DFI Response to Census 2027 Public Consultation

SUBMISSION TO THE CENTRAL STATISTICS OFFICE

January 2023

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Introduction

Who are the Disability Federation of Ireland (DFI)?

The Disability Federation of Ireland (DFI) represents the interests and the expectations of people with disabilities to be fully included in Irish society. It is comprised of member organisations that represent and support people with disabilities and disabling conditions. The vision of DFI is an Ireland where people with disabilities and disabling conditions are fully included and enabled to reach their full potential in the spirit of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). DFI's mission is to advocate for the full and equal inclusion of people with disabilities and disabling conditions in all aspects of their lives. Learn more about our work on our website.

There are over 100 organisations who are affiliates or associates of DFI. DFI's members include a range of different types of disability organisations including service providers, Disabled Person's Organisations, condition-specific organisations, advocacy organisations, family-led organisations etc. They include organisations focused on physical, sensory, intellectual and neurological disabilities and disabling conditions. Our full list of members is here.

Disability and the Census

The Census is an important source of statistical data on disability in Ireland. The data provided by the Census on disability has many important uses including analysing population trends, and planning health and social care, housing, education and other services in line with demographics.

DFI has utilised the Census data to illuminate the living situations of people with disabilities on both a national and county level. See the national and county disability profiles on our website which provide data on prevalence of types of disability, education and employment status of disabled people, and access to transport and housing. This type of data is vital in highlighting gaps, assessing needs and advocating for the services and supports that are required to meet population needs.

It is important that the data collected in Census 2027 continues to allow for this type of evidence to be extracted. There are also areas where more information would be useful in providing a more comprehensive picture of the lives of disabled people in Ireland. Sometimes a lack of more detailed and specific data can cause challenges to those working to make policies on a range of issues, including disability. Such data can support disability and equality proofing of policy decisions and actions. The UN Committee on the Elimination of Discrimination against Women, in their most recent report on Ireland in 2017, highlighted this concern, noting that "the Committee is concerned at reports of the lack of data disaggregated by sex, gender, ethnicity, disability and age."[1] The UN Committee on Economic, Social and Cultural Rights made a number of requests for data disaggregated by disability in their list of issues (March 2022) for the fourth report on Ireland.[2]

This submission outlines some areas where further evidence relating to disability could be collected. We also support the submissions of other disability organisations, including DFI members and other national umbrella organisations. We recommend that the CSO convene a specific discussion with disability organisations to further tease out, discuss and refine priority areas where there are data gaps collectively.

UN CRPD Requirements

Article 31 of the UN Convention on the Rights of Persons with Disabilities (UN CRPD) relates to 'Statistics and data collection.' It requires state parties to "collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention." It also states that data collected must comply with legally established safeguards, including data protection legislation and with human rights and ethical principles.[3] This data should support the formulation of policy in a range of areas key to the UN CRPD, including the right to employment, to an adequate standard of living and

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[1] UN Committee on the Elimination of Discrimination Against Women (2017). Concluding observations on the combined sixth and seventh periodic reports of Ireland.

[2] UN Committee on Economic, Social and Cultural Rights (2022). List of issues in relation to the fourth periodic report of Ireland.

[3] UN CRPD Article 31

social protection, and to independent living, amongst many other important areas.

Accessibility

The process of completing the Census must be accessible for people with disabilities. For example, Easy Read and Plain English guides should be provided to support the completion of the Census. The Census form itself should be available in a variety of accessible formats. Organisations including the National Disability Authority, National Adult Literacy Agency and National Council for the Blind Ireland offer provide guidance and support in this area.

The results of the Census must also be presented in an accessible manner so that people with disabilities can access the findings. This is referenced in Article 31 of the UN CRPD which states that “State Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.” Currently the CSO website is partially compliant with Web Content Accessibility Guidelines 2.1 level AA according to the accessibility statement on the website. The website states that work is underway to update older content to make it fully accessible. We support this work, and recommend that all future content is fully accessible and that the CSO works to fully comply with the level AA guidelines. The Census results should also be available in a variety of accessible formats.

National Disability Survey

Following the 2006 Census, a follow up survey of a sample of approximately 14,000 individuals who declared a disability in the 2006 Census took place.[4] This went into more depth on relevant issues relating to disability. This data has been used by many bodies, including the National Disability Authority to inform policy, and has proved extremely useful to a range of organisations. DFI recommend that a repeat of this survey takes place as soon as possible, given the length of time that has passed, to update this data. Ideally, this would take place following on from the 2022 Census.

