

Census 2027 Consultation

Chime Submission

January 2023

1.0 Introduction

1.1 Chime is the National Charity for Deafness and Hearing Loss. Chime was founded in 1964 and is dedicated to a society where deafness or hearing loss does not limit individual potential, personal choice or quality of life. Chime works to achieve this through advocating for a more accessible and inclusive society and providing a range of personal support services for Deaf and Hard of Hearing people. Chime's services entail a holistic approach, addressing the person's social, technological and emotional needs.

1.2 A significant portion of the population is affected by deafness or hearing loss. Approximately 200 children are diagnosed each year with hearing loss, with the majority diagnosed within a few months of birth. The Deaf community has approximately 5,000 members whose primary language is Irish Sign Language (ISL). Those who have acquired a hearing loss in adulthood are a much larger group. The HSE estimates that 8% of all adults (approximately 300,000 people) have a moderate or greater hearing loss and require audiological support. The prevalence of hearing loss increases greatly in later life, so that by the age of 70 approximately 50% of the population have acquired a significant hearing loss.

1.3 Chime welcomes the public consultation on Census 2027 and the opportunity to input into the process. We have previously made submissions on Census consultations (as DeafHear – our previous brand name which changed to Chime in 2018). I have included our most recent submission on Census 2021 in 2017 in Appendix I. While some changes were made in the terminology used, (e.g. the omission of the word 'serious' – see also Appendix II), we still believe that the terminology used in the Census forms to date in relation to deafness and hearing loss are problematic.

2.0 Current position

2.1 At present there has been limited data published from Census 2021. There has been no data published on the numbers of people with deafness, 'hearing impairment' or who use Irish Sign Language to communicate, and believe this data will not be available until June 2023. This means that it is difficult to evaluate what impact, if any, the changes to the Census 2021 form have made in

terms of collating more accurately data on the prevalence of hearing loss, deafness and ISL usage amongst the Irish population.

2.2 Notwithstanding the absence of data from Census 2021, Chime remains of the view that the term 'hearing impairment' is not the optimal term to use in an Irish census form. It is essentially a medical term used by health professionals, while hearing loss is a term more widely used by the general Irish population to describe reduced hearing and/or an acquired hearing difficulty. We have already highlighted in our submission in 2017 how the term 'hearing loss' used in Scotland appears more likely to result in more accurate data collection in respect of this health condition (see Appendix I).

2.3 We also note the recommendation of the United Nations for *Population and Housing Censuses* that "questions on difficulty seeing/hearing should be asked with the use of glasses/hearing aids if they are usually worn" (Page 223)¹. We believe that it would be very helpful to include this recommendation in Census 2027. Ireland has a very low uptake of hearing aids compared to other developed countries, which results in significant negative population outcomes (e.g. see Department of Social Protection 2018 report on the Affordability of Hearing Aids²). Having data on hearing aid usage across the population would be very useful for health stakeholders in addressing the high level of unmanaged hearing loss in the Irish population.

2.4. In relation to the numbers of Deaf people whose first is ISL, Census 2011 census figures represented a significant underreporting of the actual numbers of Deaf people in the Irish population whose first language is ISL. It is likely that the same scenario will occur when the 2016 results are published. Again, we have outlined our view on this matter in our previous submission (see Appendix I).

3.0 Summary

3.1 Heretofore, data on deafness, hearing loss and use of ISL has been grossly underreported by Census reports. This is both unhelpful and a lost opportunity. It results in the dissemination of inaccurate data and creates further barriers in terms of making progress to address relevant issues (e.g. the low uptake of hearing aids in Ireland). We hope that the Census Advisory Group give due attention to these matters in preparing for Census 2027.

3.2 If there are any matters in this submission requiring further clarification, Chime will be happy to provide further information.

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Dublin 1
Email: Brendan.lennon@chime.ie

References

¹ United Nations 2015. *Principles and Recommendations for Population and Housing Censuses: the 2020 Round*.

(sourced online on Jan 9th 2023 at: <https://unstats.un.org/unsd/statcom/doc15/BG-Censuses.pdf>).

² Department of Social Protection 2020. *Report under Section 23 of the Social Welfare (no 2) Act 2019 on the Cost of Hearing Aids and the Adequacy of Financial Supports*.

