

Briefing for the Cross Party Group on Deafness:

2021 Census Question on Health and Care

Background

In the 2011 Census, the Scottish Government added in a question listing a number of health conditions, including deafness as a harmonised question with other government surveys.

The question reads:

“Do you have any of the following conditions which have lasted, or are expected to last, at least 12 months? • Tick all that apply.

- Deafness or partial hearing loss
- Blindness or partial sight loss
- Learning disability (for example, Down’s Syndrome)
- Learning difficulty (for example, dyslexia)
- Developmental disorder (for example, Autistic Spectrum Disorder or Asperger’s Syndrome)
- Physical disability
- Mental health condition
- Long-term illness, disease or condition
- Other condition, please write in”

Prior to the 2011 Census, SCoD and its members attended a number of events organised by the Scottish Government and the then General Register Office Scotland (GROS), to ask that the question be worded to cover the four pillars of deafness: Deaf Sign Language Users, Deafblind, Deafened, and Hard of Hearing to give the Scottish Government, public bodies and others who use the Census real and meaningful data that could be used for future planning of information and services. SCoD also wrote to Shona Robison, Minister for Health and to Mohammed Sarwar MP on the matter.

Context

The Scottish Government and the National Records of Scotland are consulting on the 2021 Census questions, including the health question as the question that was asked in the 2011 Census did not give the data that is needed.

Many people did not seem to understand the question and there were 1,500 different illnesses and conditions given in the text box.

The government is keen to do away with the text box due to the cost of assigning code to each of the additional conditions, disabilities or illnesses mentioned by those filling in the form.

The consultation events looked at possible options.

Before the events, there was no proposal on the table to change the “deaf” part of the question, as our 2011 Census request was seen as a “want” not a “need”.

“Need” NOT “Want”

The collection of more detailed data in the 2021 Scottish Census is not a want, but a need.

There will be a significant financial cost to Scotland in terms of health, social care, mental health and information services if the Scottish Government and public bodies do not know have centrally held data on the numbers of people in Scotland across the four pillars of deafness, their age and where they live.

Why?

Research shows that numbers of people with a hearing loss increases exponentially with age, so 40% of 40year olds will have some degree of hearing loss; 60% of 60year olds; and 80% of 80 year olds. With the continuing prospect of an increased aging population in Scotland, this means that there will be an increased financial implications in terms of accessible services and information in older people’s services.

“See Hear: A strategic framework for meeting the needs of people with a sensory impairment in Scotland” (<http://www.gov.scot/Publications/2013/04/2067>) is now in its fourth year. the first recommendation in the strategy is that all

“Local partnerships should consider options for the introduction of basic sensory checks, for example, for people of a certain age, and at agreed times in their care pathway.”

At this time, this recommendation is still being considered. It could provide at least some data that would be relevant, but it will take time to implement and it will not necessarily be implemented at the same life stages throughout Scotland.

All babies born in Scotland are subject to newborn screening. This gives some data but as it is relatively new, it will have an impact on the provision of Early Years support and education planning, but is not of use when looking at service and information provision for older children, adults and older adults.

Across the four pillars of deafness, individuals’ language/communication support needs are very different. For example, the British Sign Language (Scotland) Act 2015 will help to develop a range of services and initiatives to support Deaf and Deafblind British Sign Language (BSL) users in their day to day lives as citizens in Scotland. It will have a degree of impact on the lives of other deaf people as frontline staff in service provision becomes more deaf aware. And the questions asked in the Census will help to track changes and trends in the promotion and understanding of BSL in Scotland which is the main purpose of the BSL (Scotland) Act. People who are Deafened or Hard of Hearing will not necessarily have their language/communication support needs met as a result of the Act or as a result of the increased deaf awareness. The additional questions in the 2021 Census will not add any meaningful data to services and information provision to help with their language/communication support needs.

In terms of the social model of disability and taking a person-centred, rights-based approach to the provision of services and information, all people who experience deafness across the four pillars of deafness face similar barriers to active citizenship in terms

of social isolation, lack of accessible information, a lack of frontline staff who can communicate sufficiently well and directly with individual service users to ensure that deaf people in Scotland have the same access to informed choices and consent as their hearing peers.

Approximate numbers of deaf people in Scotland

SCoD and its member organisations recognise that between 1 in 5 and 1 in 6 people in Scotland have some degree of hearing loss. This is a significant minority of people with a disability in the hearing world. It may be the biggest minority in Scotland.

The population in Scotland on Census day in 2011 was **5,295,403**.

One in six of the population equals **882,567** or **16%** of the population

One in five of the population equals **1,059,081** or **20%** of the population.

The Census figures for people who identified as having “Deafness or partial hearing loss” was **350,954** or **6.6%** of the population.

The Scottish Government is aware that there are problems with the way the question is worded and have said that the information gathered is not necessarily accurate. If the research figures are more accurate than the data gathered in the 2011 Census, the government is looking at a huge deficit in spending for a significant number of people in the future, especially with an increasingly older population.

The cost of deafness to society

As with all other disabilities, deafness comes with a cost to society and to government. People who are deaf are at a distinct disadvantage in a hearing world in a way that others with a disability are not.

The increased use of technology has helped many disabled people who, without it, would be socially isolated. There is plenty research

that shows that people who are socially isolated are more likely to have physical and mental health issues than those who are connected to and active in their communities. While the use of technology can support some deaf people – for example, Deaf BSL users who would have to travel to meet people who use the same language can now use Skype or Facetime to communicate with friends and family. Public services are more accessible due to online interpreting services such as contactSCOTLAND-BSL. YouTube and Facebook has enabled services to produce information in BSL and distribute it online so that Deaf and some Deafblind BSL users are much more informed than they were previously, although it is recognised that there is still a long way to go with producing accessible information.

On the other hand, those whose first language is a spoken language and who have a substantial hearing loss may be able to access information in their own language, but they become more and more socially isolated because society is not, in general, deaf aware and friends and families do not know how to communicate with someone who cannot hear. There is still a huge stigma involved in admitting to not being able to hear and many people will not go and get tested because of this.

Summary

There are between 882,567 and 1,059,081 people with some degree of hearing loss in Scotland. The 2011 Census recorded the profiles of 350,954 of them.

Using the social model of disability and a person-centred, rights-based approach to the provision of services and information in Scotland which now has an aging population, the government needs to know where its population who have a hearing loss across the four pillars of deafness are.

Why? Because without accurate information, deaf people in Scotland, who are a significant, if not the biggest minority, will become a financial burden to service and information provision in the near future.

Prior to the 2011 Census, SCoD was told that it would cost too much to add the extra boxes to the Census form – to include Deaf Sign

Language User, Deafblind, Deafened and Hard of Hearing – and if this level of breakdown was given for “deafness or partial hearing loss”, all other organisations/bodies would want a similar breakdown in the question.

But without this information, what will the financial cost be to Scotland as a whole in terms of unmet need?

There is no accurate data collection of the numbers of deaf people in Scotland. The most obvious place to gather this information may be from primary health care settings as most people will at some point have contact. But it is not gathered here. The majority of people with a hearing loss will not be in contact with disability services or social work and social care services; although those with additional health problems or disabilities may be.

There is no other method of gathering accurate data on the number of people with a hearing loss in Scotland. This data collection is not a “want” of the deaf sector in Scotland; it is a government “need” to ensure parity for deaf people with their hearing peers.

Please support our request to extend the health question to:

**Deaf Sign Language User
Deafblind
Deafened
Hard of Hearing**

With explanations of each term in the guidance notes, and for it to be included in both the online version AND the paper version of the 2021 Census form.