

BMJ Open Mortality in residential care facilities for people with disability: a descriptive cross-sectional analysis of statutory notifications in Ireland

Martin J McMahon ^{1,2,3}, Aisling M O'Connor,¹ Paul Dunbar,¹ Anna Delany,¹ Laura Behan,¹ Carol Grogan,¹ Laura M Keyes¹

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¹Health Information Quality Authority, Mahon, Cork, Ireland
²School of Nursing and Midwifery, Trinity College Dublin, The University of Dublin, Dublin 2, Ireland
³Trinity Centre for Ageing and Intellectual Disability, School of Nursing and Midwifery, Trinity College Dublin, The University of Dublin, Dublin 2, Ireland

Correspondence to
Dr Martin J McMahon;
martin.mcmahon@tcd.ie

ABSTRACT

Objectives To determine incidence of death in residential care facilities for people with disability in Ireland, primary cause of death, associations of facility characteristics and deaths, and to compare characteristics of deaths reported as expected and unexpected.

Design Descriptive cross-sectional study.

Setting All residential care facilities for people with disability operational in Ireland in 2019 and 2020 (n=1356).

Participants n=9483 beds.

Main outcome measures All expected and unexpected deaths notified to the social services regulator. Cause of death as reported by the facility.

Results 395 death notifications were received in 2019 (n=189) and 2020 (n=206). 45% (n=178) were for unexpected deaths. Incidence of death per 1000 beds per year was 20.83 for all, 11.44 for expected and 9.39 for unexpected deaths. Respiratory disease was the most common cause of death, accounting for 38% (n=151) of all deaths. In adjusted negative binomial regression analysis, congregated settings versus non-congregated (incidence rate ratio (95% CI): 2.59 (1.80 to 3.73)) and higher bed numbers (highest vs lowest quartile) (4.02 (2.19 to 7.40)) were positively associated with mortality. There was also a positive n-shaped association with category of nursing staff-to-resident ratio when compared with zero nurses. Emergency services were contacted for 6% of expected deaths. Of the deaths reported as unexpected, 29% were receiving palliative care and 10.8% had a terminal illness.

Conclusion Although incidence of death was low, residents of congregated and larger settings had higher incidence of death than residents of other settings. This should be a consideration for practice and policy. Given the high contribution of respiratory diseases to deaths and the potential avoidability of these, there is a need for improved respiratory health management in this population. Nearly half of all deaths were reported as unexpected; however, overlap in the characteristics of expected and unexpected deaths highlights the need for clearer definitions.

INTRODUCTION

People with disability experience poor health outcomes and have higher all-cause mortality rates than the general population.^{1 2} While

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ National-level data were used, comprehensive for all active residential care facilities in Ireland during the study period.
- ⇒ Cause of death ascertainment was from the cause reported by the person in charge of the residential care facility and not from death certificates.
- ⇒ There was a possibility of over-reporting of unexpected deaths which possibly should have been more accurately reported as expected deaths. This limits the conclusions that can be drawn from the analysis of association of service characteristics and expected and unexpected deaths.
- ⇒ Lack of demographic data of residents who died limited the ability to account for confounding; however, proxies were used for age and resident dependency level.
- ⇒ A novel framework for evaluating whether a death is expected or unexpected was developed and used for this study, shedding light on a difficult area to measure for the first time.

adults with intellectual disabilities are now living longer,³ they still die earlier^{4 5} than people without intellectual disability.⁶ Such differences are identified as health inequalities, and improving life expectancy for this population is a key international priority.⁷⁻⁹ Although there has been an increase in research examining mortality in populations with disability, the focus of recent inquiry has concentrated on populations with intellectual disability and there has been limited focus on the persons' living arrangements, that is, living in the general population or in care settings, prior to their death.^{10 11}

In Ireland, Doyle *et al*⁹ recently outlined the importance of examining the living arrangements of people with intellectual disabilities prior to death. In their study, which included 4006 deaths over 16 years, the odds of dying in congregated settings (where 10 or more



people with a disability live together in a single living unit or any number of residents are placed in accommodation that is campus based) in Ireland were four times higher than those living with family carers. Even after accounting for the severity of intellectual disability, the setting a person lived in was a significant contributor to death. In the UK, recent studies have examined the mortality of people with intellectual disability in community-based and residential settings^{12–15} to determine the factors that may influence death. These studies identified that while deaths were often not anticipated and uncommon, they occurred at a younger age and were most commonly caused by respiratory disease. These studies have highlighted the need to undertake descriptive epidemiological studies to understand how people are dying, where they are dying and if they are dying unexpectedly to inform the development of improved interventions. This is particularly important given the various, often atypical living situations that many people with a disability live in.¹⁶ It is also important to include those with disabilities other than intellectual, who also live in these settings.

There is a small body of research that has specifically examined the primary cause of death of people exclusively living in residential care facilities or identified if deaths were expected or unexpected in these settings (online supplemental figure 1 and online supplemental table 1). Nevertheless, it is well documented that mortality for people with an intellectual disability living in residential settings is higher than the general population or among individuals with intellectual disability living elsewhere.^{14 17 18} Hosking *et al* reported that the mortality rate among individuals with an intellectual disability living in communal or shared living arrangements in England was four times higher than the general population.¹⁷ Equally, a prospective longitudinal cohort study of people with Down syndrome identified that at follow-up, persons living in institutions were more likely to have died.¹⁹ Durvasula *et al*¹⁸ also reported disproportionate rates for individuals with intellectual disability living in residential settings and highlighted that 50% of deaths in their study occurred in institutional settings, despite this cohort accounting for only 25% of the study population. Similarly, the mortality rate reported by Merrick²⁰ was 9.9 per 1000 population for individuals with an intellectual disability living in residential settings in comparison with a mortality rate of 6.6 per 1000 population in the general population. Within residential settings, the cause of death for individuals with intellectual disability appears to be similar in nature, despite heterogeneity in study methods and population demographics. For example, respiratory diseases are reported as a significant cause of death in the majority of studies,^{14 17 19–23} with the percentages reported ranging from 18.8%¹⁷ to just under 50%.^{21 23} Circulatory diseases also account for between 7%¹⁹ and 35% of deaths,²⁰ with cancers reported to range from 6%^{19 20} to 20%²⁴ of deaths. However, these studies are focused on people with intellectual disability and do not account for the case mix in residential care services. Furthermore,

there is a paucity of comprehensive national-level data from any country.

Over the last decade, some studies have also drawn attention to the concept of unexpected death in this area. Two separate UK studies have identified that unexpected death for people with intellectual disability who live in social care settings can range from 43% to 64% of all deaths.^{12 25} Nevertheless, the evidence base regarding unexpected death in this population from an international perspective is underdeveloped and largely absent. From an Irish viewpoint, a similar pattern exists. One reason for this potentially lies in what constitutes an ‘unexpected death’. For example, in Ireland, within the Coroners Amendment Act 2019,²⁶ and regulations made under the Health Act 2007 which govern residential care facilities for people with a disability in Ireland, no explicit definition of ‘unexpected death’ is offered. Rather, responsibility is placed on the person in charge of the residential care facility to ‘use judgement’ when reporting whether the death was unexpected or not.²⁷ Subsequently, the evidence base regarding unexpected death in Ireland for people with a disability is vacant. Therefore, it is critically important to understand the epidemiology of death in this population as such evidence may underpin the development of targeted interventions and reduce the mortality inequality that this population experiences.