(sourced online on Jan 9th 2023 at:

https://opac.oireachtas.ie/AWData/Library3/Documents%20Laid/pdf/EASPdoclaid240820a_26082090958.pdf)

Appendices

Appendix 1 : Chime (then known as DeafHear) Census submission 2017

Census 2021 Consultation

DeafHear Submission

November 2017

Introduction

DeafHear is a national charity working to improve the lives of Deaf and Hard of Hearing people. It was established in 1964 as the National Association for the Deaf. DeafHear's Vision is of an inclusive society where Deaf and Hard of Hearing people are fully integrated, with equality of opportunity and participation. It is our role to make this Vision a reality by promoting the equal rights of Deaf and Hard of Hearing people and enhancing their life opportunities.

There are approximately 5,000 Deaf people whose first language is Irish Sign Language, most of whom were born deaf, and all of whom face significant lifelong challenges in their daily lives, primarily due to communication issues.

There are over half a million people with some level of hearing loss in Ireland, with approximately 270,000 having a moderate or greater hearing loss. This is defined as a 'significant disabling hearing loss' by the World Health Organisation. The HSE estimate that 8% of the adult population in Ireland have a significant hearing loss. The prevalence of hearing loss increases with age: it is the third most common health condition in adults, and the most common in older adults, yet it is highly underdiagnosed and treated.

Context

The focus of this submission concerns the issues of hearing loss and deafness, and how they are addressed within the census form. To date these issues have been highly underreported in previous census results in Ireland. For example, the 2011 census reported that 2% of the population had hearing problems: 92,060. This contrasts with the Scottish census of 2011 which found that 6.6% of the population had 'deafness or partial hearing loss' – a figure much closer to the known prevalence rates for significant hearing loss (i.e. moderate or greater hearing loss). DeafHear is concerned that the underreporting of hearing loss in census results reinforces the low awareness of the condition among the wider public and health professionals, resulting in a significant negative impact on population health.

Barriers

Although hearing loss is a common health condition, many people who acquire a hearing loss in adulthood are reluctant to accept and recognise their hearing loss. Some reasons for this include an association between hearing loss and ageing, a reluctance to wear hearing aids, a sense that hearing loss is something they 'have to live with' and a sense of embarrassment or stigma. Many people delay in acting on their hearing loss – only one in five of Irish adults with significant hearing loss have got hearing aids – and this is despite the fact that untreated hearing loss is strongly associated with increased stress, anxiety, depression and cognitive decline.

Most people with acquired hearing loss do not accept that they have 'deafness or a serious hearing impairment', while they may acknowledge that they have 'some level of reduced hearing'. For a lay person, a 'serious hearing impairment' often equates to an inability to hear any meaningful sounds. If the 2021 census is to accurately reflect the real numbers of people with significant disabling hearing loss, then appropriate wording must be used.

Solutions

DeafHear recently conducted some focus groups with people with acquired hearing loss. Participants variously described their experiences of hearing loss as frustrating, embarrassing, coupled with a lowering of self-confidence and increasing social isolation. They often don't see their hearing loss as a health condition, disability or something to be treated, but rather as an inevitable consequence of ageing and 'something one has to live with'.

A census question that reinforces these perceptions is likely to encourage an accurate response from individuals regarding their hearing status. Thus, the Irish 2011 census form which asked if a person has 'Deafness or a serious hearing impairment' resulted in just 2% of the population stating that they had such a hearing loss, which is approximately one third of the known rate from prevalence studies. Meanwhile, in the Scottish Census of the same year, 6.6% of their population responded as having 'Deafness or partial hearing loss'.

Therefore, DeafHear propose that the wording in relation to the deafness/hearing loss question in the census form regarding long-lasting conditions is amended to the Scottish wording, i.e.:

'Deafness or partial hearing loss'

We believe that an additional advantage of using a similar wording to Scotland's form is that it could provide a baseline of sorts to compare responses between the two countries. DeafHear doesn't believe that the headline question, ('Do you have any of the following long-lasting conditions or difficulties?'), needs to be changed, though we would also be open to using the equivalent wording in the Scottish census form.

Irish Sign Language

Previous censuses have also greatly underreported the number of people who are Deaf and use Irish Sign Language (ISL) as their primary to communicate. This outcome was definitely unhelpful in trying to advocate for appropriate access to services for this minority group. The low number of responses may be due in part to the social marginalisation that this group of people experience on a daily basis, but the structure of the question itself was also unhelpful.

The structure of the question in the census form contributed to confusion among some Deaf people we have spoken to. For example, it is not uncommon for a Deaf person whose first language is ISL not to use this language primarily in their home. The majority of Deaf people are born into hearing families, and it is the reality that many family members do not become fluent in ISL (often because in the past the State encouraged them not to do so!). But the person uses ISL to communicate with friends and colleagues outside the home and to access services with the support of interpreters. Therefore, the census form wording (2011) 'Do you speak a language other than English or Irish at home?' would not

apply in many instances. Also, one does not ‘speak’ Irish Sign Language’, so the wording of the question is potentially offensive!

