


# People with intellectual disability in Ireland are still dying young

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## Abstract

**Background:** People with intellectual disability die younger than their non-disabled peers. In recent years, greater attention has been paid to closing the gap. However, evidence that this is being achieved is limited by the dearth of longitudinal, national data.

**Method:** Over 4,000 decedents identified in the Irish National Intellectual Disability Database from 2001 to 2016 were compared to deaths in the general population based on age and gender profiles using death rates and standardised mortality ratios. A binary logistic regression analysis also identified the characteristics of persons who had a higher risk of dying.

**Results:** Irish people with intellectual disability die younger and have a higher rate of death than their non-disabled peers. Nor has the gap between their mortality and that of the general population closed in recent years.

**Conclusions:** More concentrated effort is needed in Ireland on promoting equitable access to health services for people with intellectual disability.

## KEYWORDS

deaths,

## 1 | BACKGROUND

Across the European Union, an increase in life expectancy is commonly reported with women outliving men (Eurostat, 2019). In the Republic of Ireland, the mean age of death in the general population in 2001 was 73 years and by 2016, this had increased to 76 years, although for women the mean age of death was 79 years and for males, 74 years (CSO, personal communication). However, increases in life expectancy were not uniform across the population. Lower life expectancy was found among persons living in more socially deprived areas, in urban settings, in rented accommodation provided by local authorities, and for people who were single and less educated (CSO, 2010).

Internationally, for people with intellectual disability, their mean age of death is notably lower than for the general population. A systematic review of 27 studies concluded that a gap of around 20 years exists with greater inequality for women with intellectual disability than for men (O'Leary et al., 2018). It is unclear the extent to which the gap has reduced in recent years due mainly to a dearth of longitudinal studies. Nevertheless a study of deaths of people with intellectual disability in one English city over a 33 year period up to 2012 suggested that the gap persisted although there were increases in the life expectancy of people with intellectual disability (Emerson et al., 2014).

Two previous studies have reported deaths of Irish people with intellectual disability. In the period 1996 to 2001, the mean age of

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death was 45 years and similar for males and females (Lavin et al., 2006). For the years 2003 to 2012, the average age of death had increased to 55 years but with a 19-year gap compared to the mean age of death in the general population (McCarron et al., 2015). When the standardised mortality rates were applied to deaths for persons aged 18, Ireland had the highest ratio when compared to studies undertaken in England, Finland, Canada and the USA (Glover et al., 2017).

However, comparing deaths of persons with intellectual disability across different studies is fraught with difficulty (O'Leary et al., 2018). Most studies have relied on small, selected samples rather than using national data. Differing definitions of intellectual disability have been used, and the characteristics of the samples are not always taken into account such as gender, age and level of disability. Also, little attention has been paid to the wider social influences on death rates such as living arrangements. Persons living in congregated settings may have death rates that are not representative of those living with family carers for example. In addition, different methods have been used in reporting deaths although there is a consensus that standardised mortality ratios are preferable.

Few robust studies have monitored the deaths of people with intellectual disability across time periods. Do they also experience increases in life expectancy as has happened with the general population? Moreover, in recent years, increased attention has been given to the health inequalities experienced by people with intellectual disabilities which national governments in the UK and USA have sought to address (Krahn & Fox, 2014). New measures have been introduced such as annual health screenings that aim to detect conditions such as diabetes and improve access to health services. There are emerging indications that these health checks can lead to reduced mortality rates (Kennedy et al., 2019), although it remains to be determined if these actions reduce the gap for people with intellectual experience in terms of life expectancy.

The present study aimed to address these shortcomings. It used national data on over 4,000 decedents drawn from a national register of persons with intellectual disability of all ages who received or were deemed to require specialist services because of their disability. Information was available on their core characteristics of age, gender, level of intellectual disability as well as their living arrangements prior to death and their geographical location in terms of rurality. Moreover regression analyses were used to control for possible confounding effects. Comparisons over a 16-year time period could be undertaken as the same information is recorded and updated each year. Also, the Irish Central Statistics Office (CSO) makes publicly available, annual data on the registered deaths in the general population broken down by gender and age.