Aim of study

The aims of this study were to (1) to identify the incidence of expected and unexpected death of people with disability living in residential care facilities in Ireland; (2) categorise the reported primary cause of death of people with disability using International Classification of Diseases 11th Revision (ICD-11) chapter headings;²⁸ (3) examine the association of characteristics of residential care facilities and deaths; and (4) examine the characteristics of deaths reported as expected and unexpected.

METHODS

Setting

This descriptive cross-sectional study was undertaken in Ireland and incorporated all residential care facilities for people with a disability that were operational during 2019 and 2020.

Population

At the end of 2020, there were 1356 residential disability care facilities registered by the regulator to provide a service to circa 9000 people with a disability.²⁹ By law, all residential facilities must be inspected and registered by the regulator to be allowed to operate in Ireland. As residential care facilities may have de-registered or registered during the study time frame, the number of facilities registered and their registered bed numbers on the last day of 2020 were used as the total sampling frame (n=1356). Residential care facilities in Ireland for people

with a disability incorporate both accommodation and care and support services on a short-term and long-term basis, whether or not it is their sole place of residence.

Patient and public involvement

In 2021, phone interviews were conducted with residents in residential care facilities for people with disability (n=7) during the development of the Database of Statutory Notifications from Social Care in Ireland (the database used for this analysis).^{30 31} Residents were asked for their opinions on publishing the data open access and using it for research purposes. Residents were also asked about the type of questions they would like researchers to ask of the data, who dissemination of the findings should target and dissemination formats that they considered appropriate for residents. Resident input was used to inform the prioritisation of topics for analyses using the database and to inform dissemination strategies and formats, including for this analysis.

Data

The 2007 Health Act³² provides the legislative framework for the submission of statutory notifications for residential care facilities. Within these facilities, all deaths, both expected and unexpected, are notified to the regulator. Expected deaths must be reported on a quarterly basis and unexpected deaths must be reported within 3 working days of the event.²⁷

Data used in this study are from the Database of Statutory Notifications from Social Care in Ireland and are publicly available³³ (hereafter 'the database'). This contains data on all statutory notifications received by the regulator from residential care facilities for older persons and for people with disability from 2013 onwards.³⁰ These analyses were limited to facilities for people with disability.

Total, unexpected and expected deaths

A total of 1356 residential disability care facilities were active on 31 December 2020. All notifications of expected and unexpected deaths reported to the regulator with a date of death in the years 2019 and 2020 were included. A 2-year time frame was selected to allow for adequate sample size for analyses. Deaths were coded as per the notification submitted to the regulator by the person in charge (expected or unexpected). As these notifications reported the event of death only, no personal demographic data of the person who died were available.

Cause of death

The reported primary cause of death was extracted from the notifications and coded using the ICD-11 chapter headings.³⁴ The ICD-11 chapter headings is a tabular list organised into chapters according to body system or condition, with diagnosis codes listed alphanumerically in each chapter. As the statutory notifications do not require the certified cause of death to be reported as registered on a death certificate, for the purpose of this research, chapter headings according to body system are only reported on. This process was undertaken

independently by two researchers who are also health professionals (MJM and AMO). First, the reported cause of death was extracted independently from the notification submitted by the registered provider. This information was then independently entered into the ICD-11 website for Mortality and Morbidity Statistics (V.2021-05).³⁵ Where the SARS-CoV-2 was diagnosed and identified as the cause of death, this was coded under its own ICD-11 chapter heading, RA01.0, following guidance at that time for the emergency use of ICD codes for COVID-19.³⁶ Second, when the reported cause of death was identified in the web browser, the researchers then identified the monohierarchical chapter heading according to body system of which each reported cause of death was classified within. This was then used to classify the cause of death. This process was undertaken for all deaths and an inter-rater reliability agreement of 98.8% was achieved between MJM and AMO. Third, the coding and classification of cause of death were verified for accuracy by a third researcher (LB) who randomly reviewed 50% of the cause of both expected and unexpected deaths. No discrepancies or errors were identified by LB.

Service characteristics

Service-level data available in the database were used to examine characteristics that were associated with deaths in residential care facilities. These were: care facility profile (provision for adults, children, mixed), sex (single sex, mixed), provider type (voluntary/privately operated or public health service operated in which services are provided directly by the state which includes the state employing the staff), provider funding type (Section 38 (these are typically voluntary agencies that are funded to provide a defined level of service on behalf of the government), Section 39 (these are typically voluntary agencies that are grant aided by the government), private, public health service), provider size (small, medium, large), intellectual disability service (yes, no), congregated setting (congregating vs non-congregating), size of service (number of registered beds), distance to nearest acute hospital (km), staff number and nursing staff number. Staff-to-resident ratio and nursing staff-to-resident ratio were calculated as staff number/number of registered beds at residential care facility level. Residential care facilities were determined to be a congregated setting when they had 10 or more beds in a single unit or were a campus-based setting, irrespective of the number of beds. In Ireland, the term 'congregating setting' is used as opposed to 'institutional setting' in national policy; however, for international comparison, these definitions may be viewed as synonymous particularly where settings have increased bed numbers.

Free-text data

Free-text data from the notifications were also extracted. These outlined the description of the circumstances leading up to the death and any medical intervention(s) that was made available. This narrative also included risk



comments, inspector comments, actions taken, additional details and reasons why the cause of death was unexpected.

Statistical methods and analysis

Characteristics of services were described for all services and for services that submitted a notification as n, %, mean±SD and median (IQR), as appropriate. The number of total deaths and number and per cent contribution to total, of expected and unexpected deaths were calculated for the 2-year period and by year. The number and per cent of services that submitted a notification of death were calculated. Incidence of total, expected and unexpected deaths per 1000 beds per year was estimated as (deaths for the 2-year period/registered bed numbers)×1000/2. The mean number of deaths reported by services by year was estimated and the difference estimated using a t-test.

Deaths were categorised by primary cause of death and expressed as n (% contribution to all, unexpected and expected deaths) and incidence per 1000 beds, for the total study period. The association between service characteristics and total deaths in the 2 years in residential care facilities was evaluated using negative binomial regression for each service characteristic separately. Three models were constructed: model 1—unadjusted; model 2—adjusted for bed numbers (as a proxy for number of residents), care facility profile (as a proxy for age of residents) and nurse-to-resident ratio (as a proxy to account for differences in dependency levels of residents that impact both the structure of a residential care facility and the risk of mortality); and model 3—additionally mutually adjusted for the other service characteristics examined. Bed numbers and nursing staff-to-resident ratio were collapsed into quartiles and examined as size of service and nursing staff/resident ratio category to reduce collinearity with the linear bed numbers and nurse-to-resident ratio included as covariates.

All exposures were examined for interaction with each other by inclusion of each in model 3. No interactions were significant ($p \geq 0.324$) and no interaction terms were included in the final models. An a priori agreed analysis for interaction of expected and unexpected deaths was conducted. All interactions were significant ($p < 0.001$). As such, analyses were additionally conducted, stratified by expected and unexpected deaths, using model 3 as described above.

