

Response ID ANON-4ZP6-AW3V-N

Submitted to **Consultation on the New National Health and Social Care Standards**

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About You

What is your name?

Name:

Mandy Reid

What is your email address?

Email:

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Are you responding as an individual or an organisation?

Organisation

What is your organisation?

Organisation:

Scottish Council on Deafness

Postcode

postcode:

G2 6LD

The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:

Publish response with name

We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

Yes

Did you attend an engagement event/workshop before completing this response?

No

Date:

Name of event:

Questions

1 To what extent do you think the Standards will be relevant and can be applied across all health, care and social work settings?

Agree

Comments:

But the Scottish Council on Deafness (SCoD) thinks that there is a principle missing.

The Scottish Government in co-production with ILIS - <http://www.ilis.co.uk/> - wrote the Principles of Inclusive Communication -

<http://www.gov.scot/Resource/Doc/357865/0120931.pdf>. As these standards refer to people's rights, including human rights, the overarching principle should be Inclusive Communication and Accessible Information.

This needs to be an explicit right - not simply implied. In fact, inclusion in terms of language and understandable information is not mentioned until Standard 2 and point 2.2.

According to the See Hear: Joint sensory impairment strategy, there are estimated to be around 850,000 people with hearing loss in Scotland, one in six of the population, and of those, 70% are over 70. It is projected that this figure will increase by 50% in the next 20 years. Also, according to the 2011 Census, 12,533 people use BSL as their first language at home. NDCS research has found that 40% of all children born with a hearing loss have additional disabilities (NDCS – Prevalence of additional disabilities with deafness: A review of the literature, 2012).

There are some 5,000 people who have significant hearing and sight loss, with most of those people being over 60 and having become dual sensory impaired as

part of the ageing process. There is, however, a notable number of people under 60 years of age who live with Usher Syndrome, a genetic or inherited condition that affects hearing, vision and balance. (See Hear: <http://www.gov.scot/Resource/0044/00448444.pdf>)

This is a significant number of people in Scotland who have a language/communication support need, and a reason why Inclusive Communication should be an overarching principle.

2 To what extent do these Standards reflect the experience of people experiencing care and support?

Neither agree nor disagree

Comments:

Deaf people regularly experience barriers in language and communication in health and social care settings. Deaf and Deafblind BSL users rarely receive care and treatment that is accessible in their first or preferred language, unless it is provided by a deaf organisation. Deafened people are too often expected to lipread in circumstances that are not conducive to good communication.

See answer to Q 1 as to why inclusive communication needs to be explicit in these Standards.

The SPSO upheld a complaint: The complaint which has been investigated is that it was unacceptable for the Board not to provide a BSL interpreter during Ms A's 12-day in-patient admission to the Hospital in July 2011 (upheld). <http://www.spsos.org.uk/investigation-reports/2013/march/tayside-nhs-board-0>. This is not an isolated incident nor is it the only incident looked at by the SPSO where a Deaf person has been isolated due to the lack of understanding of their language or communication support needs.

As they stand, the Standards do not adequately address the need for Inclusive Communication (a cultural mindset) and Accessible Information; without which means that people with a language/communication support need cannot make informed choices nor can they give informed consent; and their human rights are not upheld.

3 To what extent do you think this Standard describes what people should expect to experience from health, care and social work services?

3 - Standard 1: I experience high quality care and support that is right for me.:

Strongly Agree

Is there anything that is missing or should be added to this Standard?:

As above, explicit reference to language/communication support needs and providing the appropriate, professional registered language/communication support required. This is a human right and without it, how does a person with language/communication support needs "experience high quality care and support that is right for me"?

Any other comments:

While not ideal, the National Care Standards for Care Homes for people with physical and sensory impairments - <http://www.webarchive.org.uk/wayback/archive/20150305011322/http://www.nationalcarestandards.org/138.html> - understood the needs of deaf people to have language/communication support, staff who could communicate directly with the person, and environments that accommodate the person's hearing loss - loops systems, good lighting, appropriate signage, furnishings that help with the acoustics in a room. These are all important in the person's wellbeing and access to their rights.

4 To what extent do you think this Standard describes what people should expect to experience from health, care and social work services?

4 - Standard 2: I am at the heart of decisions about my care and support.:

Strongly Agree

Is there anything that is missing or should be added to this Standard?:

As above, without an explicit reference to the provision of appropriate language/communication support and staff who can communicate directly with the person using the services, a person with language/communication support needs, whether deaf or hearing, cannot be "at the heart of decisions about 'my' care and support".

"2.2 I receive and understand information and advice in a format or language that is right for me, including using independent advocacy if I want or need this." Independent advocacy is not a substitute for language/communication support and should not be included in this statement.

It should read "I receive appropriate language/communication support and information and advice in a format or language that is right for me.

Another statement would be "If I want or need independent advocacy, this will be available to me."

"2.4 I am supported to communicate in a way that is right for me, at my own pace, by people who are sensitive to me and my needs." Communication is a basic human right. Not sure how this fits with "compassion"? This should be an explicit standard on its own.

