

# Hidden lives and deaths: the last months of life of people with intellectual disabilities living in long-term, generic care settings in the UK

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## Funding information

This study was funded by the Dunhill Medical Trust, Research Grant R406/0215.

## Abstract

**Rationale:** This paper concerns mortality and needs for end-of-life care in a population of adults with ID living in generic care homes.

**Methods:** Various sampling strategies were used to identify a difficult to find a population of people with ID in generic care homes. Demographic and health data were obtained for 132 people with ID. This included the Surprise Question. At T2, 12 months later, data were obtained on the survival of this sample.

**Findings:** The average age was 68.6 years, and the majority were women (55.3%). Their health was typically rated as good or better. Responses to the Surprise Question indicated that 23.3% respondents might need EoLC. At T2, 18.0% of this population had died. The average of death was 72.2 years. The majority died within the care setting (62.9%).

**Implications:** The implications for end-of-life care and mortality research are discussed.

## KEYWORDS

care homes, end-of-life care, mortality, older people, Surprise Question

## 1 | INTRODUCTION

This paper seeks to describe the potential need for end-of-life care (EoLC) needs and patterns of mortality in older adults with intellectual disabilities living in care homes not exclusively for adults with intellectual disabilities, henceforth described as generic care homes. It reports a study that was conducted in the UK in 2017, well before COVID-19. Although there is some evidence concerning the health and social profile of this population (Bigby et al., 2008; Thompson et al., 2004), little is known about the level and nature of their mortality or potential need for EoLC. With increasing age, more and more adults with intellectual disabilities will live in service-based settings, the majority of which are provided exclusively for adults with intellectual disabilities. However, it is recognised that a significant but often unquantifiable proportion of people with intellectual

disabilities will be living in generic care homes and nursing homes for older adults (Bigby et al., 2008; Landes & Lillaney, 2019; Larson et al., 2018; Thompson et al., 2004). In Scotland, for example, it has been estimated that about 10% of adults with intellectual disabilities in care settings lived in generic services for older adults (Scottish Executive, 2000). There have been only sporadic research concerning this population over the last 2 decades (Bigby et al., 2008; Thompson et al., 2004), and little is known about levels of mortality and need for EoLC within this population. Yet, these generic care settings may be playing a more important role in supporting older people with intellectual disabilities than has hitherto been recognised. Heslop (private communication) reporting on unpublished findings in England from the Confidential Inquiry into Premature deaths of People with Learning Disabilities (CIPOLD; Heslop et al., 2013, 2014) commented that of all deaths reported to CIPOLD, 165

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(70.8%) were of people living in care settings. Of those, 65 (37.0%) had been living in generic care settings. Although they account for a small proportion of the total residential provision for adults with intellectual disabilities, generic settings seem to be significant providers of care at the end of life.

For the most part, the growing research interest in the provision and outcomes of EoLC for adults with intellectual disabilities has focused on care settings specifically for people with intellectual disabilities, see, for example (Gray & Kim, 2017; Grindrod & Rumbold, 2017; Hunt et al., 2019; Lord et al., 2017; McCarron et al., 2010, 2011; McKenzie et al., 2017; Northway et al., 2018; Todd et al., 2013, 2020; Tuffrey-Wijne et al., 2017, 2020; Tuffrey-Wijne & Rose, 2017; Wark et al., 2017; Wiese et al., 2012, 2013). However, intellectual disability settings, even allowing for the high risk of premature mortality in people with intellectual disabilities, may not have to deal with large numbers of deaths of adults with intellectual disabilities in any 1 year (Heslop et al., 2014; Todd et al., 2019, 2020). The risk of dying increases with age, so that, although people with intellectual disabilities are more likely to die prematurely than their fellow citizens, death rates in intellectual disability services reflect the predominantly middle-aged population living there. That intellectual disability-specific settings contain few older people cannot be solely explained by the higher risk of premature mortality in people with intellectual disabilities (Heslop et al., 2014). A likely contributory factor may be the number of ageing adults with intellectual disabilities who are moved into generic services for older adults (Bigby et al., 2008; Thompson et al., 2004).