Goodness of fit for all models was tested using a likelihood-ratio test of $\alpha = 0$. The probability of χ^2 being greater or equal to 0 was < 0.001 for all models.

The database was complete for services and notifications. Continuous variables included in the regression analysis were imputed to account for missingness, with missing data points for continuous variables replaced with the respective mean. Using means to account for missingness was considered appropriate as the distributions of variables were normal. Regression analyses were repeated in complete cases only to examine the effect of the imputation.

Statistical analyses were performed in R software (V.4.1.2) and Stata (StataCorp, V.16).

Qualitative methods and analysis

A categorical content analysis was conducted to describe characteristics of deaths notified to the regulator as expected or unexpected and to generate an understanding of similarities and differences between these reported notifications. We applied a deductive analysis approach using a de novo predefined coding framework (online supplemental table 2) to analyse these notifications through categorical content analysis. The framework consisted of 13 categories and rules which were informed by previous research conducted on unexpected deaths in adults with intellectual disability,¹² the National Policy for Pronouncement of Expected Death by Registered Nurses,³⁷ the Coroner's Act³⁸ and the WHO's definition of sudden death.³⁹ This literature informed expected or unexpected death indicators within the coding framework. For example, the category of a person in receipt of palliative care was informed by the National Policy for Pronouncement of Expected Death by Registered Nurses³⁷ that considers the provision of palliative care as an indicator of an expected death. Following the conceptualisation of the framework, the free text from each notification was coded according to the pre-established coding rules (online supplemental table 2). Upon completion of the coding, the categories were grouped into two main concepts: interventions and care plans, and trajectory of illness before death.

RESULTS

Incidence of death

Two hundred twenty-five (16.6% of all residential care facilities) notified the regulator of a death during the 2-year period. This was consistent across years (2019, 112 residential care facilities; 2020, 113 residential care facilities). Residential care facilities that submitted notifications were more likely to be congregated settings, provide for adults, be funded under Section 38 of the Health Act 2004,⁴⁰ have higher numbers of registered beds, have higher staff numbers and nursing staff numbers than residential care facilities that did not submit a notification ($p < 0.05$) (table 1). In total, 395 notifications of deaths were received by the regulator in 2019 (n=189) and 2020 (n=206). Of these, 45% (n=178) were unexpected deaths. There was no difference in the mean number of deaths reported by year by service (2019, 1.9; 2020, 1.6, $p = 0.251$). The % contribution of expected and unexpected deaths to total deaths did not differ across the 2 years (2019, 42% unexpected; 2020, 48% unexpected; $X^2 = 1.5599$, $p = 0.212$). Incidence of death per 1000 beds per year was—deaths: 20.83, expected deaths: 11.44, unexpected deaths: 9.39 (table 2).

Primary cause of death

The most frequent primary cause of death reported in the notifications were diseases of the respiratory system.

Table 1 Description of service characteristics of residential care facilities for people with disability in Ireland, 2019–2020

	All active centres (n=1356)	Centres that submitted a notification of death (n=225)	P-difference
Congregated setting, n (%)			<0.001
Not congregated	1144 (84.4)	129 (57.3)	
Congregated	212 (15.6)	96 (43.7)	
Sex, n (%)			0.131
Single sex	181 (13.3)	23 (10.2)	
Mixed	1169 (86.2)	201 (89.3)	
Missing data	6 (0.4)	1 (0.4)	
Care facility profile (provision by age), n (%)			0.001
Adults	1227 (90.5)	218 (96.9)	
Children	88 (6.5)	3 (1.3)	
Adults and children (mixed)	41 (3.0)	4 (1.8)	
Provider type, n (%)			0.121
Voluntary/private operated	1209 (89.2)	189 (84.0)	
Public health service operated	147 (10.8)	36 (16.0)	
Provider funding type, n (%)			<0.001
Section 38	724 (53.4)	140 (62.2)	
Section 39	487 (35.9)	52 (23.1)	
Private	1 (0.1)	0 (0)	
Public health service	144 (10.62)	33 (12.7)	
Provider size, n (%)			0.998
Small	36 (2.7)	6 (2.7)	
Medium	167 (12.3)	28 (12.4)	
Large	1153 (85.0)	191 (84.9)	
Intellectual disability service, n (%)			0.917
No	123 (9.1)	20 (8.9)	
Yes	1221 (90.1)	203 (90.2)	
Missing data	12 (0.8)	2 (0.9)	
Size of service (registered bed numbers), mean±SD	7.0±5.3 (missing n=20)	11.9±7.5 (missing n=5)	<0.001
Distance to hospital (km), mean±SD	15.0±14.1 (missing n=221)	16.3±15.3 (missing n=36)	0.179
Staff number, median (IQR)	12.9±11.0 (missing n=28)	21.0±15.0 (missing n=5)	<0.001
Nursing staff number, median (IQR)	0 (0–2.3) (missing n=32)	3.1 (0–7) (missing n=6)	<0.001

P-difference estimated using t-tests and χ^2 .
n, %; mean±SD; median (IQR).

These accounted for 38% (n=151) of all deaths (table 2). This was followed by neoplasms (19%, n=75) and diseases of the circulatory system (11%, n=42). The leading causes of expected deaths were diseases of the respiratory system (41%, n=89), neoplasms (31%, n=67), and mental and behavioural disorders (eg, dementia) (10%, n=18). The leading causes of unexpected deaths were diseases of the respiratory system (35%, n=62) and diseases of the circulatory system (18%, n=32).

Association of characteristics of residential care facilities and death

In unadjusted analysis (model 1) of service characteristics and all deaths, congregated settings, providing for

mixed sex, being a statutory provider, being funded by the public health service, having higher bed numbers, and having higher staff-to-resident ratio and nursing staff-to-resident ratio were associated with higher incidence of death (table 3). Providing for children only and being funded under Section 39 of the Health Act were associated with lower incidence of death. After adjustment for bed numbers, nursing staff-to-resident ratio and care facility profile (model 2), the associations with sex provision, provider type, funding type and staff-to-resident ratio were attenuated to null. After further mutual adjustment for other service characteristics (model 3), the positive association of congregated setting versus non-congregating

Table 2 Cause of death as notified by residential care facilities for people with disability in Ireland, 2019–2020, n notifications=395

Cause of death*	All deaths			Expected deaths			Unexpected deaths		
	n	% of all-cause mortality	Incidence per 1000 beds per year	n	% of all-cause mortality	Incidence per 1000 beds per year	n	% of all-cause mortality	Incidence per 1000 beds per year
All cause	395	100.00	20.83	217	100.00	11.44	178	100.00	9.39
J00–J99 Diseases of the respiratory system	151	38.23	7.96	89	41.01	4.69	62	34.83	3.27
C00–D48 Neoplasms	75	18.99	3.95	67	30.88	3.53	8	4.49	0.42
I00–I99 Diseases of the circulatory system	42	10.63	2.21	10	4.61	0.53	32	17.98	1.69
Other or cause of death to be confirmed	39	9.87	2.06	9	4.15	0.47	30	16.85	1.58
F00–F99 Mental and behavioural disorders	20	5.06	1.05	18	8.29	0.95	2	1.12	0.11
A00–B99 Infectious and parasitic diseases	18	4.56	0.95	9	4.15	0.47	9	5.06	0.47
RA01.0 COVID-19 identified	18	4.56	0.95	2	0.92	0.11	16	8.99	0.84
G00–G99 Diseases of the nervous system	16	4.05	0.84	7	3.23	0.37	9	5.06	0.47
N00–N99 Diseases of genitourinary system	9	2.28	0.47	4	1.84	0.21	5	2.81	0.26
K00–K93 Diseases of the digestive system	4	1.01	0.21	2	0.92	0.11	2	1.12	0.11
V01–Y89 External causes of injury and poisoning	3	0.76	0.16	0	0.00	0.00	3	1.69	0.16

*Coded using ICD-11 chapter headings; n centres=1356, n total beds=9483. ICD-11, International Classification of Diseases 11th Revision.