The study addressed three main questions:

1. How do the rates of death of men and women with intellectual disability compare with those of the general population in the Republic of Ireland?
2. Have the rates of death of people with intellectual disability decreased in recent years?

3. What are the characteristics of people with intellectual disability who have higher rates of death?

## 2 | METHOD

### 2.1 | National intellectual disability database (NIDD)

The NIDD is a national case register of persons in receipt of intellectual disability services or deemed to be in need of them. In Ireland, the bulk of services are delivered by voluntary, not-for-profit agencies who provide a range of services to children and adults with intellectual disability; including schools, day and residential services as well as clinical and support services.

In addition to an individual's demographic characteristics, the specialist services received or needed are recorded. The NIDD is considered to capture nearly all persons aged 5 years and over with moderate to severe intellectual disabilities along with those with mild intellectual disabilities who require specialist services. A very small number of family carers or persons decline to be registered, especially for those awaiting a confirmed diagnosis. Hence, the NIDD is known to undercount the number of children aged under 5 years.

In each of the nine Community Healthcare Organisations (CHO), the Health Services Executive has responsibility for identifying the service personnel—such as key workers or social workers—who either complete or update annually a Database pro-forma for each person with an intellectual disability who is in receipt of or requires services. Information from the CHOs (minus identifying details but with a unique identifier) is made available to the Disability Databases Team in the Health Research Board who manages the database on behalf of the Department of Health. Each year a report is produced that summarises the yearly data (Hourigan et al., 2018).

If a person is no longer in receipt of services, the annual return specifies a reason. As well as deaths, this includes transfer to another service, or the record was deleted as the person no longer received services or required them.

The overall prevalence rates for persons with intellectual disability recorded on the NIDD in 2001 were 6.58 per 1,000 of the Irish population, and in 2016, it was 5.97 per 1,000. The drop resulted mostly from a marked increase in the Irish population due to immigration in more recent years (McConkey et al., 2019).

### 2.2 | Data analysis

For the purposes of this study, the number of people who were recorded as having died was identified in each yearly cohort from 2001 to 2016; the last year for which data on deaths in the general population were available, broken down by gender and age groupings. Details were obtained of their age at death (based on the date they were removed from the NIDD, although the actual death may have occurred in a previous year), gender (male and female) and

**TABLE 1** The mean age of death persons with intellectual disability and the general population for the two time periods broken down by gender with 95% confidence intervals and total number of deaths

Period	Males intellectual disability	Males general	Females intellectual disability	Females general	Total intellectual disability	Total general
2001–2008	48.9 (47.7–50.2) N = 1,072	70.1 (69.8–70.4) N = 86,602	52.3 (51.0–53.8) N = 910	76.8 (76.4–77.1) N = 93,542	50.5 (49.3–51.7) N = 1,982	73.4 (72.9–73.8) N = 180,144
2009–2016	52.1 (50.1–53.3) N = 1,076	71.9 (71.2–72.6) N = 89,429	55.9 (54.7–57.2) N = 948	78.1 (77.6–78.6) N = 96,277	54.0 (52.8–55.2) N = 2,024	74.9 (74.2–75.6) N = 185,706

level of disability (mild, moderate, severe and profound according to ICD10 criteria). No neonatal deaths are recorded.

Details were extracted of the person's place of residence prior to death: namely living at home with family carers; living independently with or without support; living in a group home with mostly up to six others or resident in a congregated setting (with 10 or more other persons).

A proxy for the geographical area in which the person resided was based on three groupings: the three CHO areas that served the Greater Dublin Area; three that were a mix of urban and rural counties and three covering predominantly rural counties.