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[4] CSO. National Disability Survey 2006

Disability, Health and Carers

The demographic data provided in the Census on the numbers of people with different disabilities/long lasting health conditions is extremely useful. This allows for a range of valuable data in relation to health outcomes, education, employment, housing situation etc. to be disaggregated by disability. There are a number of changes and additions in this section that could provide even stronger data in relation to disability.

Addition of Deafblindness

Deafblindness is the combination of significant auditory and visual impairments. Whether congenital or acquired, this combination can cause barriers to communication and learning that means that individuals affected cannot avail of programmes designed for the hearing impaired, for the visually impaired, or for severe disabilities. Supplementary assistance is often required to address the unique needs of people who are deafblind

Article 24 of the UN CRPD on Education explicitly recognises deafblindness as a condition that is different from deafness and blindness.[5] In addition, EU Written Declaration 1/2004 signed by Irish MEPs recognises deafblindness as a distinct disability and states that people who are deafblind should have the same rights as all other EU citizens.

In spite of this, incidences of deafblindness in Ireland is virtually unknown. https://disfed.sharepoint.com/:w:/s/dfipolicyandresearch/EfrWHgRl3bNChr-6BxMnsd4Bu7fkib1f2_NOCUp10dR7AAOne study estimated that there could be as many as 17,000 individuals in Ireland with some level of combined hearing and vision loss.[6] Collecting this data directly in the Census would allow Ireland to understand more the prevalence and effect of deafblindness, and to meet international obligations to provide appropriate supports. The proposed change would alter Q15 in the sample questionnaire provided that the form reads:

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[5] UN CRPD Article 24

[6] European Deafblind Network (2014). Mapping Opportunities for Deafblind People Across Europe.

> *Do you have any of the following long-lasting conditions or difficulties:*
>
> *a) Blindness or a visual impairment*
>
> *b) Deafness or a hearing impairment*
>
> *c) Deafblindness or a combined visual and hearing impairment*
>
> *……etc.*

DFI's member organisation the Anne Sullivan Foundation provides advocacy, residential, day, respite, information, training and outreach and support services to individuals who are deafblind in Ireland. Further information on the requirement for Census data on deafblind prevalence is available in their submission as part of this consultation, which DFI supports.

Cost of Disability

The Census and other CSO data sources including the annual Survey on Income and Living Conditions (SILC) provide important data on the poverty and employment levels of disabled people. The annual SILC data provides extremely useful data that DFI (and many other disability organisations) make regular use of. These are significantly higher than the general population. The additional cost of disability has become an increasing area of policy focus that impacts on the poverty levels of households where someone has a disability. The government published a report prepared by Indecon International Research Economists in November 2021 on 'The Cost of Disability in Ireland.' [7] This report made use of Census data, as well as conducting in depth research including an extensive survey of disabled people. The report found that disabled people face extra costs of €8,700-12,300, as well as unaffordable extra costs of €2,706 per year.

To assist the government's ongoing policy response to the Census, we recommend that the Census collect data on additional costs faced by those who indicate that they have one or more longstanding conditions or difficulties. This would provide data at regular intervals and allow the government to analyse changes over time. For example, the Indecon's research took place before the current inflationary crisis. We recommend

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[7] Indecon International Research Economists (2021). The Cost of Disability in Ireland

the following question for those who indicate a long-lasting condition on Question 15:

> *Q Do you have to spend money on extra costs associated you're your long-lasting condition(s) or difficulty(/ies)?*
>
> *A Yes/no*
>
> *Q If yes, how much do you spend per week on this?*

Wheelchair Use and Mobility Aids

DFI support including a specific question regarding wheelchair use and mobility aids in the Census. There is no reliable up to date data available in Ireland regarding the number of people who use wheelchairs and other mobility aids. This data is essential in order to plan for an accessible public realm, public services, transport, housing etc. Many people with physical disabilities are not wheelchair users so this data cannot be extracted from the Census in its current form.

The following question should be included to capture this data:

Q. Do you use any of the following:

	Always	*Occasionally*	*Never*
Manual Wheelchair			
Power Wheelchair			
Mobility Scooter			
Wheeled Walker			

Or

Manual Wheelchair	*Always*	*Occasionally*	*Never*
Power Wheelchair	*Always*	*Occasionally*	*Never*
Mobility Scooter	*Always*	*Occasionally*	*Never*
Wheeled Walker	*Always*	*Occasionally*	*Never*

Mental Health/Psychosocial Disability

Capturing the prevalence of mental health difficulties/psychosocial disability is also important to understand and plan appropriate responses. The UN CRPD explicitly includes psychosocial disability. It is also valuable to understand how mental health difficulties can coexist alongside other disabilities and health conditions, and the impact this has on housing, employment etc.