(incidence rate ratio (95% CI): 2.59 (1.80 to 3.73)) and higher bed numbers (highest vs lowest quartile) (4.02 (2.19 to 7.40)) remained significant. There was also a positive non-linear association with category of nursing staff-to-resident ratio when compared with zero nurses. The second highest quartile (0.5 to 0.99 nursing staff:resident ratio) was associated with the highest risk (4.35 (2.21 to 8.55)).

When stratified by expected and unexpected deaths, using model 3, congregated setting and higher bed numbers had a larger positive association with expected than unexpected deaths, and a positive association of nursing staff-to-resident ratio and mortality was only significant for expected deaths (table 4). Being a statutory provider was also positively associated with unexpected deaths.

Repetition of analyses in complete cases did not materially change results (online supplemental table 3).

Characteristics of expected and unexpected deaths from the categorical content analysis

Concept 1: interventions and care plans

Categories relating to interventions and care plans were identified in all notifications received (table 5). A total of 48.1% of all deaths reported were for residents in receipt of palliative care. There was the presence of categories

in expected deaths that would not be anticipated, for example, emergency services were called for 6.0% of reported expected deaths and 28.7% of reported unexpected deaths were for residents in receipt of palliative care.

Concept 2: trajectory of illness before death

Categories relating to the trajectory of illness before death were identified in all notifications (table 5). For length of illness, there was a spread across all categories of length for both expected and unexpected. Longer illnesses were reported more as expected deaths and shorter as unexpected, although some deaths from sudden illnesses were reported as expected deaths and some deaths from terminal illnesses were reported as unexpected deaths.

A total of 21.2% of expected deaths and 59.6% of unexpected deaths reported hospital admission prior to death. Expected deaths tended to have had longer stays in hospital with zero deaths within 3 days reported.

DISCUSSION

This study provides national population-based evidence about the mortality of people with disability who live in residential care facilities in Ireland. As far as we are aware, this is the only nationally representative study to date that

Table 3 Association of service characteristics and mortality in residential care facilities for people with disability in Ireland, n centres=1356

Service characteristics	Model 1: unadjusted				Model 2: additionally adjusted for bed numbers, nursing staff-to-resident ratio and service type*				Model 3: additionally adjusted for other service characteristics†			
	n	Incidence rate ratio	95% CI	P value	n	Incidence rate ratio	95% CI	P value	n	Incidence rate ratio	95% CI	P value
Congregated setting	1356				1324				1305			
Not congregated	1144	Reference group			1118	Reference group			1101	Reference group		
Congregated	212	8.18	6.10 to 10.96	<0.001	206	2.57	1.79 to 3.68	<0.001	204	2.59	1.80 to 3.73	<0.001
Sex	1350				1318				1305			
Single sex	181	Reference group			179	Reference group			177	Reference group		
Mixed	1169	1.69	1.03 to 2.79	0.039	1139	1.19	0.72 to 1.95	0.497	1128	1.21	0.74 to 1.96	0.444
Care facility profile (age range)	1356				1324				1305			
Adults	1227	Reference group			1199	Reference group			1181	Reference group		
Children	88	0.11	0.32 to 0.37	<0.001	85	0.26	0.79 to 0.89	0.029	84	0.32	0.10 to 1.10	0.070
Adults and children	41	0.39	0.13 to 1.18	0.094	40	0.34	0.12 to 0.99	0.048	40	0.37	0.13 to 1.05	0.062
Provider type	1355				1323				1305			
Voluntary/private operated	1209	Reference group			1187	Reference group			1169	Reference group		
Public health service operated	147	2.53	1.64 to 3.91	<0.001	136	1.23	0.82 to 1.85	0.319	135	2.13	0.46 to 9.94	0.338
Provider funding type	1355				1323				1305			
Section 38	724	Reference group			713	Reference group			700	Reference group		
Section 39	487	0.44	0.31 to 0.63	<0.001	475	0.77	0.53 to 1.11	0.163	471	0.76	0.52 to 1.16	0.216
Public health service	144	1.79	1.14 to 2.80	0.011	135	1.15	0.77 to 1.74	0.497	134	0.55	0.12 to 2.06	0.453
Provider size	1356				1324				1305			
Small	36	Reference group			36	Reference group			35	Reference group		
Medium	167	1.90	0.59 to 6.14	0.281	166	2.16	0.67 to 6.97	0.196	165	1.67	0.56 to 5.03	0.359
Large	1153	1.75	0.58 to 5.25	0.319	1122	2.49	0.82 to 7.57	0.108	1105	1.71	0.59 to 4.94	0.320
Intellectual disability service	1344				1312				1305			
No	123	Reference group			118	Reference group			117	Reference group		
Yes	1221	1.00	0.58 to 1.71	0.997	1194	0.90	0.54 to 1.49	0.678	1188	0.80	0.48 to 1.32	0.385
Size of service	1356				1324				1305			
1–4 beds	551	Reference group			502	Reference group			494	Reference group		
5–9 beds	192	1.46	0.77 to 2.77	0.247	189	1.28	0.67 to 2.43	0.455	187	1.50	0.77 to 2.91	0.233
10–19 beds	318	3.52	2.20 to 5.65	<0.001	307	2.21	1.35 to 3.63	0.002	301	2.59	1.53 to 4.38	<0.001
20–49 beds	335	13.72	8.99 to 20.96	<0.001	326	4.27	2.41 to 7.59	<0.001	323	4.02	2.19 to 7.40	<0.001
Distance to hospital (km)	1356	1.00	0.99 to 1.00	0.867	1324	1.00	0.99 to 1.02	0.200	1305	1.00	1.00 to 1.02	0.058

Continued



Table 3 Continued

Service characteristics	Model 1: unadjusted				Model 2: additionally adjusted for bed numbers, nursing staff-to-resident ratio and service type*				Model 3: additionally adjusted for other service characteristics†			
	n	Incidence rate ratio	95%CI	P value	n	Incidence rate ratio	95%CI	P value	n	Incidence rate ratio	95%CI	P value
Staff-to-resident ratio	1356	0.88	0.78 to 0.99	0.030	1324	0.99	0.88 to 1.13	0.939	1305	0.98	0.87 to 1.11	0.748
Nursing staff-to-resident ratio category	1324				1324				1305			
0	798	Reference group			798	Reference group			787	Reference group		
0.1 to 0.49	275	4.35	3.02 to 6.27	<0.001	275	2.16	1.42 to 3.29	<0.001	271	1.92	1.24 to 2.96	0.003
0.5 to 0.99	181	9.86	6.77 to 14.40	<0.001	181	5.29	2.79 to 10.02	<0.001	178	4.35	2.21 to 8.55	<0.001
1.0 to 4.0	70	3.60	1.96 to 6.60	<0.001	70	3.49	1.03 to 11.72	0.044	69	3.44	0.97 to 12.27	0.057

*Bed numbers (continuous, as a proxy for number of residents), nursing staff-to-resident ratio (continuous, as a proxy for resident dependencies), service type (categorical, as a proxy for age).