Three indicators of mortality were examined for persons with intellectual disability:

1. The mean age of recorded death.
2. Their rate of death calculated per 1,000 of the population of persons with intellectual disability recorded in the previous year as that would have included the deceased persons.
3. Standardised mortality rates (SMRs) were calculated for persons with intellectual disability. The death rate of the general population by gender and age was applied to the population of persons with intellectual disability to give an expected number of deaths. The observed rate of death for these persons was divided by the expected rate to give a SMR. A ratio of 1 indicates that the observed and expected rates are the same whereas SMRs >1 specify higher observed rates for persons with intellectual disability and an SMR under 1 indicate lower observed rates than would be expected.

Comparisons were also made with registered deaths per 1,000 in the general population also broken down by age and gender. This data were publicly available from the Central Statistics Office (<https://www.cso.ie/en/statistics/population/>). These figures also include persons with intellectual disability, but no adjustment was made as the numbers were <1%.

Due to the relatively small number of deaths per year of people with intellectual disability, the mean rates of deaths were calculated for two, 8-year periods (2001–2008 and 2009–2016) in order to compare changes over time. A similar calculation was made for the general population.

The rate of death for people with intellectual disability in each time period was also calculated by level of disability, place of residence and urban/rural settings.

Finally, a binary logistic regression analysis was undertaken to identify the characteristics of those persons who had died in the 16-year period compared to those who were recorded on the NIDD as alive in 2017. By definition, the 2017 cohort includes those who were still alive from each of the previous yearly cohorts. Also, 'new' people who were added to the yearly cohorts during the years 2002 to 2016 would be added to either the death total or to the alive total in 2017. However, people who were removed from each yearly cohort for reasons other than death will be missed from the 2017 cohort. These amount to around 12,000 persons over the 16 years. Around three-quarters were children with mild intellectual disability and around one quarter were persons with moderate to profound intellectual disability. Although no information is available about their death rates, arguably they are similar to that found in the available data.

### 3 | RESULTS

Over the 16 years from 2001 to 2016, a total of 4,006 people with intellectual disability were recorded as decedents. This makes it one of the largest datasets relating to mortality in persons with intellectual disability (O'Leary et al., 2018). The mean number of deaths per year was 250 (range 212–300). The mean number of persons recorded on the NIDD per year over the 16 years were 24,430 (range 23,018–25,559).

For the general population, the total number of deaths over the 16 years was 464,306 with a mean per year of 29,019 (range 27,961–30,667). The total population rose from 2.796 million in 2001 to 4.940 million in 2016.

#### 3.1 | Mean age of death

In 2001, the mean age of death in the general population was 73 years, and by 2016, this had increased to 76 years. The mean age of death for persons with intellectual disability rose from 47.1 years in 2001 to 53.1 years in 2016.

Table 1 summarises the mean age of death for males and females with intellectual disability compared to the general population in the two, 8-year periods. In both time periods, females with intellectual disability had a higher mean age of death than males although both genders did show an increase in the mean age of death in more

recent years. However, people with intellectual disability of both genders had a lower mean age of death than the general population by around 20 years.

Table 2 explores gender differences and changes over time in the rate of death per 1,000 for males and females in the general population and similarly for people with intellectual disability.

In the general population, the rate of deaths per 1,000 of the population steadily declined: an average of 9.9% over the two time periods. Also, the mean rate for all persons with intellectual disability also decreased although to a lesser extent (5.6%). However, the decrease in the mean rate of male deaths was more pronounced: a 9.5% decrease compared to a 0.7% decrease for females.

Nevertheless, the differential between people with intellectual disability and the general population remains. For the period 2001 to 2008, the mean rate of deaths for people with intellectual disability was 39% higher than for the general population, while in the period 2009–2016, it was 46% higher. This was particularly marked for females. In the period from 2009 to 2016, the mean death rate for females with intellectual disability was 64% higher than for females in the general population, whereas for males with intellectual disability, the difference was 30%.

### 3.2 | Age and gender differences

The rate of death can also be compared across four main age groupings: children and youths under 20 years, young adults 20–44 years; older adults 45–64 years and those aged 65 years and over (see Table 3).

The rate of death increases as people age across the time periods which is to be expected. However, people with intellectual disability have higher rates in the four age groups compared to the general population. This holds for both genders and across the two time periods.