Question 15 in the sample form allows people to identify if they have "(f) a psychological or emotional or mental health issue" as one of the categories. We support updating the language used to 'mental health difficulties,' in line with Ireland's national mental health policy 'Sharing the Vison,' and to include 'psychosocial disability' in line with the language of the UN CRPD, as awareness around disability rights and mental health difficulties is still low.

The inclusion of mental health difficulties as a standalone question would also provide valuable anonymised data. We suggest splitting question 17 'How is your health in general?' into two questions i.e.:

> *17. How is your physical health in general?*
>
> *18. How is your mental health in general?*

This would capture a broad picture of people's health more accurately, as well as allowing for a better comparison of any relationship between how people rate their physical and mental health.

Augmentative and Alternative Communication

The Census should gather data on those who use Augmentative and Alternative Communication (AAC). It is positive that Irish Sign Language is provided as one of the examples of an additional language spoke in the home on Q14. Additional information on other forms of communication could be requested as an additional option on Q16 in the sample form, such as:

> *Q. As a result of a long-lasting condition, do you have difficulty doing any of the following?*
>
> *A. …..*
>
> *(e) Difficulty communicating that requires the use of Augmentative and Alternative Communication (Lámh, Pictures, Technology, Gestures, Body Language etc.)*

Access to Health and Social Care Services

Information on access to health and social care services, and how people rate their access to these services, would be valuable. A generic question could be added after Q.17 on how people rate their health, such as:

> *Q. How would you describe your experience accessing health and social care services?*
>
> *A. Very good/good/fair/bad/very bad*

This would allow for insight into how people with different long-lasting health conditions and disabilities experience accessing health and social care services. It would also allow for analysis of geographical variations, and variation correlating to other factors including employment status, ethnicity, education level etc.

Q.23 allows respondents to identify if they provide unpaid personal care to a family member, neighbour or friend. However, there is no question that allows for a respondent to identify that they are *in receipt* of personal care, either from a family member or service provider. We recommend asking the following question mirroring the wording in Q24:

> *Q. Do you receive regular personal help or support from a family member, neighbour, or friend relating to a long term illness, health issue, or issue relating to old age or disability?*
>
> *(a) from a family member, neighbour or friend yes/no*
>
> *(b) home support from a social care service such as home care, Personal Assistance service, home help etc.   yes/no*

This question from the perspective of the person receiving care would provide a fuller picture of home care and family care in Ireland. Furthermore, there is a particular data gap in this area. The Department of Health's 'Disability Capacity Review to 2032',[8] which makes use of the Census data, among other data sources, acknowledges that there is a lack of systematic data on personal assistance and home help. It would be valuable if there was also scope for the respondent to indicate that they require support in the home but do not have access to this presently. This was a particular gap in the data available in the Disability Capacity Review that hinders policymaking in this area. We would be happy to discuss further the formulation of an appropriate question on this topic.

The inclusion of questions on access to specific disability and mainstream supports and services in the community would provide valuable data. Further consultation with disability organisations and other stakeholders would be needed to refine this question.

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[8] Department of Health (2021). Disability Capacity Review to 2032

Housing/Housing Characteristics

The data on housing in the Census is valuable in providing evidence on disabled people that can inform better planning. Recently, Census 2016 data was used in the National Housing Strategy for Disabled People, 2022-2027.[9] Census data was also used extensively in DFI and Citizens Information Board's report '[The Right Home: the Housing Needs of People with Disabilities,'](#) published in December 2022.[10]

Communal Establishments

Census 2016 provided data on the number of disabled people living in private households, communal establishments and who are homeless. A further breakdown of the Census 2023 on the different types of communal accommodation that disabled people live in would provide a clearer picture and allow for better planning. As noted in 'The Right Home' report, 'nursing and children's homes' is the most common type of communal establishment lived in by people with disabilities, but the CSO does not publish separate data for nursing homes and children's homes individually (p.30). This individual data would be very useful, particularly considering the government's policy focus on disabled people under 65 living in nursing homes, whose situation was highlighted in the Ombudsman's 'Wasted Lives' report.[11] There is no reliable data on the total number of disabled people under 65 living in nursing homes presently. Furthermore, there is no specific category of 'disability residential institution' among the types of communal establishments. Again, given the national policy commitment to decongregation and disabled people living in community rather than communal settings, this data would be valuable.