†Sex (dichotomous), service type (categorical), provider type (dichotomous), provider funding type (categorical), provider size (categorical), intellectual disability service (dichotomous), distance to hospital (continuous), staff-to-resident ratio (continuous).

includes the deaths of all people with a disability who live in residential care facilities. In addition, in the absence of a legal definition in Ireland, this study provides a novel framework for evaluating the characteristics of expected and unexpected deaths. These make important contributions to this area given the proportion of people with disabilities who live in residential care facilities internationally.

Similar to Todd *et al's* study in the UK,¹⁴ our study found that death is not a common event in disability services with just over 16% of residential care facilities reporting a death during 2019 and 2020. Although the incidence of death may be considered low, we report an association of risk of death and living in a congregated setting, higher bed numbers and nursing staff-to-resident ratio (second highest quartile (0.5 to 0.99 nursing staff:residents)) when compared with zero nurses. The association of congregated setting and higher bed numbers and death was larger for expected than unexpected deaths, and the association of nursing staff-to-resident ratio and mortality was only significant for expected deaths. However, due to the overlap in the characteristics of expected and unexpected deaths (which were identified through the categorical content analysis), there is a potential that incorrect classification by the service provider may impact these results and should be interpreted with caution. Other studies have reported similar findings regarding the association of congregated settings and death.^{9 14 19} Although it may be argued that people with more severe disabilities are more likely to live in residential care facilities, our analyses accounted for this by adjusting for nursing staff-to-resident ratio. Even after adjusting directly for severity of disability, another Irish study⁹ had similar findings insofar as the severity of disability did not account for increased deaths in such settings. This has important implications for policy in Ireland and in other countries where there is a bias towards institutional and other forms of residential care for people with a disability.^{29 41} This finding also signals an important avenue for future research given that larger datasets, of which much of the current mortality data are drawn, largely do not always identify the place of residence. In terms of the mechanisms by which these service characteristics are associated with mortality, when thinking about patient/resident outcomes, determinants are oftentimes separated into process measures and organisational structures.⁴² Organisational structures can impact on the quality of care provided through culture, management structures and physical environment impacting on processes and in turn on quality of care.⁴² As such, service characteristics are unlikely to impact directly on mortality, but they are a modifiable characteristic that can, through processes, impact.

Ireland's legislative framework does not set out any minimum requirements of staff that must be on duty nor specifies staffing ratios. As provided in regulations made under the Health Act 2007, staffing requirements are largely determined based on the number and profile of the people living in these residential care facilities and

Table 4 Association of service characteristics with expected and unexpected mortality in residential care facilities for people with disability in Ireland, n centres=1305

Service characteristics	Expected deaths (n=217)*			Unexpected deaths (n=178)*		
	Incidence rate ratio	95% CI	P value	Incidence rate ratio	95% CI	P value
Congregated setting						
Not congregated	Reference group			Reference group		
Congregated	4.04	2.41 to 6.74	>0.001	1.67	1.06 to 2.62	0.026
Sex						
Single sex	Reference group			Reference group		
Mixed	1.49	0.70 to 3.19	0.302	1.04	0.59 to 1.80	0.897
Care facility profile (age range)						
Adults	Reference group			Reference group		
Children	0.59	0.12 to 2.94	0.527	0.15	0.02 to 1.11	0.063
Adults and children	0.62	0.19 to 2.13	0.457	N/A		
Provider type						
Voluntary/private operated	Reference group			Reference group		
Public health service operated	0.98	0.09 to 10.96	0.986	4.63	1.08 to 19.85	0.039
Provider funding type						
Section 38	Reference group			Reference group		
Section 39	0.47	0.24 to 0.91	0.026	1.10	0.70 to 1.72	0.691
Public health service	1.34	0.12 to 15.18	0.814	0.23	0.05 to 1.04	0.058
Provider size						
Small	Reference group			Reference group		
Medium	0.83	0.18 to 3.88	0.808	0.54	0.15 to 2.02	0.363
Large	1.25	0.61 to 2.56	0.541	0.88	0.51 to 1.54	0.654
Intellectual disability service						
No	Reference group			Reference group		
Yes	0.62	0.29 to 1.37	0.241	0.99	0.53 to 1.83	0.975
Size of service						
1–4 beds	Reference group			Reference group		
5–9 beds	3.16	0.93 to 10.69	0.064	1.04	0.47 to 2.34	0.911
10–19 beds	5.60	1.97 to 15.93	0.001	1.96	1.08 to 3.55	0.026
20–49 beds	8.91	2.86 to 27.80	>0.001	2.69	1.37 to 5.26	0.004
Distance to hospital (km)	1.00	0.99 to 1.01	0.400	1.00	1.00 to 1.00	0.024
Staff-to-resident ratio	0.68	0.50 to 0.91	0.010	1.09	0.98 to 1.23	0.123
Nursing staff-to-resident ratio category						
0	Reference group			Reference group		
0.1 to 0.49	2.65	1.34 to 5.22	0.005	1.67	0.99 to 2.78	0.051
0.5 to 0.99	10.39	3.71 to 29.07	>0.001	1.91	0.87 to 4.18	0.103
1.0 to 2.9	11.85	1.87 to 75.22	0.009	1.08	0.23 to 5.12	0.921

N/A where there is insufficient case to calculate an incidence rate ratio.

*Adjusted for bed numbers (continuous), nursing staff-to-resident ratio (continuous), service type (categorical), sex (dichotomous), provider type (dichotomous), provider funding type (categorical), provider size (categorical), intellectual disability service (dichotomous), distance to hospital (continuous), staff-to-resident ratio (continuous).

**Table 5** Categorical content analysis of characteristics of deaths from free text included in statutory notifications from residential care facilities for people with disability in Ireland, 2019–2020, n notifications=395

Categories	All deaths (n=395)	Expected deaths (n=217)	Unexpected deaths (n=178)
	% (n)	% (n)	% (n)
Interventions and care plans*	100 (395)	100 (217)	100 (178)
Reviewed by community doctor 28 days prior to death	19.7 (78)	16.6 (36)	23.6 (42)
Receiving palliative care	48.1 (190)	64.1 (139)	28.7 (51)
DNAR in situ at time of death	5.8 (23)	7.8 (17)	3.4 (6)
Emergency services contacted	29.6 (117)	6.0 (13)	58.4 (104)
Coroner notified of death	18.2 (72)	3.3 (7)	36.5 (65)
Trajectory of illness before death	100 (395)	100 (217)	100 (178)
Length of illness*	38.0 (150)	30.9 (67)	46.6 (83)
Person experienced sudden death (less than 24 hours after onset of illness)	22.0 (33)	4.5 (3)	36.1 (30)
Person died from a short illness (1–27 days)	38.0 (57)	20.9 (14)	51.8 (43)
Person died from a longstanding illness (28 days or more)	19.3 (29)	34.3 (23)	7.2 (6)
Person identified as death imminent (terminal illness)	26.7 (40)	46.3 (31)	10.8 (9)
Length of hospital admission prior to death	38.5 (152)	21.2 (46)	59.6 (106)
Hospital admission recorded, length not recorded	56.6 (86)	65.2 (30)	52.8 (56)
<24 hours	6.6 (10)	0 (0)	9.4 (10)
1–3 days	7.2 (11)	0 (0)	10.4 (11)
4–7 days	9.2 (14)	8.7 (4)	9.4 (10)
More than 7 days, but less than 28 days	13.8 (21)	13.0 (6)	14.2 (15)
≥28 days	6.6 (10)	13.0 (6)	3.8 (4)