Thankfully, since the last census considerable progress has been made toward recognising ISL as an official language within the State, and it is expected that this will be enacted before the end of 2017. Therefore we believe that the language question should explicitly list the three indigenous languages recognised within the State. Suggested draft as follows:

What is the language you mainly use to communicate?

English

Gaelge

Irish Sign Language

Other...

Summary

The census provides a range of important information to Government and other stakeholders. There is a high level of public trust in the information generated by the census process. It is therefore important for a variety of reasons, some of which are outlined elsewhere in this submission, that every effort is made to ensure that the information generated is accurate. To date, this has not been the case with reference to deafness and hearing loss. We earnestly hope that the CSO will take on board the proposals we have made in this submission, and we will be available to assist in any way we can to ensure that the 2021 census provides more accurate data in these areas.

For further information on this submission please contact:

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DeafHear
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Dublin 1
Tel: 01-8175700
brendan.lennon@deafhear.ie

DeafHear November 2017

Appendix II: Emails between CSO and Chime re Census 2021 Form

From: Marcella.Joyce@cs0.ie [mailto:Marcella.Joyce@cs0.ie] **On Behalf Of** census2021consultation@cs0.ie
Sent: 06 June 2018 12:49
To: Brendan Lennon
Subject: RE: Census 2021 Consultation

Hi Brendan

Further to our conversations over the past weeks, I am following up with an email as promised.

You contacted CSO to express your dissatisfaction with two issues, one being the wording of the deafness element of the disability question and second being how Irish Sign Language is addressed as part of the languages question.

As the process to finalise the content in the Census Pilot Survey questionnaires has been completed, I regretfully informed you that we were not in a position to change the wording of either question. I explained the process by which the wording of the question was arrived at and offered some alternative survey suggestions on the disability question.

Census Questions on disability

The decision on the wording of the questions to be tested in the Pilot survey is decided by the Census Advisory Group (CAG). The framing of the disability question, which was your main concern, was discussed at the first meeting of the CAG held on Dec. 12th, 2017. Members of the CAG received all submissions related to health and disability made as part of the public consultation prior to the meeting. The CAG decided that a sub-group should be formed to discuss in greater depth the issues around the health and disability questions. The sub-group meeting was held on Jan. 22nd, 2018 and attendees were also provided with the relevant submissions, including the one from DeafHear and the discussion around disability was framed in that context.

The sub-group reflected on the need to update the disability questions that were used in Census 2016, and in particular to move some way towards the Washington Group formulation when testing new variants of the questions in the 2018 Pilot in line with several of the submissions received. However, there was also strong support for the questions as they were framed in 2016 and the benefit of maintaining as much comparability over time as possible was discussed. It was recommended that new variants of Questions 16 and 17 from Census 2016 would be tested in the Pilot and that a balance would be struck between incorporating the Washington Group approach towards measuring intensity of experience and maintaining the wording used in 2016. The group also recommended that the 2016 formulation of the questions be retained as a control in half of the Pilot sample, to provide the most accurate assessment of how the new questions had been answered. This decision entailed that only one alternative formulation of the two questions would be tested in the Pilot.

In relation to the question 16, DeafHear had requested the wording "Deafness or a serious hearing impairment" be replaced with "Deafness or partial hearing loss". This submission was discussed, and the group recommended the removal of the word "serious" while the word "impairment" was to be retained.

The partial incorporation of the Washington Group formulation entailed that the response options to all of the categories of disability would be

- 1) Yes - to a great extent,
- 2) Yes - to some extent,
- 3) No

The full versions of the questions recommended for testing by the sub-group were as follows:

16 Do you have any of the following long-lasting conditions or difficulties?			
	1 YES, to a great extent	2 YES, to some extent	3 NO
(a) Blindness or a vision impairment	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
(b) Deafness or a hearing impairment	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
(c) A difficulty with basic physical activities such as walking, climbing stairs, reaching, lifting or carrying	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
(d) An intellectual disability	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
(e) A difficulty with learning, remembering or concentrating	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
(f) A psychological or emotional condition or a mental health issue	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
(g) A difficulty with pain, breathing or any other chronic illness or condition	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

17 As a result of a long-lasting condition, do you have difficulty doing any of the following?			
<i>Include issues due to old age</i>			
	1 YES, a lot	2 YES, a little	3 NO
(a) Dressing, bathing or getting around inside the home	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
(b) Going outside the home alone to shop or visit a doctor's surgery	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
(c) Working at a job or business or attending school or college	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
(d) Participating in other activities, for example leisure or using transport	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

The CAG reconvened on Feb. 21st, 2018 and was presented with a report on the sub-group meeting including these recommendations. The CAG approved the approach recommended within the sub-group.