The rate of death for adults with intellectual disability aged 20–64 years of both genders is over four times higher than for the equivalent general population, although for those aged 65 and over, the difference is much less but for children it is greater. The children's rates may be an under-estimate for the reasons given earlier.

As Table 3 also shows, over the two time periods, the rates of death have fallen in the general population for all age groups. For people with intellectual disability, however, the rate of death for females aged 45–64 years did not fall whereas it did for this age group of males with intellectual disability. Similarly, the decrease in the rate of death of males aged 65 years and over (28%) was higher than that experienced by females with intellectual disability (18% decrease).

### 3.3 | Standardised mortality ratios (SMRs)

Gender and age differences in deaths among the intellectual disability population were further investigated in terms of SMRs. This ratio takes into account changes in the rate of death of the general population. SMRs >1 indicate a greater number of deaths in the intellectual disability population compared to the expected number using general population rates for the gender and age group. The overall SMR for all persons with intellectual disability was 1.5 in the period 2001 to 2008, and this had risen to 1.6 in the years 2009 to 2016. However, these summary figures mask marked differences in the SMRs when calculated by gender and age groups as shown in Table 4.

Standardised mortality ratios are markedly higher for children, and this has increased rather than decreased in recent times. However, given the relatively small numbers involved and the year-by-year variation, the confidence intervals are very wide for their SMRs. Nonetheless, the rise in SMRs for male children from 2009 to 2016 seems particularly marked compared to female children.

Across the adult age groupings, the SMRs change little in recent years but only come closest to 1 for those aged 65 years and over. However, for younger adults (aged 20–44), females have notably higher SMRs than males. This same trend is also apparent for older adults.

### 3.4 | Level of disability

The rate of deaths could also be examined according to the person's level of disability. As Table 5 shows, the mean rate of death increases from those with mild disabilities to those with profound disabilities (over a five to eight-fold increase). Over the two time periods, only those with mild disabilities showed a decrease in the death rate (17%) whereas those with moderate and severe disabilities the rate remained constant and for those with profound disabilities the rate increased by 11%. Thus, persons with profound disabilities in particular experience higher death rates and this has not changed and may even have worsened in recent years although the confidence intervals are very wide given the small numbers of persons involved.

It is worth noting that the rate of death for persons with mild disability is lower than those for the general population which for 2001–2008 was 6.98 and for 2009–2016 was 6.29. On the NIDD, more children are recorded as having a mild disability which would lead to lower death rates for this group.

TABLE 2 The rates of deaths per 1,000 of persons per year in the intellectual disability population and the general population in the two time periods broken down by gender with 95% confidence intervals

Period	Males intellectual disability	Males general	Females intellectual disability	Females general	Total intellectual disability	Total general
2001–2008	9.37 (8.11–10.63)	7.24 (6.70–7.78)	10.17 (8.72–11.62)	6.72 (6.33–7.11)	9.70 (8.45–10.95)	6.98 (6.53–7.43)
2009–2016	8.48 (7.88–9.08)	6.44 (6.35–6.53)	10.10 (9.36–10.66)	6.14 (6.03–6.25)	9.16(8.56–9.76)	6.29 (6.19–6.39)

**TABLE 3** The mean rate of death per 1,000 in the periods 2001–2008 and 2009–2016 by gender and year groups in the general population and persons with intellectual disability<sup>a</sup>

Gender	Groupings	0–19 years	20–44 years	45–64 years	65+ years
Males	2001–2008 general	0.53	1.21	6.08	54.44
	2001–2008 intellectual disability	3.75	5.27	22.42	85.65
	2009–2016 general	0.14	1.01	4.93	43.53
	2009–2016 intellectual disability	2.41	4.75	19.25	61.25
Females	2001–2008 general	0.39	0.55	3.49	46.00
	2001–2008 intellectual disability	3.83	5.54	17.17	73.49
	2009–2016 general	0.27	0.46	3.18	39.64
	2009–2016 intellectual disability	3.26	4.04	17.43	60.49
Total	2001–2008 general	0.46	0.88	4.77	49.70
	2001–2008 intellectual disability	3.78	5.39	19.79	78.89
	2009–2016 general	0.20	0.71	4.06	41.42
	2009–2016 intellectual disability	2.71	4.44	18.36	60.85

<sup>a</sup>For ease of reading, details of confidence intervals have been omitted but they can be obtained from the authors on request.