Community Group Homes

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[9] Department of Housing, Local Government and Heritage (2022). National Housing Strategy for Disabled People 2022-2027.

[10] Citizens Information Board and Disability Federation of Ireland (2022). The Right Home: The Housing Needs of People with Disabilities.

[11] Ombudsman (2021). Wasted Lives: Time for a better future for younger people in nursing homes.

‘The Right Home’ report also notes that there are in the region of 5,000 persons with a disability living in designated centres of less than 10 people, which may be enumerated as ‘private households’ on the Census (p.31). We recommend the Census form for private households include the option for people to select whether they live in:

- *A disability group home with up to 4 people*
- *In a disability residential service of 4-10 people*

Satisfaction with Housing Situation

A question on people’s levels of satisfaction would be beneficial. From a disability perspective, it would allow for comparing the satisfaction levels of those living in congregated settings, in their own home, with family, in private rental accommodation, social housing etc. More broadly, given the current housing crisis it would be useful to understand the proportion of the population who are satisfied with their current housing situation. A sample question could be:

Q. Are you satisfied with your current housing situation?

A. Very satisfied/Quite satisfied/Fair/Quite unsatisfied/Very unsatisfied

Social Housing

Accessing suitable housing is a particular challenge for disabled people. This was the case prior to the current housing crisis, and has been exacerbated due to the crisis. More data in relation to time spent on social housing waiting lists would support a deeper analysis of this challenge. We know anecdotally that many disabled people spend a long time on social housing waiting lists. However, as stated in ‘The Right Home,’ “there are significant shortcomings in certain data available, especially at Local Authority level, relating for example to the length of time people with disabilities spend on the social housing waiting lists and reasons for same” (p.12). While the number of households on waiting lists on the basis of disability is available through the Housing Agency’s annual Summary of Social Housing Assessments, this publication does not provide information on the length of time on the waiting list specifically for applicants with a disability. We recommend a question such as the following:

Q. Are you on a waiting list for social housing?

A. Yes/no

Q. If yes, how long have you been waiting for social housing?

A. Less than a year/between 1-5 years/between 5-10 years/more than 10 years

This would address a current data gap and allow for comparing the experience of disabled people and the general population, and indeed for analysis of other factors that correlate with longer waiting times. It could also be compared across different areas to see where there are particular challenges in terms of social housing delivery. This data would allow for better planning of housing delivery at national and local level.

Home Adaptations

A question should be included on whether people have special adaptations to their home, such as ceiling track hoists, bathroom adaptations, stair lift, assistive technology etc. Further consultation with disability organisations and local authorities could assist in refining such a question.

Other Areas for Consideration

There are some other areas relating to disability, including feedback from DFI members and other stakeholders, that could be considered for Census 2027 that we have not discussed in as much depth. We provide a short overview of some of these areas here:

- Question 19 in the sample form should include reference to those travelling to attend a day service
- Question H11 should include an option to indicate that respondents cannot access the Internet due to lack of coverage in their area
- Questions should be added on the availability, quality and accessibility of public transport
- Questions should be added related to educational supports for those with disabilities in early years, primary, secondary, further and higher education
- Include a question on whether children of respondents attend mainstream or special schools, or are in a special class
- The question on gender should include an option to select ‘other’ for those who identify as non-binary

We would recommend specific consultation with disability organisations, people with disabilities, and other relevant stakeholders to further discuss and refine these areas.

Conclusion

DFI welcome the public consultation on Census 2027. The Census is one of the most valuable sources of disability data that is available, and there is significant scope to improve this data which in turn would better inform policy making. DFI are open to discuss any of our recommendations, or other matters relating to disability more. We would strongly urge the CSO to continue to actively engage with disability organisations, people with disabilities and other stakeholders at all stages of Census development and through the Census Advisory Group process to ensure that the Census is accessible to disabled people and collects meaningful evidence about their lives that would have a positive impact on policymaking and planning processes.

DFI’s vision

An Ireland where people with disabilities are participating fully in all aspects of society.

DFI’s mission

DFI is a federation of member organisations working with people with disabilities to implement the UN CRPD and ensure their equal participation in society.

Four-year goal

Member organisations are actively involved in DFI, working to implement the UN CRPD and to achieve the equal participation of people with disabilities in society.

DFI, Fumbally Court, Fumbally Lane, Dublin 8
Tel: 01-4547978
Email: info@disability-federation.ie
Web: www.disability-federation.ie

Registered Charity Number: 6177 Company Number: 140048
Charities Regulator Number: 20010584

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