Foreign Languages

At the first meeting of the CAG, CSO informed the group that the data generated from the languages question (Question 15 on Census 2016) was widely used, in particular in identifying the prevalence of where languages other than English and Irish were spoken, and to facilitate users in tailoring their service provision accordingly.

Key users of the data deriving from the question include the HSE, commercial bodies, IDA Ireland and researchers. CSO gave its view that the question worked well and should be retained for Census 2021, and therefore not be tested in the Pilot Survey. The CAG agreed with this recommendation.

Further detail on the consultation process can be found here:

<https://www.cso.ie/en/census/census2021consultation/>

Upcoming Surveys

As mentioned there are three other surveys which may be of interest to you

- Labour Force Survey (LFS): The CSO are planning to introduce a special module on disability which will include the Washington Group Disability Questions (short set) in the Labour Force Survey in Q4 2018 - the results of this should be published in the middle of next year. Further details are available at:

<https://www.cso.ie/en/methods/labourmarket/labourforcesurvey/aboutthelabourforcesurvey/>

- European Health Interview Survey (EHIS): The CSO are also planning on conducting this EU survey in 2019, the questions here will focus on hearing aid use. I have spoken to the Senior Statistician in this area, Paul

Crowley and he advised there was a similar survey conducted in 2015, due to the volume of data collected, not all results were published by CSO but can be made available on request. If you wish to do so, please contact Paul with details of the data you are requesting at Paul.M.Crowley@csso.ie

Further details on the specific questionnaire is available at <http://ec.europa.eu/eurostat/web/products-manuals-and-guidelines/-/KS-02-18-240?inheritRedirect=true> (P35-38 of the PDF on this page)

More general information on the survey (including other participating countries) is available at <http://ec.europa.eu/eurostat/web/microdata/european-health-interview-survey>

• **Healthy Ireland Survey** The Dept. of Health are also planning to conduct a survey which will include disability questions (incorporating hearing). This survey will take place in Q3 2019 with the results will be published in Q4 2019. The Dept. have indicated they would welcome submissions in March/April of 2019 and have asked that you channel any submissions you may have, through Rosalyn E. Tamming at the National Disability Authority. Rosalyn's email address is RETamming@nda.ie

Further information on this survey is available at <http://www.healthyireland.ie/accessibility/healthy-ireland-survey/>

I am acknowledging your continued dissatisfaction as expressed in our conversation on Monday June 28th last.

Notwithstanding the limitations as mentioned above, if I can be of further assistance please do not hesitate to get back in touch.

Best regards

Marcella

Marcella Joyce
Census 2021 Consultation
Central Statistics Office
01 8951446

▼ Brendan Lennon ---25/05/2018 14:57:35---***** Attachment(s)
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From: Brendan Lennon <Brendan.Lennon@deafhear.ie>
To: "census2021consultation@csso.ie" <census2021consultation@csso.ie>
Date: 25/05/2018 14:57
Subject: RE: Census 2021 Consultation

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http://cmsd02/vsm_live/ServiceManager.aspx?lite and request that the mail be released with the
attachment (s). If no contact is made within 7 days the message will be automatically deleted.

Hi Marcella,

No problem...talk to you Monday.

My mobile is probably best...086 8171583.

Kind regards

Brendan

From: Marcella.Joyce@cso.ie [<mailto:Marcella.Joyce@cso.ie>] **On Behalf Of** census2021consultation@cso.ie
Sent: 24 May 2018 15:14
To: Brendan Lennon
Subject: RE: Census 2021 Consultation

Hi Brendan

Sorry I missed you today. I am out of the office tomorrow.

I have just received the information I was waiting for and will call you again on Monday.

I was hoping to speak to you first, to talk through the information and will then follow up with an email.

