

Consultation Response

Scotland

Mental Health Strategy for Scotland: 2011-15

Scottish Government

31 January 2012

About us

1. Action on Hearing Loss Scotland is the new name for RNID Scotland. We're the charity working for a world where hearing loss doesn't limit or label people, where tinnitus is silenced and where people value and look after their hearing.
2. Our response will focus on key issues that relate to people with hearing loss. Throughout this response we use the term 'people with hearing loss' to refer to people with all levels of hearing loss, including people who are profoundly deaf. We are happy for the details of this response to be made public.

Deafness and hearing loss

3. There are 850,000 people who are deaf or hard of hearing in Scotland. It is estimated that 1 in 6 of the general population has some degree of hearing loss. There are many reasons why some people are deaf or hard of hearing or lose their hearing. The most common is age-related deafness with more than 50% of people over the age of 60 with some form of hearing loss. Other people may lose their hearing because of exposure to noise at work or because of prolonged and repeated exposure to loud music. Deafness can be congenital, and Universal Newborn Hearing Screening, introduced in Scotland in 2005, is identifying more deaf babies than ever before. There are also some conditions such as damage to the eardrum or inflammation in the middle ear that cause deafness. There is a broad spectrum of levels of a hearing loss ranging from people with mild deafness to people who are profoundly deaf.

4. Depending on their level of deafness and on when they became deaf or hard of hearing, people who are deaf and hard of hearing use a range of methods to communicate. Between 5,000 and 6,000 deaf people in Scotland use British Sign Language (BSL) as their preferred or first language; many rely on lip reading, others use note takers or rely on equipment such as hearing aids; and some use a combination of these. For those who use BSL as a first language, English is often a second language and access to written English can be challenging.

People with hearing loss and mental health

5. People with hearing loss are more likely to experience mental health problems. Up to 40% of the deaf and hard of hearing community experience mental health problems at some point, nearly double the proportion in the general population of one in four (footnote 1).
6. Many people with hearing loss experience social and cultural isolation because others may not understand their hearing loss and they may find it hard to communicate their frustrations. This can also lead to problems in their closest and most personal relationships. Similarly, they experience difficulties in accessing everyday services such as health, education, employment, social security benefits, transport, arts and culture because of communication barriers. As they experience barriers to social interaction and services, they are more likely to be isolated from the rest of society, which can have an impact on their mental health and wellbeing.
7. Additionally, when it comes to people with hearing loss accessing mental health services for help and support, they continue to experience barriers. Our research on access to health services (footnote 2) showed that the level of services people with hearing loss receive in both GP surgeries and hospitals often falls short of what they could reasonably expect. For example, over half of people with hearing loss had experienced difficulties hearing their

Footnote 1 - Paddock, M, O'Neill, B and Howell (4 October 2008) 'Actions speak louder than words', *BMJ* p. 8 and 9.

Footnote 2 – Edmond, F (2010) *Are you listening? Access to health services for people who are deaf or hard of hearing*, RNID Scotland.

name being called when they were in their GP's or hospital's waiting room.

8. According to the BMJ, thousands of profoundly deaf people still struggle to communicate with healthcare professionals on a daily basis. The BMJ further notes that "*(the) mental health needs of these people are often undermined. Lack of contact with appropriate healthcare professionals and subsequent ineffective treatment through miscommunication compromises access to basic health care.*" (footnote 3)
9. Action on Hearing Loss Scotland commissioned Glasgow Caledonian University health school to carry out more in-depth research about the experience of deaf and deaf/blind people accessing mental health services in Scotland. The research (footnote 4) revealed that people with hearing loss still experience barriers when accessing both community and acute services. Barriers include, for example:
 - Communication services were not available outside of 9am to 5pm;
 - People are not provided with relevant communication support in a crisis situation; and
 - Staff deaf awareness training varied from one NHS Board to the other, with some offering in-depth training and others only a few hours as part of an overall disability awareness training.

Case study

"When I was in the hospital I didn't know why I was there but you know, the doctors, psychiatrist, social worker, mental health officer, were asking me what was my name, you know birth date, things like that, and later on they basically just offered me some tablets and I didn't know what they were for and they made me feel very, very dizzy and very frightened." CS2 / Line 14 (footnote 5).