*Categories are not mutually exclusive, as such, % within concepts can sum to >100%.
DNAR, do-not-attempt resuscitation.

their assessed needs. Regarding staff ratios, however, the findings of our study show an association of nurse-to-resident ratio and expected death, a finding tentatively expected as the increasing complexity of resident needs may be associated with increased nurse-to-resident ratios. Nevertheless, while unexpected deaths were not significant, our results indicate the existence of an n-shaped relationship between nursing staff-to-resident ratio and unexpected death. This may imply that unexpected deaths may be theoretically reduced by increasing nurse-to-resident ratios. An important caveat exists given the non-significance; however, this is a very valuable area for further research to consider given the important role nurses play in reducing health inequalities that this population experiences.⁴³ For example, there is extensive literature that highlights the discrimination this population faces when accessing healthcare,^{44–48} and it is theoretically possible that nurses in these environments act as a broker with specialist knowledge between disparate health and disability systems^{49 50} and as a result play an important role in reducing health inequalities that contribute to mortality.

Primary cause of death

Respiratory disease was the largest cause of death in this study, as well as circulatory system diseases. While

there were no differences observed between intellectual disability versus non-intellectual disability services in this study, the results match the experience of death in the intellectual disability cohort more broadly as diseases of the respiratory system accounted for 38% of all deaths,^{6 8 11 18 21 51} while neoplasms and diseases of the circulatory system accounted for 19% and 11% of deaths, respectively.^{4 10 24} Given the high levels of dysphagia in this population,⁵² deaths from respiratory disease are potentially predictable given the serious health complications associated with swallowing difficulties that this population experiences. Although our study illustrated that people with a disability die from the same conditions as the general Irish population, the cause of death has a different pattern insofar as neoplasms, disease of the circulatory and respiratory systems are the leading causes, in this order, for the general Irish population.⁵³

Nearly half of all deaths reported were unexpected and it has been reported that such deaths are higher in people with an intellectual disability,²⁵ particularly those with epilepsy.^{54 55} There are two other potential reasons for this: first, deaths in intellectual disability services are rare. In our study, only 16.6% (n=225) of residential care facilities notified a death over the 2-year period. Similar results have been found in the UK.¹⁴ Consequently, this

uncommon event is more likely to hasten residential care facilities reporting to the regulator as soon as possible and therefore use the 3-working day notification which then classifies a death as unexpected. This is reinforced by the findings from our categorical content analysis that 28.6% of all unexpected deaths were currently receiving palliative care. Second, there is no definition of what constitutes an unexpected death in Irish legislation,^{26 56} and while the regulator cites an unexpected death as one that was not anticipated or occurred earlier than expected,⁵⁷ in the absence of a clear legal definition, there is likely to be ambiguity. While a recent UK study from Bernal *et al*¹² in this area distinguishes deaths derived from guidance from Blackmore *et al*,⁵⁸ the Irish context does not permit similar comparison due to reporting mechanisms. Nonetheless, a clear definition in this area is essential to help understand unexpected deaths and facilitate the instigation of appropriate levels of inquiry.⁵⁹ In comparison with the general Irish population where nearly 45% of all deaths occur in hospital, the categorical content analysis indicated that 38% of all deaths occurred in hospital in our study of which nearly 60% were unexpected. This finding is similar to another UK study which found that 56.4% of all deaths of people with an intellectual disability occurred in hospital; however, it is consistent with the findings that of people who die unexpectedly, they are more likely to die in hospital.¹⁴

Deaths from respiratory diseases are likely to reflect underlying vulnerabilities in this population and while it is the leading cause of death in this study, other studies have reported that deaths from cardiovascular disease are now the most common cause of death in this population.^{17 20 24 60} In this context, many studies have drawn data from multiple sources that include death certification, national registers and local registers. Consequently, as our study concentrates solely on residential care, this may signal an area that requires immediate public health action to mitigate potentially avoidable deaths from respiratory disease in these environments.^{11 51} Older studies that use residential samples have had similar findings to our study and this may suggest that health improvements in this area have been slow.^{22 23 61} The evidence is largely consistent regarding increased rates of mortality in congregated settings.^{14 19 24} While it is not clear if congregated settings are a cause or contributor to mortality, it is evident that there are poorer outcomes in such environments. This underlines the critical need to move to smaller-scale living environments for people with a disability.⁶²

In terms of unexpected deaths, the evidence in this area is scarce, and while both Heslop *et al*²⁵ and Bernal *et al*¹² had higher incidence of unexpected death in their studies (43% and 64%), findings from our categorical content analysis indicate that in approximately 27% (n=51) of all unexpected death notifications submitted, the person who died was receiving palliative care. This raises the question of if such deaths are genuinely unexpected. From this perspective, it is important that death is

anticipated and there is a need to develop measures that identify frailty⁶³ and predict death⁶⁴ to help improve the end-of-life experiences of this population.¹²

Strengths and limitations

The primary strength of this study is the nationally representative data that include all deaths of persons with a disability who live in residential care facilities in Ireland, in a 2-year period. As it is a legal duty⁶⁵ to report each death to the regulator, this is a complete dataset. A second strength is the development and use of a novel framework for evaluating whether a death is expected or unexpected; this sheds light on a difficult area to measure for the first time and has been developed to be reusable by others.

Limitations of the study warrant consideration. There was potential for over-reporting of unexpected deaths. Given the infrequency of death that occurs in residential care facilities, facilities may report a death as unexpected where it may be more correctly classified as expected. Cause of death ascertainment was from the cause reported by the person in charge of the residential care facility and not from death certificates. In the absence of death certificates, we relied on researchers extracting and coding deaths as per the ICD-11 monohierarchical chapter heading according to body system. While this is useful in terms of higher-order coding, if deaths were coded at the underlying cause to fully distinguish and assign the external or pathological causation of death, this would offer a greater insight into the cause of deaths of people with a disability who live in residential services in Ireland. Additionally, the researchers did not receive any formal training for coding purposes and this limitation also needs to be factored in when considering the reliability of the findings. The absence of demographic data of the residents who died to account for associations in the analysis, particularly severity of disability, is an important limitation to acknowledge. While our analysis did use proxies of nursing staff-to-resident ratio for resident dependencies and care facility profile for age, this cannot fully mitigate the absence of these demographic data. In particular, given the known association of age and mortality risk, the implications of care facility profile (under 18 years, over 18 years and any age), to account for age, should be factored into the interpretation of the findings, as it may be that congregated settings have an older population than other settings. That said, we have no evidence to suggest that they do. Nevertheless, this study is representative of the entire population of people with a disability who live in residential care facilities and this significantly enhances the evidence in this regard. As the study period includes the years 2019 and 2020, years where SARS-CoV-2 was not and was in circulation, respectively, there is a possibility that excess mortality from COVID-19 may have impacted on the analyses. We considered this carefully in the design of the analysis and as COVID-19 reported deaths were low (n=18) and there was no difference in mean total deaths reported by services between



the 2 years (2019, 1.9; 2020, 1.6; $p=0.251$), we did not take any actions such as including fixed or random effects in models or exclusions from cause of death analyses.

