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The prevalence of intellectual disability: A comparison of national census and register records

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ABSTRACT

Background: International prevalence rates for intellectual disability vary widely with estimates often based on samples. In Ireland people with an intellectual disability are identified in the national census. Moreover, a national register of people receiving or requiring intellectual disability services is maintained and updated annually.

Aims: The prevalence rates from the census were contrasted with those from the register along with variations in prevalence across the 26 counties of Ireland.

Methods: 2011 and 2016 Census of Population prevalence per 1000 for children (aged 5–19 years) and adults (20 years and over) stratified by the 26 countries were contrasted with similar prevalence in the national register. Publically available data from the 2011 census in Northern Ireland and Scotland were obtained.

Results: The Irish census identified nearly twice as many children and adults than were on the national register. Prevalence rates also varied across the 26 counties; more so on the register than the census. The Irish census had lower prevalence rates than Northern Ireland but higher than Scotland.

Conclusions: Determining the prevalence of intellectual disability is challenging due to variations in terminology. A national register has advantages over reliance on census data for service planning.

1. Background

Intellectual disability is among the most common impairments with children and the number of adults with the condition is thought to be increasing due to longer life expectancy (World Health Organization, 2007). Internationally, attempts have been made to ascertain the prevalence of intellectual disability within countries. The highest estimates have come from low and middle-income countries but even in high income countries prevalence rates have varied from 3.31 to 36.75 per 1000; giving a pooled prevalence rate of 9.2 per 1000 (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011).

Various methodologies have been used to obtain prevalence estimates but the more reliable are likely to be those based on robust representative samples or better still on total populations (Friedman, Gibson Parrish, & Fox, 2018). However the latter invariably means relying on nationally collected datasets, such as census returns or national registers of persons with the condition (Westerinen, Kaski, Virta, Almqvist, & Livanainen, 2007). Equally such information is also needed to assure the representativeness of samples. Yet a survey of 12 countries covering over 150 population datasets relating to health or education for instance, found that only 25%

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screened for people with intellectual disability and only three countries at that time – Ireland, Northern Ireland and Egypt –included a question relating to intellectual disability in their population census (Fujiura, Rutkowski-Kmitta, & Owen, 2010).

In recent years, interest has grown in the use of administrative datasets for research studies and particularly the linking of anonymised data about individuals from different sources (Glasson & Hussain, 2008). Examples are starting to emerge in the field of intellectual and developmental disabilities (Hughes-McCormack et al., 2018; Trollor, Srasuebkul, Xu, & Howlett, 2017). The utility of population data for research relating to intellectual disability, depends on these persons being identified as such within the datasets (Lin et al., 2014). Differing terminology exists and includes learning disability, learning difficulties, cognitive impairment and developmental disability. However these terms may capture more persons than those who meet the accepted definition of intellectual disability which has remained largely unchanged in recent decades although the newly issued International Classification of Diseases refers to 'disorders of intellectual development' (World Health Organization, 2018).

A further difficulty in estimating prevalence may be the use of self or proxy reporting inherent in many administrative datasets. This runs the risk of people over- or under-reporting the presence of an intellectual disability depending on the benefits or risks they perceive to doing so. The application of standard criteria across informants is one possible solution (Friedman et al., 2018). For example, the use of registers of person who have been assessed as meeting the criteria for intellectual disability and who are then entitled to health, educational or social care services. The register also needs to include persons who do not currently access such services as well as those who do or have done. Often this information is collected by services but rarely is it collated to provide a national database of persons with an intellectual disability (Bakel et al., 2014). However such a dataset could help to validate information obtained in a national census or contained in other administrative systems especially when data linkage is possible.

The Republic of Ireland offers a unique opportunity internationally to contrast the prevalence rates of persons with an intellectual disability derived from a national census with those from a national register of persons in receipt of, or eligible to receive, intellectual disability services. Moreover two neighbouring jurisdictions – Northern Ireland and Scotland – included in their last census held in 2011, a question relating to intellectual disability – albeit using different terminology. Their prevalence can be compared with that found in the Republic of Ireland census for that same year. Also the Irish census was repeated in 2016 thereby providing an opportunity to assess the robustness over time of the prevalence rates identified. In addition, the Irish data could also be used to examine the intra-country variations in prevalence arising from both census and register records. In sum, the main aims of the study were:

- To compare the prevalence rates of children and of adults recorded as having an intellectual disability in the national census in Ireland in 2011 and 2016 with those registered on the national intellectual disability database for the same years.
- To examine intra-country variations in Ireland of the prevalence rates.
- To contrast the findings with census prevalence in Northern Ireland and Scotland.