Footnote 3 - Paddock, M et al. *Op. Cit.*

Footnote 4 – RNID Scotland (2009) *Scottish Mental Health Services: the experience of deaf and deafblind people*

Footnote 5 - RNID Scotland (2009) *Op. Cit*

Mental health strategy for Scotland

5. Against this background, we have recommendations about the Scottish Government's strategy *Mental Health Strategy for Scotland 2011-15*. While we welcome the strategy and many of the recommendations it contains, we recognise that people with hearing loss still experience barriers to accessing mental health services.
6. The *Mental Health Strategy for Scotland* sets out the Scottish Government's priorities for the next 4 years. It is based on the Government's existing approach which promotes good mental health; ensures that mental health services are person centred; and aims for a culture of continuous improvement into mental health service delivery. The strategy focuses on 14 outcomes and we comment on relevant ones below.

People and communities act to protect and promote their mental health and reduce the likelihood that they will become unwell

7. We agree that "*preventing suicide and self-harm are everybody's business.*" There are no completely reliable statistics about the number of people with hearing loss who commit suicide. However, some studies indicate higher suicide rates for people with hearing loss (footnote 6). Also, for people who suffer from tinnitus, research suggests that some end up contemplating suicide: "*I got to the stage when I couldn't take anymore; I took an overdose.*" (footnote 7)
8. We welcome initiatives such as Breathing Space, a free confidential phone and web based service for people in Scotland. The service is available in BSL two days a week. Using a webcam, BSL users can connect to a BSL advisor who is trained to deal

Footnote 6 – Sign Health (2009) Factsheet on *Deaf People and Suicide*

Footnote 7 – Redmond, S (2010) *What's That Noise? A profile of personal and professional experience of tinnitus in Northern Ireland*, RNID Northern Ireland

with their concerns. All advisors have relevant professional qualifications and experience of counselling, nursing, social work or psychology. We welcome the initiative and would like similar services to be made available.

9. We agree that there is a need to continue to reduce the stigma of mental illness and ill health and to reduce discrimination. People with hearing loss may experience a double stigma: that of their mental ill health and that of their hearing loss. We would like campaigns such as *See Me* to improve public attitudes towards people with mental illness and sensory impairment or other disabilities.
10. For campaigns such as *See Me* to address discrimination, we would like the message to be accessible to people with hearing loss. All literature should be written in plain English for those whose first language is BSL and who may find written English challenging. We welcome the fact that information is available as BSL video clips on the *See Me*'s campaign website and recommend that all mental health campaigns include BSL video clips.
11. We agree that mental wellbeing should be promoted. We would like services to be accessible to people with hearing loss and recommend that all mental healthcare professionals be trained in deaf awareness. Good practice includes maintaining face-to-face and eye-to-eye contact with the people who are deaf or hard of hearing so that they can lip-read; if using a BSL interpreter, talking directly to the person rather than the interpreter; and speaking clearly but not too loudly. Action on Hearing Loss Scotland runs deaf awareness raising and equality training courses.

People have an understanding of their own mental health and if they are not well take appropriate action themselves or by seeking help

12. We agree that people should have access to a range of information, support and services to enable them to take ownership of their mental health. As mentioned above, information and support should be accessible. Written information should be in plain English, internet video clips should be translated into BSL and telephone based support services should offer an alternative

to the telephone such as email or SMS text messages.

13. Priority actions to ensure that people with hearing loss take action to seek help should include:

- All information websites that include information about mental health should be accessible. They should be written in plain English and as far as possible they should include clips in British Sign Language (BSL).
- All agencies/organisations involved in providing mental health services are accessible to people with hearing loss. This means that their staff are trained in both counselling skills and deaf awareness.
- Communication support services are available throughout. Communication support services include, for example, BSL/English interpreters, lipspeakers or electronic notetakers. These need to be booked well in advance because there is a shortage of communication support workers.
- Induction loops are available wherever possible and if a main loop system is not possible (because conversations could be overheard from outside the room), we suggest that organisations invest in personal listeners.
- Appointment times are extended as it may take people who are deaf or hard of hearing longer to lipread and communicate with counsellors.