Generic care settings are significant places of care at the end of life for many people in the general population, especially older adults (Shah et al., 2013). In the UK, it is estimated that about one fifth of all deaths occur within a care home, and that about one third of those aged over 75 years of age will die there (Public Health England, 2019). Their role in providing EoLC has been increasingly recognised and supported by policy and service developments, see, for example, (NHS England, P, 2017). However, the evidence base has been criticised for often failing to recognise the diversity both of care settings (Froggatt & Payne, 2006) and of the population they support (Badger et al., 2009; Sampson et al., 2012). Adults with intellectual disabilities within these settings are not visible within this literature. Their invisibility may be an outcome of the size and dispersed nature of this population. It is likely that many generic settings contain no people with intellectual disabilities, and in those that do in the England, they may make up <2% of the supported population (Thompson et al., 2004). Bigby et al. (2008) report that in similar settings in Victoria, Australia there were 207 people with intellectual disabilities living across 144 settings, or on average 1.8 people with intellectual disabilities per setting.

The mortality and EoLC needs of adults with intellectual disabilities in generic care settings have largely been overlooked by both Intellectual disability and EoLC researchers. There is some support for the idea that the population of adults with intellectual disabilities within these services may be distinct both from others in Intellectual Disability services and from those in care homes for older adults.

They will be older than those in intellectual disability settings and younger than their fellow residents in generic care settings (Bigby et al., 2008; Thompson et al., 2004; Todd et al., 2019, 2020). People with intellectual disabilities in generic settings are also likely have a different health profile from those in intellectual disability care settings because of age-related illnesses (Bland et al., 2003; Cooper & van der Speck, 2009; Haveman, 2004; Haveman et al., 2011; Hermans & Evenhuis, 2014; Lifshitz et al., 2008; Lin et al., 2016; McCarron et al., 2011). Their health profile may be more similar to their fellow residents in generic care settings for older adults but with lower reported levels of dementia (Bigby et al., 2008). There are good reasons, therefore, to assume that patterns of death and dying for adults with intellectual disabilities in generic care settings may be distinct and require focused research attention.

In this paper, we provide a description of this population from a mortality and EoLC perspective. We describe the demographic and health characteristics of a sample of adults with intellectual disabilities; the mortality patterns and risk of death; and the level of potential need for EoLC. Mindful of the importance of setting specific characteristics in this field (Froggatt & Payne, 2006), we make comparisons between adults with intellectual disabilities living in two types of generic care settings for older adults, Registered Care Homes (RCH) and Nursing Homes (NH). To address the potential need for EoLC in these 2 populations of adults with intellectual disabilities in this paper, we not only look at prevalence of dementia and cancer, and reported causes of death, but use the Surprise Question (SQ). This is a widely used screening tool that aims to identify people nearing the end of life and who might benefit from palliative care interventions (Lilley et al., 2017; Thomas, Armstrong Wilson, & Team, 2016; Weissman & Meier, 2011). In the UK, it forms part of the Prognostic Indicator Guidance (PIG) within the Gold Standards Framework for EoLC issued by the Royal College of General Practitioners (Thomas et al., 2016). Its use as a tool to predict death has limitations (Downar et al., 2017) but it may have some value in prompting consideration that EoLC might be beneficial (White et al., 2017). It has been suggested that the question may have some utility in intellectual disabilities services (Vrijmoeth et al., 2018) and research (Todd et al., 2020).

## 2 | METHODS

### 2.1 | Participating services

Participating settings were Registered Care or Nursing homes. Settings solely for people with intellectual disabilities were excluded. We used a series of recruitment strategies. Initially, we held discussions with several community Intellectual Disability teams, providers of Intellectual Disability services, commissioners of Intellectual Disability services and commissioners of services for older people in England and Wales. Commissioners told us that Intellectual Disability was not always used as an identifier once people were in generic care settings. Therefore, like others (Schaper et al., 2019; Thompson et al., 2004), we experienced considerable difficulty in

**TABLE 1** Gender and age distribution within Registered Care Homes (RCH) and Nursing Homes (NH) for residents with intellectual disability and for all other residents