2. Method

2.1. National census

A national census is undertaken in Ireland every five years. This records each person resident in the state on a specific date and alongside other information, the question is asked: "Do you have any of the following long-lasting conditions or difficulties?" A listing of seven impairments is given of which 'an intellectual disability' is one and to each, the response by proxy or self-report is Yes or No (see Table 1).

Table 1
The options provided in each national census.

Ireland	Scotland	Northern Ireland
"(a) Blindness or a serious vision impairment. (b) Deafness or a serious hearing impairment. (c) A difficulty with basic physical activities such as walking,climbing stairs, reaching,lifting or carrying. (d) An intellectual disability (e) A difficulty with learning, remembering or concentrating. (f) A psychological or emotional condition. (g) A difficulty with pain, breathing, or any other chronic illness or condition."	"Developmental disorder (for example, Autistic Spectrum Disorder or Asperger's Syndrome). Learning difficulty (for example, dyslexia). Learning disability (for example, Down's Syndrome). Blindness or partial sight loss. Deafness or partial hearing loss. Mental health condition. Physical disability. Long-term illness, disease or condition. Other condition, please write in."	"Deafness or partial hearing loss. Blindness or partial sight loss. Communication difficulty (a difficulty with speaking or making yourself understood). A mobility or dexterity difficulty (a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, lifting or carrying). A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty. An emotional, psychological or mental health condition (such as depression or schizophrenia). Long-term pain or discomfort. Shortness of breath or difficulty breathing (such as asthma). Frequent periods of confusion or memory loss. A chronic illness (such as cancer, HIV, diabetes, heart disease or epilepsy). Other condition. No condition."

Historically Ireland is divided into 26 administrative counties and although some local government reorganisations have since taken place, the counties are still largely used as the basis of service delivery and planning. For the 2011 and 2016 Census, the Central Statistics Office provided the total number of children (aged 5–19 years) and adults (20 years and over) reported to have an 'intellectual disability' within each of the 26 counties of Ireland along with the total population in each county.

People living in communal establishments on the census date were not included in these figures which amounted to around 1% of children and 3% of adults. The list of communal establishments provided in the Census includes: 'nursing/children's homes; hospitals and other types of establishments'. It is not known the extent to which various types of congregated settings for people with an intellectual disability - such as group homes - were classed by respondents as communal establishments. Given that proportionately more people with an intellectual disability live in residential accommodation that could be classed as 'communal', the resulting prevalence rates derived from the census could be an under-estimate.

Comparisons with prevalence rates in Scotland and Northern Ireland were obtained from publically available data provided on the census websites (http://www.scotlandscensus.gov.uk/ods-web/home.html: https://www.opendatani.gov.uk/…/type-of-long-term-condition-by-age-by-sex-dc310).

In Scotland, the 2011 census included the question: "Do you have any of the following conditions which have lasted, or are expected to last, at least 12 months?" Eight options were provided as listed in Table 1, including "Learning Disability (for example, Down's Syndrome)"; the term commonly used in the United Kingdom in lieu of intellectual disability. Prevalence rates for children and adults were calculated on the Yes responses to this option.

The 2011 Census in Northern Ireland also asked the same root question as the Scottish census but with 10 options provided as listed in Table 1; one of which was "a learning difficulty, an intellectual difficulty, or a social or behavioural difficulty". Prevalence rates were calculated on the Yes responses to this option.

2.2. National Intellectual Disability Database

The National Intellectual Disability Database (NIDD) in the Republic of Ireland was established in 1995 to ensure that information is available to assist the government and the non-statutory agencies to plan and provide appropriate services for people with intellectual disabilities and their families. Those in receipt of, or in need of specialist disability services for intellectual disability and anyone with a moderate, severe or profound intellectual disability regardless of service use are likely to be registered, given the way services are delivered in Ireland on a locality basis from early childhood through to old age, including social work and clinical services from the one provider.