Implications

Results from this study show the importance of examining the role that congregated settings have on the deaths of people with disability. While this study has not investigated the mechanisms of how congregated settings are associated with death, future research should examine the role the place of residence has on mortality. Additionally, there is a need to develop and implement evidence-informed strategies to reduce respiratory diseases. This is a significant health inequity that people with a disability experience. Given the high degree of overlap in characteristics of expected and unexpected death in this study, there is a need to standardise the definition and undertake further descriptive epidemiological studies to determine the trajectories of death in this population and determine how people with a disability are dying in residential care facilities.

CONCLUSION

Although incidence of death was low, residents of congregated settings and larger settings had higher incidence of death than residents of other settings, and this should be a consideration for practice and policy. Given the high contribution of respiratory diseases to deaths and the potential avoidability of these, there is a need for improved respiratory health management in this population. Nearly half of all deaths were reported as unexpected; however, overlap in the characteristics of expected and unexpected deaths highlights the need for clearer definitions.

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Contributors MJM and LMK conceived and designed the analysis. MJM and AMO performed the literature search, undertook analysis and drafted the manuscript. LMK undertook the statistical analysis. PD prepared the data. MJM, AMO, PD, AD, LB, CG and LMK contributed to methodology development and provided input and critical comment throughout and agreed the final manuscript. LMK as guarantor accepts full responsibility for the work and/or the conduct of the study, had access to the data, and controlled the decision to publish.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not required.

Ethics approval Ethical approval was not required for this analysis as it is a secondary analysis of notification of events and does not include identifiable personal data; the included data are about events not people. Patient and public engagement was undertaken as part of the wider research project on statutory notifications in Ireland. Ethical approval was sought for this as it involved a vulnerable population group. Ethical approval to engage with people with disability

living in residential care facilities for patient/public involvement purposes was granted by the Research Ethics Subcommittee of the Daughters of Charity Disability Support Service Ethics Committee on 26 January 2021.

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Data availability statement Data are available in a public, open access repository. Data used in this study are from the Database of Statutory Notifications from Social Care in Ireland. The Irish Database of Statutory Notifications from Social Care is a national data collection of the statutory notifications received and generated by the Health Information and Quality Authority. An open access version of this database has been published for research and public use and is available at <https://www.hiqa.ie/sites/default/files/2021-02/Database-of-statutory-notifications-from-social-care-in-Ireland-2013-2020.csv>; this contains desensitised and pseudonymised facility-level data. The unredacted database is not available publicly but access to these data is possible following data custodian approval.

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ORCID iD

Martin J McMahon <http://orcid.org/0000-0002-3340-9537>

REFERENCES

- 1 Forman-Hoffman VL, Ault KL, Anderson WL, *et al*. Disability status, mortality, and leading causes of death in the United States community population. *Med Care* 2015;53:346–54.
- 2 Park JM, Oh U, Roh B-R, *et al*. Disparities in mortality by disability: an 11-year follow-up study of 1 million individuals. *Int J Public Health* 2017;62:989–96.
- 3 Landes SD, McDonald KE, Wilmoth JM, *et al*. Evidence of continued reduction in the age-at-death disparity between adults with and without intellectual and/or developmental disabilities. *J Appl Res Intellect Disabil* 2021;34:916–20.
- 4 Landes SD, Stevens JD, Turk MA. Cause of death in adults with intellectual disability in the United States. *J Intellect Disabil Res* 2021;65:47–59.
- 5 Landes SD, Stevens JD, Turk MA. Heterogeneity in age at death for adults with developmental disability. *J Intellect Disabil Res* 2019;63:1482–7.
- 6 O'Leary L, Cooper S-A, Hughes-McCormack L. Early death and causes of death of people with intellectual disabilities: a systematic review. *J Appl Res Intellect Disabil* 2018;31:325–42.
- 7 Learning Disability Mortality review Programme L. *Annual report 2020*. University of Bristol, 2021.
- 8 Cooper S-A, Allan L, Greenlaw N, *et al*. Rates, causes, place and predictors of mortality in adults with intellectual disabilities with and without Down syndrome: cohort study with record linkage. *BMJ Open* 2020;10:e036465.
- 9 Doyle A, O'Sullivan M, Craig S, *et al*. People with intellectual disability in Ireland are still dying young. *J Appl Res Intellect Disabil* 2021;34:1057–65.
- 10 Glover G, Williams R, Heslop P, *et al*. Mortality in people with intellectual disabilities in England. *J Intellect Disabil Res* 2017;61:62–74.
- 11 Trollor J, Srasuebkul P, Xu H, *et al*. Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. *BMJ Open* 2017;7:e013489.
- 12 Bernal J, Hunt K, Worth R, *et al*. Expecting the unexpected: measures, outcomes and dying trajectories for expected and unexpected death in adults with intellectual disabilities in social care settings in the UK. *J Appl Res Intellect Disabil* 2021;34:594–605.