	ID in RCH	Non-ID in RCH	ID in NH	Non-ID in NH
Male	40 50.6%	283 33.1%	19 35.8%	370 36.1%
Female	39 49.4%	573 66.9%	34 64.2%	656 63.9%
Average age	69.5 years	81.9 years	67.3 years	79.5 years
Aged under 60 years	17 21.5%	54 6.8%	10 18.9%	93 9.0%
Between 60 and 79 years	47 59.4%	211 26.4%	38 71.7%	445 33.4%
80 years or older	15 19.0%	534 66.8%	5 9.4%	596 57.6%

locating this population and spent significant effort and time identifying settings that met our inclusion and exclusion criteria. Further sources of information were then explored, including provider websites, professional networks and contacts currently working in the care home sector. In total, 558 individual settings were identified and contacted by telephone or e-mail. Many settings ( $n = 249$  settings, 44.6%) did not respond to, or declined, our invitation to discuss the research. Others ( $n = 78$ , 14.0%) were care settings exclusively for people with intellectual disabilities, and a further 3 (0.54%) were settings that only offered respite care. Of the 228 settings that met our inclusion criteria and expressed an interest in participation, 158 (69.3%) reported that they currently did not support anyone with intellectual disabilities. 70 (30.7%) settings confirmed that they were RCH or NH settings that were not exclusively for people with intellectual disabilities and were currently supporting at least one person with intellectual disabilities. Of those 70, 66 (94.3%) participated in the study. Most participating services were based in England and Wales ( $n = 63$ , 95.5%), and 3 (4.5%) were in Scotland.

## 2.2 | Procedure and materials

Data were obtained from participants (usually a manager or senior nurse within each setting) concerning the supported population: the number of people living in the setting, their age and gender; and the number of people with intellectual disabilities living in the setting. We were not able to verify whether these individuals had intellectual disability or to determine the severity of their intellectual disability. We then sought more detailed data on the individuals with intellectual disabilities. We discussed the practicalities of data collection with provider organisations prior to data collection. It was clear that participants had many calls on their time and would be unable to give detailed responses on more than three people. We decided that, when there were more than three people, we would seek data only for the three eldest. This was consistent with the aim of the study to describe the care situations of the “oldest old” with intellectual disabilities. The numbers of younger people on whom we did not obtain data for are outlined below. We decided, for the same reason that we could not collect detailed information on deaths in the population without intellectual disabilities, as we had originally intended. We also had to restrict the number of health conditions about which we enquired. The data obtained for each individual

included previous place of care; length of time in the current setting; whether they had seen someone from Intellectual Disability services in the previous 3 months; the absence or presence of certain illnesses or conditions; and a global assessment of their current health and projected health in 12 months' time. Participants were asked the SQ, that is, “Would you be surprised if this person was to die within six months?” The data were collected between April and June 2017. 12 months later (April to June 2018; T2), participants were contacted again and asked to complete the same questionnaire for each of the three people with intellectual disabilities identified at T1. If a person with intellectual disability had died or moved since T1, participants were asked to provide details of their death or new place of care. We also asked participants to identify deaths of people with intellectual disabilities that had occurred in the previous 12 months and to provide data on the age, gender, perceived cause of death and place of death.

## 2.3 | Ethics

Ethical approval was sought and obtained from the FLSE Ethics Committee at the University of South Wales.

## 2.4 | Data analysis

Differences in the characteristics of people in each of the two settings at T1 were compared, as were the responses to the SQ and how many individuals had died before T2. *T* tests for independent samples were used and assessed for equal variance. Yates's chi-squared test was used to avoid the risk of overestimating statistical significance that is associated with smaller samples. Fisher's exact test was used when expected values in any one cell were  $<5$ . Where appropriate, two-tailed tests were used and, in all cases, statistical significance was set as  $p < .05$ . Missing data were excluded from analysis but are identified, where appropriate, on tables.