The records for each individual are reviewed annually by the person's service provider usually in consultation with the person and/or family carer to ensure accuracy. Periodic audits are also undertaken which have found over 85% accuracy in records (Dodd, Craig, Kelly, & Guerin, 2010). Individual records are later collated anonymously at a national level for each particular year.

For the purposes of this paper, the numbers of children and adults registered on the database in 2012 and 2017 were identified within each of the 26 counties in Ireland. These cohorts were chosen in order to ensure similar coverage to the census data which was taken mid-year in 2011 and 2016. This information was further broken down into those who were living with family carers or in their own accommodation and those who lived in some form of residential accommodation such as group homes. Young children undergoing assessment are not always registered on the database so the records held on those under five years of age are much fewer than those aged five and over. Only the latter group in the NIDD were included in the study and matched to an equivalent age group in the census.

2.3. Data analysis

Prevalence rates for children and adults with intellectual disability from both the Census and the NIDD were calculated per 1000 of the equivalent general population. This was done for 2011 and for 2016 for each of the 26 counties as well as nationally.

A non-parametric test – Kendall's Tau-B – was used to assess the extent of concordance between the prevalence rates in the 26 counties across the two data sources and over time. As with correlations, a coefficient of 1.0 reflects perfect concordance with 0.0, no concordance. This test served as a proxy indicator of concordance across the two datasets and over time, as it was not possible to match the individual records across the census and the NIDD, and over the two years.

3. Results

3.1. Country profile

In 2011 the total child population of Ireland aged 5–19 years was 897,312 persons which had risen to 968,701 in 2016: an increase of almost 8%. Comparable figures for the adult population (aged 20 years and over) were 3,226,839 in 2011 and 3,337,490 in 2016: an increase of 3.4%. Two-thirds of the population live in metropolitan areas. Life expectancy at birth is around 81 years. Ireland is classed by the World Bank as a High Income country.

Across the 26 counties of Ireland, the median child population in 2011 was 25,060 (range 6199–223,647) which had risen in 2016 to a median of 25,893 children (range 6604–243,771). The comparable figures for adult persons in 2011 was a median of 83,293 (range 22,640 to 915,289) and in 2016, the median was 85,558 (range 22,734–964,242). For both children and adults, Dublin city had the highest populations followed by Cork and Galway. The lowest populations were in the rural counties of Leitrim and Longford.

Table 2
The number and prevalence rates per 1000 for children (5–19 years) and adults (20 years and over) with intellectual disability in the Census and on the NIDD in 2011 and 2016.

	Children Census 2011	Adults Census 2011	Children Census 2016	Adult Census 2016	Child NIDD 2011	Adult NIDD 2011	Child NIDD 2016	Adult NIDD 2016
Number	15,904	30,637	21,494	34,936	8672	17,372	9142	18,332
National Prevalence per 1000	17.7	9.5	22.2	10.5	9.7	5.2	9.4	5.3

A comparison was made of the concordance between the rank order of county populations of children and of adults in the 2011 and 2016 census using Kendall's Tau B coefficient. For the child population this was 0.975 and for adults it was 0.994 which indicates a high degree of concordance in the county populations in the census years.

3.2. Prevalence of intellectual disability

Table 2 summarises the number of children and adults recorded with intellectual disability in the national census and registered in the NIDD in 2011 and 2016 along with the corresponding prevalence rates.

In sum, the census identified 1.8 times more children in 2011 than were registered in the NIDD and this had risen to 2.35 times more in 2016. Likewise for adults, the census identified 1.8 times more adults in 2011 with 1.9 times more being identified in 2016. Moreover the census returns showed an increased prevalence rate in 2016 compared to 2011 especially for children, whereas this was not reflected in the prevalence rates based on the NIDD.

3.3. Intra-country variation

The prevalence rates showed marked variation across the 26 counties as shown in Table 3.

The variation in prevalence rates was more marked for registrations on the NIDD with up to a threefold increase in some counties for children and for adults. By contrast the variation in the Census prevalence rates was between 1.3 and 1.8 times that of counties with the lowest prevalence.