**TABLE 4** The mean SMRs in the 2 year groupings by gender and age groupings level of disability for persons with intellectual disability (with 95% CIs)

Year groupings	0–19 years	20–44 years	45–64 years	65+ years
Male 2001–2008	7.60 (5.60–9.60)	4.39 (3.90–4.88)	3.69 (2.94–4.44)	1.57 (1.27–1.87)
Male 2009–2016	18.22 (9.87–26.57)	4.75 (3.95–5.55)	3.91 (3.48–4.34)	1.41 (1.29–1.53)
Female 2001–2008	9.79 (8.38–11.20)	10.17 (8.01–12.33)	6.03 (2.07–9.99)	1.57 (1.27–1.87)
Female 2009–2016	12.34 (8.92–15.76)	8.79 (6.34–11.24)	5.51 (4.86–6.16)	1.52 (1.36–1.67)
Total 2001–2008	8.38 (7.11–9.65)	6.17 (5.33–7.01)	4.23 (3.14–5.32)	1.59 (1.43–1.75)
Total 2009–2016	13.66 (10.84–16.48)	6.09 (5.18–7.00)	4.54 (4.11–4.97)	1.47 (1.37–1.57)

Note: A ratio of 1 indicates that the observed and expected rates of death are the same whereas SMRs >1 specify higher observed rates for persons with intellectual disability and an SMR under 1 indicate lower observed rates than would be expected.

**TABLE 5** The mean rate of death per 1,000 in the periods 2001–2008 and 2009–2016 by level of disability for persons with intellectual disability (with 95% CIs)

Year groupings	Mild	Moderate	Severe	Profound
Male 2001–2008	5.47 (3.96–6.98)	9.19 (7.83–10.55)	16.95 (13.93–19.97)	32.62 (23.70–41.54)
Male 2009–2016	4.50 (3.71–5.29)	8.21 (7.13–9.29)	17.46 (14.42–20.50)	37.31 (30.87–43.75)
Female 2001–2008	6.14 (4.68–7.60)	9.19 (7.63–10.75)	20.20 (15.48–24.92)	31.19 (24.74–37.64)
Female 2009–2016	5.18 (4.33–6.03)	10.28 (9.32–11.24)	20.33 (18.55–22.11)	33.42 (27.29–39.55)
Total 2001–2008	5.76 (4.71–6.81)	9.19 (7.38–11.00)	18.36 (15.18–21.54)	31.97 (24.84–39.10)
Total 2009–2016	4.79 (4.22–5.36)	9.10 (8.17–10.03)	18.69 (16.57–20.81)	35.50 (30.41–40.59)

### 3.5 | Place of residence

Table 6 provides a breakdown by rates of death of people with intellectual disability by different living arrangements. For those living

at home with family carers and those living independently, the rate of death reduced over time for both males and females. However, the converse occurred for persons living in group homes (49% increase in rate of death) and for those in congregated settings (28%

**TABLE 6** The mean rate of death per 1,000 in the periods 2001–2008 and 2009–2016 by place of residence for persons with intellectual disability (with 95% CIs)

Year groupings	Home	Independent	Group home	Congregated
Male 2001–2008	5.06 (4.50–5.62)	10.89 (4.85–16.93)	10.82 (8.24–13.40)	25.03 (21.65–28.41)
Male 2009–2016	3.70 (2.78–4.62)	7.21 (4.60–9.82)	13.47 (11.06–15.86)	32.13 (27.57–36.69)
Female 2001–2008	5.37 (4.17–6.57)	4.64 (2.33–6.95)	6.27 (4.47–8.07)	30.66 (24.72–36.60)
Female 2009–2016	4.00 (3.53–4.47)	3.70 (1.54–5.86)	11.91 (10.04–13.78)	39.04 (33.53–44.55)
Total 2001–2008	5.19 (4.51–5.87)	7.94 (4.53–11.35)	8.54 (6.77–10.31)	27.64 (23.29–31.99)
Total 2009–2016	3.82 (3.16–4.48)	5.48 (4.12–6.84)	12.70 (10.95–14.45)	35.28 (31.06–39.50)