## 3 | RESULTS

Although 70 settings agreed to participate in the study, 4 (5.7%) did not return data. Of the 66 participating services, 42 (63%) were

Registered Care Homes and 24 (36.4%) were Nursing Homes. Sixty-one settings provided data on the total number of people they supported, a total of 2049. The average size of RCH ( $n = 37$ ) was 24.6 residents per setting and was 47.4 residents in NH ( $n = 24$ ). NH were larger than RCH ( $t = 4.72, p < .01$ ). Within the 66 settings, there were 162 people with intellectual disabilities, or an average of 2.45 people, per setting. In RCHs, this was 2.29, and NHs 2.79 ( $t = 1.24, p = .22$ ). The proportion of people with intellectual disabilities within a setting was significantly higher in RCH (9.7% in 37 homes) than in NH (5.9% in 24 homes;  $\chi^2 = 9.76, p < .01$ ).

Table 1 compares the two supported populations of people with intellectual disabilities with those residents without intellectual disability within RCH and NH settings. Since data were only obtained for a maximum of three people with intellectual disabilities per setting, further data were obtained for 132 out of the 162 (81.5%) people with intellectual disabilities identified as living in the setting. 7 out of 43 RCH settings (16.3%) had more than three people with intellectual disabilities so no data were obtained for 15 people with intellectual disabilities. There were six NH settings (25.0%) with more than three people with intellectual disabilities per setting, so no data were obtained for another 15 people with intellectual disabilities.

The majority of people with intellectual disabilities were women ( $n = 73, 55.3%$ ). In NH, 34 residents with intellectual disability (64.2%) were women. In RCH, there were more men with intellectual disability compared to the overall resident population ( $\chi^2 = 09.11, p < .01$ ). In NH, the gender distribution for people with intellectual disabilities was more similar to that of the other residents ( $\chi^2 = 0.07, p < .79$ ). People with intellectual disabilities were, on average just over 12 years younger than fellow residents without intellectual disability in both RCH ( $\chi^2 = 88.85, p < .01$ ) and NH ( $\chi^2 = 35.65, p < .01$ ). In RCH and NH, the majority of all residents were aged over 80 years of age, 66.8% and 57.9%, respectively. For people with intellectual disabilities, the predominant age grouping was 60–79 years of age (59.4% and 71.7%, respectively). Almost one half of people with intellectual disabilities across both settings were aged over 70 years of age ( $n = 64, 48.4%$ ).

Table 2 shows details about care history and length of time in their current setting for the 132 people with intellectual disabilities. The two most common places of previous residence were either a family setting or single person accommodation ( $n = 45, 36.6%$ ) or an intellectual disability service ( $n = 40, 32.5%$ ). Almost a quarter ( $n = 29, 23.6%$ ) had lived in another generic setting. Those currently living in NH were twice as likely to have moved there from another non-intellectual disability care setting ( $n = 17, 35.4%$ ) than those in RCH ( $n = 12, 16.0%$ ). People living in RCH had lived longer in their current setting ( $n = 73, \text{mean} = 6.4 \text{ years}$ ) than those in NH ( $n = 48, \text{mean} = 4.2 \text{ years}; t = 2.57, p < .05$ ). The average age at which people had moved to their current care setting was 63.0 years. For the 3 months preceding T1, just under a half of all residents ( $n = 59, 45.0%$ ) had had contact with a professional from an intellectual disability service. This was not significantly different between the two types of setting ( $\chi^2 = 2.74, p = .10$ ). Length of time in current place of residence seemed to influence contact with intellectual disability