The greater variation in the NIDD may be due to the location of residential services for persons with intellectual disability in certain counties but which also had people from neighbouring counties placed in them, thereby leading to an increased prevalence in some countries with a concomitant decrease in others. To examine this possibility, prevalence rates were recalculated for the NIDD based on adults living with family carers or independently in their own homes. In Ireland as a whole, this totalled 9490 persons in 2011 and 10,912 in 2016. The median prevalence rate across the 26 counties was 3.35 per 1000 in 2011 (range 2.4–4.5) and in 2016, the median prevalence was 3.8 (range 2.5–5.1). In both years, the variation in the prevalence had reduced. The biggest discrepancies in prevalence rates were in rural counties where residential facilities had been established, notably Sligo, Limerick, Kildare, Kilkenny, Westmeath and Louth. However the Census prevalence rates were no greater in these counties compared to those which had less discrepancy in the NIDD prevalence rates.

3.4. Consistency in prevalence rates

Kendall's Tau-B Test was used to test the consistency in prevalence rates across the 26 counties over the two census years and by comparing prevalence rates obtained from the census with that derived from the NIDD. Table 4 summarises the results for the prevalence rates of children and for adults.

The coefficients across the two years were statistically significant for both the Census and NIDD prevalences suggesting some degree of concordance across the counties, especially for adult persons derived from the NIDD across the two years. These all exceed or come close to Cohen's criteria of 'a large effect size' (coefficients greater than 0.5). However the concordance across the counties between the prevalence rates derived from the Census with those from NIDD was only statistically significant for adults and not for children.

3.5. Comparison with Scotland and Northern Ireland

Table 5 compares the prevalence rates for children and adults in the Irish 2011 Census with those reported for Scotland and Northern Ireland in the same year. In Scotland's census, 26,349 persons were returned as having a 'learning disability' which is the terminology commonly used for intellectual disability in the UK. However the published Scottish data is for children aged 0–15 years and adults are 16 years and over. To facilitate comparison with the two other jurisdictions, an estimate was made of the numbers of persons aged 16–19 years who were recorded as having a learning disability based a yearly average of the numbers aged 16–24 years. The resulting prevalence rates are shown in brackets in Table 5.

In Northern Ireland, 40,177 persons were identified as having "a learning difficulty, an intellectual difficulty, or a social or behavioural difficulty" giving much higher prevalence rates for children and adults. Thus the prevalence rates were highest for

Table 3
The median, minimum and maximum prevalence rates per 1000 for children and adults with intellectual disability in the Census and on the NIDD across 26 counties.

	Child Prevalence Census 2011	Adult PrevalenceCensus 2011	Child Prevalence Census 2016	Adult PrevalenceCensus 2016	Child Prevalence NIDD 2011	Adult PrevalenceNIDD 2011	Child Prevalence NIDD 2016	Adult Prevalence NIDD 2016
Median	18.05	9.85	21.7	11.15	9.60	5.55	9.30	5.8
Minimum	12.8	7.3	18.5	8.8	6.5	3.6	5.0	3.9
Maximum	22.20	12.0	26.5	13.4	15.2	10.8	15.1	10.3

Table 4
Kendall Tau-b coefficients across prevalence rates derived from the Census and NIDD data across the 26 counties for children and adults.

	2011 & 2016 Census	2011 &2016 NIDD	2011 Census & NIDD	2016 Census and NIDD
Children	0.640**	0.549**	0.028	−0.171
Adults	0.554**	0.867**	0.485**	0.534**

** $p < 0.01$ two-tailed test.

Table 5
Prevalence rates from 2011 Census in Ireland, Scotland and Northern Ireland.

	Ireland	Scotland	Northern Ireland
Children (0–19 yrs)	17.7	5.71* (5.98)	47.6
Adults (20+ yrs)	9.5	4.82* (4.69)	16.2

* The Scottish data for children is for 0–15 years and adults are 16 years and over. The prevalence rates in brackets are based on estimates for 0–19 yrs and 20+ yrs.

Northern Ireland with the Scottish prevalences lower than those found in the Irish Census but closer to those derived from the NIDD (see Table 2).