Year groupings	Urban-rural	Mostly rural	Greater Dublin
2001–2008	10.10 (8.59–11.61)	10.28 (8.22–12.34)	10.99 (8.31–13.67)
2009–2016	10.14 (9.21–11.07)	9.37 (8.59–10.15)	10.82 (9.89–11.75)

**TABLE 7** The mean rate of death per 1,000 for people with intellectual disability in the periods 2001–2008 and 2009–2016 by geographical region of place of residence (with 95% CIs)

**TABLE 8** The characteristics of persons with intellectual disability who had died from 2001 to 2016) compared to those alive in 2017

Predictors	df	Sig.	Exp (B)	95% C.I. for EXP (B)	
				Lower	Upper
<b>Level of disability</b>					
Mild <sup>a</sup>					
Moderate	1	.000	1.259	1.137	1.395
Severe	1	.000	2.200	1.957	2.472
Profound	1	.000	4.040	3.470	4.704
<b>Age groups</b>					
65 years and over <sup>a</sup>					
0–19 years	1	.000	.147	.126	.173
20–44 years	1	.000	.172	.152	.195
45–64 years	1	.000	.390	.352	.432
<b>Living arrangements</b>					
Family home <sup>a</sup>					
Independent	1	.036	.779	.617	.984
Group home	1	.321	1.064	.942	1.202
Congregated	1	.000	3.552	3.177	3.971
<b>Geographical area</b>					
Rural <sup>a</sup>					
Greater Dublin	1	.007	.877	.797	.964
Urban rural	1	.931	1.004	.917	1.100
<b>Gender</b>					
Male <sup>a</sup>					
Female	1	.816	1.009	.935	1.089
Constant	1	.000	.253		

<sup>a</sup>Reference group used in the regression.

increase). A confound with person's age may contribute to these findings as older persons with intellectual disability are more likely to live in group homes and congregated settings.

### 3.6 | Urban v rural

As noted previously, people in Ireland who live in rural settings tend to live longer (CSO, 2010). In order to explore this factor for people with intellectual disability, their rates of death were calculated for those living in three geographical regions to approximate possible urban-rural differences in death rates found in the general population. Table 7 summarises the rates of death summated across age, gender, level of disability and type of living arrangements for those living in the three geographical regions. Some decrease did occur in rural counties (9%) but not in more urban areas although the confidence levels suggest this is not a strong effect.

### 3.7 | Regression

The foregoing analyses can be misleading due to confounding among the various variables used in the bivariate analyses. To overcome this, a binary logistic regression analysis was undertaken contrasting those who had died in the 16 year period ( $n = 3,842$ : reduced due to missing data on one or more variables) with those who were alive in 2017 ( $n = 25,577$ ). The resulting model—shown in Table 8—was significant (Chi Sq=4406.59; d.f. 12;  $p < .001$ ) and accounted for around 25% of the variance (Nagelkerke  $R^2 = .258$ ).

Table 8 identifies the significant predictors ( $p < .01$ ) and the odds ratio of each. For people with profound intellectual disability, their odds of dying were nearly five times higher than those with mild intellectual disability. Likewise, people with severe and moderate



disabilities had lower but still a significantly increased odds ratio over those with mild intellectual disability. In addition, children and adults up to 44 years of age had much lower odds of dying compared to those aged 65 years and over, but the odds reduced for those aged 45–64 years. The person's living arrangements also affected the odds ratios. For those living in congregated settings, the odds of their dying were nearly four times higher than those living in family homes whereas the odds were similar for people living independently or in group homes. Also for those living in the Greater Dublin area, the odds of dying were lower than those in rural areas but the same for those in urban-rural areas. Gender did not contribute significantly to the regression model when the other variables were taken into account.