First contact services work well for people seeking help and people move on to assessment and treatment services quickly

14. In order to ensure that first contact services work well for people with hearing loss, we recommend that there is an alternative to the telephone to contact early services. Indeed, people with hearing loss often have to rely on relatives or friends to contact health services such as their GP or hospitals. As a patient with hearing loss told us: "*Hospital outpatient resist using Typetalk [now Text Relay] so my husband has to phone for me (...) It is always difficult to communicate via a third person.*" (footnote 8) Having to rely on a third party undermines a patient's privacy and confidentiality and disempowers them from managing their own health. A patient with hearing loss might be deterred from accessing a mental health

Footnote 8 – Edmond, F (2010) *Op. Cit.*

service if he/she has to involve a relative/friend because of the stigma attached to mental health issues.

15. To ensure quick progression to treatment, we would like communication support services to be booked as soon as possible after a patient with hearing loss has made the initial contact with early services.

Appropriate, evidence-based care and treatment for mental illness is available when required and treatments are delivered safely and efficiently

16. We agree that there is a need to make better use of existing resources. We believe that NHS Boards and key partners should invest in deaf awareness training sessions for their staff. The investment both in time and financially would mean that in the long run, staff would take less time to provide relevant support.

Care and treatment is focused on the whole person

17. We agree that services users should be at the centre of care and treatment and welcome the statement that "*services users are involved in decisions about their own care and treatment and in service design and planning.*" Involving people with hearing loss should not just mean consulting people face-to-face but also through written communication or through the internet. In a survey of our members (footnote 9) asking if they would be interested in having a greater involvement in local health services, 30% of respondents in Scotland said they would like to let the health services know what they think in writing. Twenty three percent of respondents would be interested in contact through the internet and one fifth of respondents stated that they would be interested in attending a local user group (with communication support). Only 11% of respondents would be interested in letting them know their views over the telephone. This is not surprising when the vast majority of respondents have some degree of hearing loss.

18. We are delighted with the statement that "*all such information should be provided in a way which renders it most likely to be*

understood." As mentioned above, this should include information written in plain English.

The role of family and carers as part of a system of care is understood and supported by professional staff

19. We agree that "*families and carers can play a crucial role in care and treatment.*" Family members and carers with hearing loss need to be provided with communication support to play this role. As mentioned above, this ranges from BSL/English interpreters to lipspeakers or notetakers.
20. Equally, we would like to ensure that family members and carers are never asked to act as intermediaries, for example interpreting on behalf of the patient, as this would be a breach of confidentiality.

The reach of mental health services is improved to give better access to minority and high risk groups

21. We strongly agree that "*some people can experience more difficulties than others in accessing mental health services that meet their needs.*" This includes people with hearing loss. We would recommend that services such as the Scottish Mental Health Service for Deaf People are sustained and, if possible, expanded. We would also like the information recorded about patients accessing services to include data on people's self-reported levels of hearing.

Case study – Scottish Mental Health Service for Deaf People

The Scottish Mental Health Service for Deaf People provides specialist support in Scotland for deaf people with mental health problems across Scotland. The service provides:

- Advice on 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 patients at request of or in liaison 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.

Mental health services work well with other services

22. We agree that patients in different settings such as acute general hospital may have different needs such as dementia. However, we would like to ensure that hearing loss does not lead to a misdiagnosis. For example, older people may be diagnosed with dementia simply because they cannot hear the questions asked.

The health and social care workforce has the skills and knowledge to undertake its duties effectively

23. We agree that "*having a trained, competent and supervised workforce is fundamental to ensuring safe care and treatment.*" We would like training to include deaf awareness training. This should be a stand-alone training session lasting at least half a day and repeated regularly so that staff continuously refresh their knowledge.

The process of improvement is supported across all health and social care settings

24. We agree that there can be efficiency opportunities in mental health services. We believe that specialist services such as the Scottish mental health service for deaf people will alleviate mental health staff's workload. We would like staff guidance to include information about such services and clear information on other support services including communication support services.

Conclusion

25. Action on Hearing Loss Scotland welcomes the Scottish Government's strategy *Mental Health Strategy for Scotland 2011-15*. People with hearing loss experience a number of barriers to accessing mental health services. Actions to ensure that mental health services are accessible to people with hearing loss include: all written information is written in clear English; all staff involved including frontline staff are trained in deaf awareness; patients with hearing loss are provided with timely communication support and given information on relevant support and services.

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