4. Discussion

This study on prevalence has two particular strengths. First, it compared the prevalence rates of intellectual disability derived from a national census with information on persons in receipt of, or in need of specialist services because of an intellectual disability. Second it examined the consistency in prevalence rates in 2011 and in 2016. Moreover the intra-country variation in prevalence was also examined as well as comparisons made between Irish prevalence rates and those from neighbouring jurisdictions: Scotland and Northern Ireland.

To take the latter first, the variation in the census questions relating to intellectual disability creates a difficulty in comparing prevalence rates across the three jurisdictions. Northern Ireland used the broadest definition and unsurprisingly had a much higher prevalence rate for children and adults than Ireland or Scotland. Ireland used the specific term 'intellectual disability' and here prevalence rates for both children and adults were higher than in Scotland. It is possible that these figures reflect real variations in the prevalence of intellectual disability in these three jurisdictions but until there is uniformity in census questions – both in terms of terminology used and options given - this will be difficult to ascertain. A study that cognitively tested the range of options used in past censuses with representative samples from each jurisdiction could assist in identifying the most suitable wording in relation to intellectual disability as well as other conditions listed in Table 1 (Miller, Mont, Maitland, Altman, & Madans, 2011). Equally these insights might inform and encourage other countries – notably England and Wales - to identify people with intellectual disability within their census. With a further Census planned in 2021 for all four jurisdictions, it may now be too late to achieve greater uniformity.

The Irish data also enabled comparisons to be drawn between the prevalence rates from the census and those obtained for persons who has been assessed as having an intellectual disability and who were in receipt of services or in need of them. For both children and adults, the census prevalence rates were nearly twice as high as those from the intellectual disability service database. Possible reasons include people with milder forms of intellectual disability no longer requiring or wanting specialist services, the lack of suitable services in the person's locality and the inclusion in the census returns of persons who had other impairments such as autism. Indeed, as Table 1 shows, the Irish census did not include as options to the disability question other impairment categories such as developmental disorders or autism spectrum. Hence the increased prevalence of children recorded as 'intellectually disabled' in the Irish census in 2016 compared to 2011 may reflect a desire on parents' part to ensure their child's needs arising from other developmental conditions are recorded, especially as the legislation relating to special education assessments and provision has not been enacted as yet (Government of Ireland, 2004). The bigger lesson to be drawn is that Census figures may not provide a wholly accurate reflection of the population who may require specialist services because of an intellectual disability (Emerson & Glover, 2012). Also the relatively low levels of concordance between prevalence rates across counties from the Census and from the NIDD further bears this out.

The Irish data also identified marked regional variations in prevalence rates from both Census and the NIDD which were replicated in both years. The reason for the variation in the prevalence rates for children and adults based on Census data were not ascertained but may be linked to social deprivation as other studies have suggested (Emerson, 2012). However individual indicators of social deprivation are not publically available in the Irish Census for persons identified as having an intellectual disability nor are they available on the national register. The intra-country variations in prevalence rates from the NIDD were even more marked and were in part related to the historical provision of services within particular counties. Thus national prevalence rates should be applied cautiously to different regions within a country which is another argument for investing in the national coverage of datasets (McKenzie, Milton, Smith, & Ouellette-Kuntz, 2016).

However the Irish data also highlighted the variations that can arise even over a five-year period in prevalence rates derived from the Census or from the NIDD. Although the concordance in prevalence rates across counties was statistically significant, there were still marked differences in the prevalence rates derived from the Census in particular. Hence service planners may be ill-served by census data gathered in 2011 as a basis for current and future planning of services or in funding allocations. Rather consistency in prevalence rates was best for adult persons on the specialised register for intellectual disability. Moreover such a database is regularly updated allowing longitudinal studies to be undertaken of policy implementation for example. Such investigations are sparse in the literature relating to intellectual disability.

In sum, determining the prevalence of intellectual disability remains a challenge. The use of national census data is limited by the terminology used and the options provided on census forms for identifying persons with this impairment, the changes that occur over time in national and regional populations and the inclusion of persons who may not require or want specialised provision. A national register of persons specifically assessed as having an intellectual disability is advantageous although this could be optimised by being able to link it to census returns and also to other known predictors of prevalence, such as social deprivation. Nevertheless the cautions identified in this study should be borne in mind as more studies based on administrative datasets start to appear in the intellectual disability literature.

Conflicts of interest

The authors declare they have no conflicts of interest.

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