## 4 | DISCUSSION

This national study of deaths of people with intellectual disability over a 16-year period included comparisons with deaths in the general population. Three different mortality indicators were used to assess changes over time which were analysed by age group and gender. In addition, an analysis of possible confounding factors relating to people with intellectual disability—level of their disability, living arrangements and geographical location—was also undertaken which previous studies have not done. A number of conclusions can be drawn from these analyses, and although they are particular to Ireland, it is possible that they will apply to other comparable countries.

People with intellectual disability continue to die younger than their peers in the general population. Although there has been some improvement in the mean age of death and in rates of death of people with intellectual disability, the decrease is less than that experienced by the general population, and as the standardised mortality ratios suggest, there has been little change over the 16 years, and for children with intellectual disability, the SMRs may have worsened. Hence, there is no evidence that the gap in death rates for people with intellectual disability and the general population is closing in Ireland.

Children with intellectual disability show the greatest disparity in the rates of deaths compared to the general population which may reflect the additional co-morbidities associated with genetic conditions which are not readily amenable to life prolonging treatments (O'Leary et al., 2018). Also in recent years, extreme premature babies are surviving beyond the neonatal period due to medical advances but often with complex healthcare needs which may ultimately result in death in later childhood (Myrhaug et al., 2019). This may be a factor in the increased SMRs of children with intellectual disability, whereas child deaths in the general population have declined which has been identified as one of the major drivers in increased life expectancy worldwide (UNICEF, 2020).

The Irish data also confirm a higher rate of premature deaths among adults aged 20–64 with intellectual disability, particularly for females. Moreover, there has been little change in SMRs for these age groups over the 16 years. Previous studies that have

examined the cause of death have suggested that over one third of these deaths could be classed as avoidable (Hosking et al., 2016). Yet preventative actions appear not to have been taken within health services or if they had, there has been no discernible impact thus far on reducing death rates for young and middle age adults with intellectual disability.

As other studies have found, the level of disability has a major impact on rates of death (O'Leary et al., 2018). People with profound intellectual disabilities had the highest rate of death which has been attributed to their various co-morbidities such as epilepsy, impaired mobility and chronic illnesses. In Ireland, the rate of death for this group may even have worsened in recent years rather than improved. Yet a recent study in Ireland identified that people with severe and profound intellectual disability were the group most likely to be seen by four or more multi-disciplinary clinicians on four or more occasions in a year (Doyle et al., 2020). Thus, the availability of medical, nursing and therapeutic services per se does not appear to have impacted on rates of death.

By contrast, persons with mild intellectual disabilities showed a decrease in rates of death over the two time periods and these were lower than the comparable rates for males and females in the general population. This could reflect the younger age of people with mild intellectual disability on the NIDD as many are registered when attending special schools or training courses for young adults but no longer avail of other specialist services for adult persons or are deemed to require them. However, other studies suggest that in adulthood, they may experience poorer health which in part may be allied to poorer socio-economic circumstances (Emerson et al., 2016) which has been reported also for the general population in Ireland (CSO, 2010).

The Irish data also illustrate the importance of examining the living arrangements of people with intellectual disability prior to their death. For people who reside in congregated settings, their odds of dying were four times higher than those living with family carers. Although higher proportions of people living in congregated settings in Ireland were older and had more severe disabilities, the impact of setting was still a significant contributor to the number of deaths as the regression analysis suggests. A possible reason could include the increased risk of infections in such settings (Gallagher et al., 2018) which the Covid-19 experience has confirmed in England for people with learning disabilities and autism (Care Quality Commission, 2020). Also, a recent analysis of over 600 inspection reports of residential facilities for people with intellectual disability carried out by the Irish regulator (HIQA) found that health was the most featured category in terms of required improvements including: 'comprehensive healthcare assessments, evidence based practice, access to appropriate healthcare/healthcare professionals, admission/discharge from hospital and end of life care' (Murphy & Bantry-White, 2020: p.9). This was despite this sector having much greater access to health professionals—nurses and therapists—than those living with families or independently in community settings (Doyle et al., 2020).