Any other comments:

For example, too often professionals expect family members to translate/interpret for a Deaf/Deafblind person.

When this happens, how can the professional know that what is being said is what the Deaf/Deafblind person is saying or what the family member wants. They cannot. This is also a breach of Article 8: Right to a private and family life.

If independent advocacy is mentioned, then the government needs to invest more widely in independent advocacy as well as providing independent advocacy organisations the necessary funds to provide language/communication support so that they can work with people with language/communication support needs.

5 To what extent do you think this Standard describes what people should expect to experience from health, care and social work services?

5 - Standard 3: I am confident in the people who support and care for me.:

Agree

Is there anything that is missing or should be added to this Standard?:

see comment below.

Any other comments:

Deaf people and other people with language/communication support needs will only have confidence in the people who support and care for them when these people can communicate directly with them. This needs investment in training and personal development, which needs to be part of the work done in tandem with the modernisation of the National Standards.

6 To what extent do you think this Standard describes what people should expect to experience from health, care and social work services?

6 - Standard 4: I am confident in the organisation providing my care and support.:

Agree

Is there anything that is missing or should be added to this Standard?:

Communication is the key for this to be true.

Any other comments:

As above -a commitment to inclusive communication needs to be explicit throughout all of the standards; as does the provision of appropriate, registered professional language/communication support.

7 To what extent do you think this Standard describes what people should expect to experience from health, care and social work services?

7 - Standard 5: And if the organisation also provides the premises I use.:

Agree

Is there anything that is missing or should be added to this Standard?:

There is no mention of having an "assistance dog" staying with the person, only pets are mentioned.

Any other comments:

Acoustics in buildings affect a deaf person's enjoyment of their surroundings and life. Do premises have hearing loops; do they have flashing alarms or vibrating pads that can be given to people; what systems do organisations use for people to contact them - are they accessible? Can people get into the building? If there is a door entry, how will a deaf person access services? If the person is called for their appointment, how will a deaf person know it is their turn?

Communication is more than one to one and face to face.

8 To what extent do you think this Standard describes what people should expect to experience from health, care and social work services?

8 - Standard 6: And where my liberty is restricted by law.:

Agree

Is there anything that is missing or should be added to this Standard?:

Even more important that language/communication support needs are looked at. For example, the SPS is looking at how to communicate with deaf prisoners as most communication is verbal and prisoners are not allowed mobile phones.

Any other comments:

9 To what extent do you think this Standard describes what people should expect to experience from health, care and social work services?

9 - Standard 7: And if I am a child or young person needing social work care and support.:

Is there anything that is missing or should be added to this Standard?:

Any other comments:

10 To what extent do you agree these new Standards will help support improvement in care services?

Neither agree nor disagree

Comments:

As they stand, SCoD does not think that they will support improvement in care services for deaf people in Scotland. There is too little emphasis on good communication, inclusive communication and accessible information.

11 Is there anything else that you think needs to be included in the Standards?

Yes

If yes, please provide details:

See all the comments above on the Principles of Inclusive Communication and the need for accessible information, including training for frontline and delivery staff.

12 Is there anything you think we need to be aware of in the implementation of the Standards that is not already covered?**Comments:**

see comments above.

13 What should the new Standards be called?

National Health and Social Care Standards

If you answered other, please provide details:**14 Any other comments, suggestions?****Any other comments, suggestions?:**

The final version of the standards need to be accessible and portable. Not everyone has access to or can use online services; first language BSL users need information in BSL not in English or Easy Read (this needs to be portabl too - on DVD, for example).

15 We recognise that people may have more than one experience of / involvement with health and care services. For example; you may work in a hospital or care home and also be a registered carer for a friend or relative receiving care services. For the purposes of this consultation please indicate the main capacity in which you are responding.

As a representative of an organisation / service provider

Acute health care (emergency care, hospitals etc), Primary health care (GP and other community health services), Independent health care, Adult social care, Early learning and childcare, Social work (including fostering, adoption, care homes for children and young people), Community justice, Other: (please state below)

If you answered other, please provide details:

Third sector and private sector support services, independent advocacy

16 Once finalised these new Standards will be made available in various formats. It would be helpful to know which format(s) may be required. Please indicate from the list below which formats you are most likely to use.**Other languages (please indicate which)::**

British Sign Language - The BSL version needs to be interpreted not just translated, so that it makes sense and Deaf BSL users understand some of the terms used.

17 Please indicate how you are most likely to access these Standards:

Both

Evaluation

Please help us improve our consultations by answering the questions below. (Responses to the evaluation will not be published.)

Matrix 1 - How satisfied were you with this consultation?:

Neither satisfied nor dissatisfied

Please enter comments here.:

Was the consultation document available in BSL? Haven't seen one, but may have missed it.

Matrix 1 - How would you rate your satisfaction with using this platform (Citizen Space) to respond to this consultation?:

Neither satisfied nor dissatisfied

Please enter comments here.:

Not the most accessible space. Would be better if we could save as we go, but not simply "save and come back later" - not clear if this facility is available.