability Sport](#) provides support for disabled people to become involved in sport in Scotland. The majority of people with a hearing loss who they provide support to are involved in mainstream sports associations and clubs in their own geographical communities. SCoD would like to see more support offered across Scotland to allow more people across the four pillars of deafness with to take part and to have the opportunity to develop their health, wellbeing and employment prospects through sport.

Priorities

1. **DCAMHS:** The business case for a Scottish DCAMHS service is re-visited and every effort is made to ensure equity of service for children and young people in Scotland who have a hearing loss and mental health issues.
2. **Deaf awareness training:** SCoD would like to see the Scottish Government, working with colleges and universities, setting standards for training in deaf awareness and mental health in all health/social care professions, and annual deaf awareness training as part of the CPD of all mental health professionals in Scotland.
3. **Deaf awareness in Scotland:** SCoD would like to see the Scottish Government taking the lead on an awareness-raising campaign across Scotland to tell people in Scotland what it means to lose your hearing and what steps to take to prevent this loss. This would mean that fewer people who lose their hearing would be isolated from their communities, friends and families and help to reduce mental ill-health.
4. **Scottish Mental Health First Aid:** This should be available to all staff who work with or support people with a hearing loss across the four pillars of deafness in Scotland. At the present time, it is cost-prohibitive to too many organisations.

5. **Mental Health Awareness training:** All Language Support Professionals should have access to mental health awareness training, not just BSL/English Interpreters.
6. **Breathing Space and other support:** While Breathing Space is accessible for Deaf BSL users through contact SCOTLAND-BSL, it is not accessible for people who are Deafened or who are Hard of Hearing and cannot use a telephone. Textphones are no longer being used by people with a hearing loss; they are following the rest of the population and using mobile phones and SMS or email and messaging. Breathing Space and other support organisations need to look at how to incorporate inclusive communication into their services.

Appendix:

1. Loneliness: A threat to Scotland's Health Briefing paper: Voluntary Health Scotland. <https://vhscotland.org.uk/wp-content/uploads/2017/03/Loneliness-Briefing-Paper.pdf>

2. Scottish Mental Health Service for Deaf People

They are “a consultancy and liaison service that provides:

- Advice on the local management of deaf people with moderate or severe mental health problems which present challenges in assessment and/or treatment across Scotland;
- Assessment and/or treatment of deaf patients at request of or with local clinicians on an outreach basis;
- Advice/assessment of the possible requirement for specialist inpatient treatment;
- Provision of training in deaf awareness and deaf mental health issues for mental health professionals.

The deaf person is referred to local mental health services, where the clinician assesses the need for specialist input. If this is the case, then a referral is made to a regional clinic, and an appointment will be made to see the deaf person.

Patients will be seen by an Advanced Nurse Practitioner on an individual basis for assessment of mental state and diagnosis in complex cases.

Specific time limited treatment may be offered.

Other services

- Support for local teams in providing direct patient care. Advice can be given regarding further treatment and signposting to local deaf organisations.
- Assessment of patients for inpatient treatment in the John Denmark Unit in Greater Manchester, including liaison with the inpatient team and facilitation of and support during the discharge process back to Scotland.

The team has a Clinical Lead, three Advanced Nurse Practitioners and a team administrator. All staff can communicate in British

Mental Health and Wellbeing across the four pillars of deafness

Sign Language (BSL), Sign Supported English (SSE) and spoken English.

<http://www.nhslothian.scot.nhs.uk/Services/A-Z/mhdeafservice/Pages/default.aspx>

3. In the 2015 [Active Scotland Outcomes: Indicator Equality Analysis](#), access to services (including leisure services) has been identified by the Equalities and Human Rights Commission (EHRC) as one of seven significant inequalities in Scotland.

Adults with physical and mental health conditions expected to last 12 months or more are less likely to feel that they have access to a useable local greenspace within a five minute walk from their home (65% vs 70%) (Active Scotland Outcomes: Indicator Equality Analysis)

Adults with disabilities report lower levels of satisfaction with local authority sport and leisure facilities than those with no disability (47% are very/fairly satisfied vs 62% of those with no disability). This is related to the fact that those with a disability are much less likely to have used these facilities either in the past year or at all, 74% vs 55% of those with no disability) and are, therefore, more likely to state they have no opinion about facilities. (Active Scotland Outcomes: Indicator Equality Analysis)

4. Briefing: Hearing, older people and mental health
From the perspective of those do not use sign language: Available from Ideas for Ears - <https://www.ideasforears.org.uk/contact-us/>

5. BSL National Plan

Health, Mental Health and Wellbeing

Mental Health and Wellbeing across the four pillars of deafness

“Our long-term goal: BSL users will have access to the information and services they need to live active, healthy lives, and to make informed choices at every stage of their lives.

By 2020, Scottish Ministers will:

45

Ensure that – in line with Scotland’s Mental Health Strategy 2017-2027 – BSL users* should get the right help at the right time, expect recovery, and fully enjoy their rights, free from discrimination and stigma. By 2020:

a) NHS Boards and Integration Authorities should take action so that psychological therapies can be offered on a fair and equal basis to BSL users*.

b) NHS 24 and NHS Health Scotland will develop information about mental health accessible for BSL users* through ‘NHS Inform’.

c) NHS 24 will explore how telemedicine initiatives like ‘Breathing Space’ can provide counselling in BSL as an easy-to-access mental health support.

46

Implement a new national Interpretation and Translation Policy which includes BSL provision. This will be led by NHS Health Scotland and will provide guidance to support delivery across all NHS boards by 2018.

47

Work with partners to deliver and evaluate two training programmes aimed at supporting BSL/English interpreters to work within the Health sector, with a view to informing a longer-term approach.

48

Mental Health and Wellbeing across the four pillars of deafness

Work with sport governing bodies and with 'sportscotland' to improve access to information and sporting opportunities for BSL users*.

49

Ensure that the national strategy to address social isolation and loneliness which will be published for consultation in Autumn 2017 will make explicit reference to the experience and needs of BSL users*." <https://beta.gov.scot/publications/british-sign-language-bsl-national-plan-2017-2023/pages/8/>

6.





Contact SCoD

Scottish Council on Deafness
C/o The Alliance
The Venlaw Building
349 Bath Street
Glasgow
G2 4AA



Telephone: 0141 248 2474
Mobile/SMS: 07925 417 338

Email: admin@scod.org.uk
Website: www.scod.org.uk