In the general Irish population, people living in rural areas live longer than those in cities and large towns (CSO, 2010) yet the

regression analysis suggested that a greater number of deaths occur in the Greater Dublin area although the rates of death for people with intellectual disability seemed to have decreased in recent years for those living in rural areas. Some possible confounding factors should be borne in mind, notably people with more severe disabilities are more likely to move to residential provision which is usually located in larger towns or cities. Nonetheless, the influence of broader socio-geographical factors deserve greater attention in terms of the health and well-being of people with intellectual disability than they have received to date (Heslop & Emerson, 2017).

Finally, the difference between Irish males and females in the number of deaths was no longer significant when other confounding variables such as age group, level of disability and place of residence were controlled statistically. However, the differences in the mean age of death and the rate of death still point to males with intellectual disability showing more improvements than females over the two periods. Females with intellectual disability have a death rate that is over two-thirds higher than for the general female population. To date, there seems to be little evidence of gender differences in relation to the risk of death due to specific causes commonly reported for people with intellectual disability (Robertson & Hatton, 2019), although lifestyle factors such as obesity and physical inactivity may be more prevalent among females (Sadowsky et al., 2019). Future analyses of deaths need to take account of possible confounding variables as happened in the present study as they may be more of a contributing factor to death rates than gender.

Various strategies have been proposed to reduce the health inequalities experienced by people with intellectual disability (Taggart & Cousins, 2014). These include the provision of annual health checks for adults with intellectual disability, awareness training for all healthcare staff, developing personalised health action plans and participation in national screening programmes. Although small-scale studies had evidenced the effectiveness of these measures, as yet details are lacking of their implementation nationally which would need to happen for an impact on death rates to occur and a reduction in the mortality gap with the general population to be achieved (McConkey et al., 2020). One impetus to effecting change would be a greater realisation in specialist services of the variation in death rates within the population of people with intellectual disability as well as the discrepancies they experience with the general population. Ireland is well placed to embark on such an awareness raising strategy based on the data held in the national database; a monitoring resource that is not readily available to other countries. However, in that respect, this study may provide an example for other nations to follow. Evidence of disparities in death rates should stimulate health improvement initiatives for this population.

Finally, comparisons between deaths of Irish people with intellectual disability and those in other countries are risky due to the variations in the nature of the samples, the age ranges covered, the levels of disability included and whether the rates computed take account of the age and gender structure of the general population (O'Leary et al., 2018). Future research could usefully explore the

impact of socio-economic and geographical factors on the health and mortality of persons with intellectual disability.

## 5 | LIMITATIONS

As with any administrative database, there are limitations to the NIDD. It records persons known to specialist intellectual disability services. Persons with intellectual disability who do not require or desire these services are not included. However, other studies suggest their health may be worse than those in receipt of services although mortality data are not readily available for these persons (Emerson & Glover, 2012). In that case, the data reported here may paint a more positive picture than is the possible reality in Ireland.

The year of death is assumed to be the year in which the person's record was removed from the database but the actual date of death may have occurred in an earlier year. Hence, the age at death may be exaggerated in some instances.

The cause of death is not recorded on the database. It would be advantageous to be able to link the NIDD to the national register of deaths as this contains detailed information on causation.

## 6 | CONCLUSIONS

National studies of the deaths of people with intellectual disability are rare. The Irish data confirm that people with intellectual disability die younger and have a higher rate of death than their non-disabled peers. Nor has the gap between their mortality and that of the general population closed in recent years. Those most at risk of dying young are children, persons with more severe and profound disabilities and those who live in congregated residential settings. When these factors are taken into account, the gender differences reported in previous studies are less apparent although younger female adults seem to have a heightened risk compared to their female peers in the general population. International comparisons depend on standardised methodologies being employed to monitor deaths, but this remains an elusive goal.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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