Best Regards

Marcella

Marcella Joyce
Census 2021 Consultation
Central Statistics Office

Brendan Lennon ---18/05/2018 14:14:51---***** Attachment(s) image001.gif has been stripped from t

From: Brendan Lennon <Brendan.Lennon@deafhear.ie>
To: "census2021consultation@cso.ie" <census2021consultation@cso.ie>
Date: 18/05/2018 14:14
Subject: RE: Census 2021 Consultation

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Hi Marcella,

Thanks for the update for now.
Have a good weekend,
Brendan

From: Marcella.Joyce@cso.ie [<mailto:Marcella.Joyce@cso.ie>] **On Behalf Of** census2021consultation@cso.ie

Sent: 18 May 2018 11:52
To: Brendan Lennon
Subject: Re: Census 2021 Consultation

Hi Brendan

Unfortunately, I did not get back to you as planned. I am still following up on areas and one person I need to speak to was out this week, but should be in next week. Once I have spoken to them I will revert straight away. Again, I apologise but feel it is better to give as complete and detailed a response as possible.

Best regards

Marcella

Marcella Joyce
Census 2021 Consultation
Central Statistics Office

Brendan Lennon ---10/05/2018 14:45:41---Hi Marcella, no problem and thanks for update. Brendan Sent from my iPhone

From: Brendan Lennon <Brendan.Lennon@deafhear.ie>
To: "census2021consultation@cs0.ie" <census2021consultation@cs0.ie>
Date: 10/05/2018 14:45
Subject: Re: Census 2021 Consultation

Hi Marcella, no problem and thanks for update. Brendan

Sent from my iPhone

On 10 May 2018, at 14:30, "census2021consultation@cs0.ie" <census2021consultation@cs0.ie> wrote:

Hi Brendan

Further to our telephone conversation. I had hoped to get back to you with a full response before now, however, I am still following up on some points. I hope to have these resolved by tomorrow or early next week and will be back in touch then.

Best regards

Marcella

Marcella Joyce
Census 2021 Consultation
Central Statistics Office

<[graycol.gif](#)>Brendan Lennon ---03/05/2018 09:45:47---Hi Marcella, I just spoke to your colleague Sinead this morning, and she suggested I email you at thi

From: Brendan Lennon <Brendan.Lennon@deafhear.ie>
To: "census2021consultation@cs0.ie" <census2021consultation@cs0.ie>
Date: 03/05/2018 09:45
Subject: FW: Census 2021 Consultation

Hi Marcella,

I just spoke to your colleague Sinead this morning, and she suggested I email you at this address.

I briefly highlighted my concerns to Sinead, which included:

- the concerns we raised in our submission to the consultation in November 2017;
- the fact that the CAG minutes of December 12th indicated that the CSO will invite organisations not represented at the main CAG meeting but who made a submission to the sub group addressing the disability questions, but we were not in fact invited to the sub group meeting;
- and of most concern, no indication in the minutes of February 2018 that the issues we raised in our submission are being considered.

I would appreciate it if you were able to give me some further clarity on these issues at this point. My mobile is 086 8171583.

Kind regards

Brendan

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People who seek help with their hearing loss experience better quality of life. Find out more at www.mindyourhearing.ie

From: Marcella.Joyce@cso.ie [<mailto:Marcella.Joyce@cso.ie>] **On Behalf Of** census2021consultation@cso.ie

Sent: 13 April 2018 12:56

Subject: Census 2021 Consultation

Update on the consultation process

Good Afternoon,

At the outset we would like to thank you for the time you took to make a submission on the questionnaire content for the 2021 census of Population. We also wish to inform you of developments and draw your attention to our website where our updates are recorded.

Following the submission stage, to which we had an unprecedented response, the Census Advisory Group (CAG) was established. The remit of the group is to assist the CSO in the framing of the Census 2021 questionnaire.

To date the group has met twice and have considered all submissions, both meetings were notable by their constructive and frank debates. CSO has also consulted with many relevant National bodies and other National Statistical Institutes on the framing of various questions.

The questions are now ready for testing in the Census Pilot which will take place in September of this year.

When the pilot is complete, and the results are analysed, the group will meet again to discuss the findings and recommend the final content of the Census 2021 questionnaire.

It is anticipated that this will happen in the first quarter of 2019. A final report on the Census Pilot will be posted on CSO's website in late Q1 or early Q2 2019.

The agreed questionnaire for Census 2021 is required to be submitted to government for final approval.

Please see the link below to our consultation page on the CSO website for details.

<http://www.cso.ie/en/census/census2021consultation/>

If you require further information, please get back in touch.

In conclusion, please note that all further developments will be updated on our website.

Thank you again for your interest in the census.

Best regards

Marcella

Marcella Joyce
Census 2021 Consultation
Central Statistics Office