TABLE 2 Service histories of people with ID in RCH and NH settings

	RCH $n = 79$	NHs $n = 53$	All $n = 132$
<b>Place of previous residence</b>			
Own home	13 17.3%	6 12.5%	19 15.4%
Family home	18 24.0%	8 16.7%	26 21.1%
ID setting	25 33.3%	15 31.2%	40 32.5%
Other care home	12 16.0%	17 35.4%	29 23.6%
Hospital	7 9.3%	2 4.2%	9 7.3%
Not known	4	4	8
Missing	0	1	1
<b>Length of time in residence</b>			
<1 year	12 16.4%	9 18.8%	21 17.4%
1–2 years	10 13.7%	14 29.2%	24 19.8%
3–5 years	16 21.9%	11 22.9%	27 22.3%
6–10 years	17 23.3%	10 20.8%	27 22.3%
11–15 years	15 20.5%	2 4.2%	17 14.0%
15+ years	3 4.1%	2 4.2%	5 4.1%
Missing	6	5	11
Mean	6.4 years	4.2 years	5.5 years
<b>Age moved to current place of care (years)</b>			
<50	9 12.7%	8 16.7%	17 14.3%
50–59	19 26.8%	10 20.1%	29 24.4%
60–69	23 32.4%	14 29.2%	37 31.9%
70–79	13 18.3%	14 29.2%	27 22.7%
80–89	7 9.9%	2 4.2%	9 7.6%
90+	0	0	0
Missing	8	5	13
Mean age at admission	62.8 years	62.6 years	62.7 years
<b>Contact with ID professional in last 3 months</b>			
Yes	30 38.5%	29 54.7%	59 45.0%
No	48 61.5%	24 45.3%	72 55.0%
Missing	1	0	1

teams: about three quarters ( $n = 26, 74.3%$ ) of those who had lived in their current place for <2 years had seen someone from intellectual disability service in the previous 3 months compared to about one third of those ( $n = 17, 34.7%$ ) who had lived there for more than 5 years ( $\chi^2 = 11.3, p < .01$ ).

Table 3 shows data on the health characteristics of the sample. There were few differences between the two supported populations in terms of the health conditions we asked about. Most of the reported health conditions were more prevalent among those in NH. However, the difference in prevalence between the two populations was only significant for epilepsy ( $\chi^2 = 7.46, p < .01$ ). About in ten people in both populations were reported to be people with Down syndrome (DS). The prevalence of dementia in people with DS was higher ( $n = 9, 64.3%$ ) than in those without DS ( $n = 15, 14.3%$ ).

**TABLE 3** Health characteristics of people with ID living in RCH and NH

	RCH	NH	All
The person has the following underlying conditions			
Down syndrome	8 10.1%	6 12.0%	14 10.8%
Challenging behaviour	25 34.7%	15 30.0%	40 32.8%
Sensory impairment	25 32.5%	18 36.7%	43 34.1%
Mental health difficulties	25 34.7%	10 20.0%	35 28.7%
Cancer	3 3.8%	2 4.1%	5 3.9%
Dementia	11 15.3%	10 21.3%	21 17.6%
CV disease	5 6.7%	8 7.4%	13 10.7%
Epilepsy	14 18.2%	21 42.0%	35 27.6%
Diabetes	13 20.0%	8 16.3%	21 18.9%
Arthritis	10 13.5%	11 27.5%	21 18.4%
Osteoporosis	3 3.8%	7 14.3%	10 7.9%
Chronic constipation	8 10.1%	10 20.8%	18 14.2%
Perception of current health			
Excellent or very good	18 24.7%	7 14.0%	25 20.3%
Good	29 39.7%	14 28.0%	43 35.0%
Fair	24 32.9%	17 34.0%	41 33.3%
Poor	2 2.7%	12 24.0%	14 11.4%
Missing	6	3	9
Projection of health in 12 months			
Significantly improved	9 11.7%	0 0%	9 7.1%
Much the same	57 74.0%	40 80.0%	97 76.4%
Significantly worse	11 14.3%	10 20.0%	21 16.5%
Missing	2	3	5
Has the person been admitted to hospital in past 6 months			
Yes	11 13.9%	10 20.0%	21 16.3%
No	68 86.1%	40 80.0%	108 83.7%
Missing	0	3	3
For those admitted, average number of admissions	1.85	1.63	1.75
Has the person fallen in the last 6 months?			
Yes	33 42.3%	24 48.0%	57 44.5%
No	45 57.7%	26 52.0%	71 55.5%
Missing	1	0	1

However, the majority of people with dementia were people without DS ( $n = 15$ , 62.5%). When participants were asked to rate the individual's health, the majority were reported to be in good health or better ( $n = 68$ , 55.3%). Only 14 were reported to be in poor health. The health of those in NHs was more likely to be rated as poor ( $n = 12$ , 24.0%) than those in RCH ( $n = 2$ , 2.7%;  $\chi^2 = 11.27$ ,  $p < .01$ ). There was a sense of perceived stability in their health status, with the majority expected to be much the same in 12 months' time ( $n = 97$ , 76.4%). For those in good health, participants felt it was likely that they would