- 13 Northway R, Todd S, Hunt K, *et al*. Nursing care at end of life: a UK-based survey of the deaths of people living in care settings for people with intellectual disability. *J Res Nurs* 2019;24:366–82.
- 14 Todd S, Bernal J, Shearn J, *et al*. Last months of life of people with intellectual disabilities: a UK population-based study of death and dying in intellectual disability community services. *J Appl Res Intellect Disabil* 2020;33:1245–58.
- 15 Todd S, Bernal J, Worth R, *et al*. Hidden lives and deaths: the last months of life of people with intellectual disabilities living in long-term, generic care settings in the UK. *J Appl Res Intellect Disabil* 2021;34:1489–98.
- 16 Kozma A, Mansell J, Beadle-Brown J. Outcomes in different residential settings for people with intellectual disability: a systematic review. *Am J Intellect Dev Disabil* 2009;114:193–222.
- 17 Hosking FJ, Carey IM, Shah SM, *et al*. Mortality among adults with intellectual disability in England: comparisons with the general population. *Am J Public Health* 2016;106:1483–90.
- 18 Durvasula S, Beange H, Baker W. Mortality of people with intellectual disability in northern Sydney. *J Intellect Develop Dis* 2002;27:255–64.
- 19 Coppus AMW, Evenhuis HM, Verberne G-J, *et al*. Survival in elderly persons with Down syndrome. *J Am Geriatr Soc* 2008;56:2311–6.
- 20 Merrick J. Mortality of persons with intellectual disability in residential care in Israel 1991–1997. *J Intellect Develop Dis* 2002;27:265–72.
- 21 Oppewal A, Schoufour JD, van der Maarl HJK, *et al*. Causes of mortality in older people with intellectual disability: results from the HA-ID study. *Am J Intellect Dev Disabil* 2018;123:61–71.
- 22 McLoughlin IJ. A study of mortality experiences in a mental-handicap Hospital. *Br J Psychiatry* 1988;153:645–9.
- 23 Carter G, Jancar J. Mortality in the mentally handicapped: a 50 year survey at the stoke Park group of hospitals (1930–1980). *J Ment Defic Res* 1983;27:143–56.
- 24 Heslop P, Blair PS, Fleming P, *et al*. The Confidential inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *Lancet* 2014;383:889–95.
- 25 Heslop P, Blair P, Fleming P, *et al*. *Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)*. Bristol: Norah Fry Research Centre, 2013.
- 26 Government of Ireland. *Coroners (Amendment) act 2019*. 2019.
- 27 Health Information and Quality Authority. *Statutory notifications: guidance for registered providers and persons in charge of designated centres*. Dublin: Health and Information Quality Authority, 2016.
- 28 World Health Organization. *International classification of diseases 11th revision*. 2021. Available: <https://icd.who.int/en2021>
- 29 Health Information and Quality Authority. *Annual report 2020*. Dublin, 2021.
- 30 O'Regan S, McGrane N, Dunbar P, *et al*. Public reporting of adverse events from long-term care facilities for older persons and people with disability in Ireland 2013–2019: development of an openly accessible database and descriptive analyses. *J Am Med Dir Assoc* 2022;23:1328–34.
- 31 McGrane N, Dunbar P, Keyes LM. To summarise the approach to and findings of the ppie undertaken as part of a programme of secondary research with a vulnerable, hard to reach population during the covid-19 pandemic. *In Review* [Preprint].
- 32 Government of Ireland. *Health act 2007 (as amended)*. 2007.
- 33 Health Information and Quality Authority. *Database of statutory notifications from social care*. 2022.
- 34 World Health Organization. *Internajonal classification of diseases, 11th Revision*. 2018.
- 35 ICD-11 for Mortality and Morbidity Statistics. *International classification of diseases 11th revision-ICD-11 for mortality and morbidity statistics (version 2021-05)*. 2022. Available: <https://icd.who.int/browse/11/2021-05/mms/en>
- 36 World Health Organisation. *Emergency use ICD codes for COVID-19 disease outbreak 2020*. n.d. Available: <https://www.who.int/standards/classifications/classification-of-diseases/emergency-use-icd-codes-for-covid-19-disease-outbreak>
- 37 Health Service Executive. *National policy for pronouncement of expected death by registered nurses*. Health Service Executive: Dublin. 2017.
- 38 Government of Ireland. *Coroners (Amendment) Act 2019*. 2019.
- 39 World Health Organisation. *Sudden cardiac death: report of a WHO scientific group*. World Health Organization, 1985.
- 40 Government of Ireland. *Health Act 2004*. 2004.
- 41 Health Information and Quality Authority. *The need for regulatory reform: a summary of HIQA reports and publications examining the case for reforming the regulatory framework for social care*. HIQA, 2021.
- 42 Rademakers J, Delnoij D, de Boer D. Structure, process or outcome: which contributes most to patients' overall assessment of healthcare quality? *BMJ Qual Saf* 2011;20:326–31.
- 43 McMahon M, Hatton C. A comparison of the prevalence of health problems among adults with and without intellectual disability: a total administrative population study. *J Appl Res Intellect Disabil* 2021;34:316–25.
- 44 McCormick F, Marsh L, Taggart L, *et al*. Experiences of adults with intellectual disabilities accessing acute hospital services: a systematic review of the International evidence. *Health Soc Care Community* 2021;29:1222–32.
- 45 Michael J, Richardson A. Healthcare for all: the independent inquiry into access to healthcare for people with learning disabilities. *Tizard Learning Disability Rev* 2008;13:28–34.
- 46 Ali A, Scior K, Ratti V, *et al*. Discrimination and other barriers to accessing health care: perspectives of patients with mild and moderate intellectual disability and their carers. *PLOS ONE* 2013;8:e70855.
- 47 Cuypers M, Tobi H, Huijsmans CAA, *et al*. Disparities in cancer-related healthcare among people with intellectual disabilities: a population-based cohort study with health insurance claims data. *Cancer Med* 2020;9:6888–95.
- 48 Emerson E, Hatton C. *Health inequalities and people with intellectual disabilities*. 2013.
- 49 Jaques H, Lewis P, O'Reilly K, *et al*. Understanding the contemporary role of the intellectual disability nurse: a review of the literature. *J Clin Nurs* 2018;27:3858–71.
- 50 Wilson NJ, Wiese M, Lewis P, *et al*. Nurses working in intellectual disability-specific settings talk about the uniqueness of their role: a qualitative study. *J Adv Nurs* 2019;75:812–22.
- 51 Truesdale M, Melville C, Barlow F, *et al*. Respiratory-associated deaths in people with intellectual disabilities: a systematic review and meta-analysis. *BMJ Open* 2021;11:e043658.
- 52 Robertson J, Chadwick D, Baines S, *et al*. People with intellectual disabilities and dysphagia. *Disabil Rehabil* 2018;40:1345–60.
- 53 Central Statistics Office. *Analysis of underlying cause of death data, including COVID-19*. Dublin, 2021.
- 54 Kiani R, Tyrer F, Jesu A, *et al*. Mortality from sudden unexpected death in epilepsy (SUDEP) in a cohort of adults with intellectual disability. *J Intellect Disabil Res* 2014;58:508–20.
- 55 Young C, Shankar R, Palmer J, *et al*. Does intellectual disability increase sudden unexpected death in epilepsy (SUDEP) risk? *Seizure* 2015;25:112–6.
- 56 Government of Ireland. *Coroners Act 1961*. 1962.
- 57 Health Information and Quality Authority. *Monitoring notifications handbook: Guidance for registered providers and persons in charge of designated centres for persons children and adults with disabilities*. Dublin, 2018.
- 58 Blackmore S, Verne J, Pring A. Predicting deaths-estimating the proportion of deaths that are unexpected. *BMJ Supportive & Palliative Care* 2011;1:106.
- 59 Mazars L. *Independent review of deaths of people with a Learning Disability or Mental Health problem in contact with Southern Health NHS Foundation Trust April 2011 to March 2015*. Mazars LLP. 2015.
- 60 Janicki MP, Dalton AJ, Henderson CM, *et al*. Mortality and morbidity among older adults with intellectual disability: health services considerations. *Disabil Rehabil* 1999;21:284–94.
- 61 Carter G, Jancar J. Sudden deaths in the mentally handicapped. *Psychol Med* 1984;14:691–5.
- 62 Health Services Executive Dublin. *Time to move on from congregated settings: a strategy for community inclusion*. 2011.
- 63 Ouellette-Kuntz H, Martin L, Burke E, *et al*. How best to support individuals with IDD as they become frail: development of a consensus statement. *J Appl Res Intellect Disabil* 2019;32:35–42.
- 64 Downar J, Goldman R, Pinto R, *et al*. The surprise question for predicting death in seriously ill patients: a systematic review and meta-analysis. *CMAJ* 2017;189:E484–93.
- 65 Government of Ireland. S.I. no.367/2013-health act 2007 (care and support of residents in designated centres for persons (children and adults) with disabilities). 2013.