**TABLE 4** Responses to the Surprise Question for residents in RCH and NH at T1 and status at T2

	RCH	NH	ALL
'Would you be surprised if the person was die in the next 6 months?'			
Yes	64 81.0%	35 70.0%	99 76.7%
No	15 19.0%	15 30.0%	30 23.3%
Missing	0	0	
Status at T2			
Alive	64 88.9%	36 72.0%	100 82.0%
Had died	8 11.1%	14 28.0%	22 18.0%
Not obtained-person had moved	5	1	6
Not obtained at follow-up	1	2	3

preserve or improve their current health ( $n = 52$ , 98.1%). For those in less than good health, a stable or worsening health status was predicted ( $n = 39$ , 92.8%). Individuals in RCH were reported to probably see improvements in their health ( $n = 9$ , 11.7%), whereas no-one in NHs was reported to likely see a health improvement (Fisher's exact  $p < .01$ ).

Table 4 looks at responses to the SQ and also the level of mortality in the two groups. The SQ was used as a proxy of participants' views on potential need for EoLC. A negative response, indicating a potential need for such care, was given for 30 (23.3%) individuals. Although the proportion of negative responses was higher in NH ( $n = 15$ , 30.0%) than in RCH ( $n = 15$ , 19.0%), this difference was not significant ( $\chi^2 = 7.46$ ,  $p < 1.51$ ,  $p = .2$ ). Between T1 and T2, there had been 22 (18.0%) deaths. Mortality in NH was significantly higher ( $n = 14$ , 28.0%) than in RCH ( $n = 8$ , 11.1%;  $\chi^2 = 5.43$ ,  $p < .05$ ). This gives an annual death rate of 180 deaths per 1000 people with intellectual disabilities supported: 280 deaths per 1000 per year in NH and 111 in RCH. There was an association between SQ responses and the likelihood of death within the sample. For those who staff thought might die within the next 6 months, 40.7% ( $n = 11$ ) had died by T2 compared to 10.1% ( $n = 9$ ) of those staff thought would likely survive the subsequent 6 months (Fisher's exact  $p < .01$ ). However, in terms of predicting death, the SQ, in this population, had low sensitivity (55.0%) and higher specificity (84.5%). Sensitivity here refers to the ability of the question to correctly identify individuals likely to die within the stated time, with few false-negative results, missing few of the individuals who did die. The specificity is the ability of the SQ to correctly identify individuals who were unlikely to die within the time, with few false positives. This implies then that the SQ was better at predicting survival than it was at predicting death. This held across both settings. In NH, sensitivity of the SQ was 58% and 50% in RCH (Fisher's exact  $p = .99$ ). The specificity of the SQ was 82% in NH and 84% in RCH ( $\chi^2 = 0.01$ ,  $p = .92$ ).

For the 22 deaths, there seemed to be a higher risk of death amongst those who had lived in their current place of care for

<2 years ( $n = 11, 34.4\%$ ) than amongst those who had lived there for 2 years or more ( $n = 8, 13.1\%$ ;  $\chi^2 = 4.6, p < .05$ ). The average age at death was 72.2 years. There was no significant difference in the age at death of men (72.4 years) and women (72.1 years;  $t = 0.10, p < .92$ ). As well as the 22 deaths described above, which had occurred by T2, data were also obtained on 13 deaths that had occurred in the 12 months before T1. Data on all 35 deaths are presented in Table 5. The age of death for decedents was mainly between 70 and 79 years of age ( $n = 15, 44.1\%$ ), and a further 7 (20.6%) died when they were 80 or older. Thus, just over three quarters of decedents were aged over 70 years of age when they died. There was no significant difference in age at death between the two care populations (Fisher's exact  $p = .99$ ). For almost a third of decedents ( $n = 10$ ), a precise cause of death could not be coded from the data provided. In some cases, responses such as "natural causes" or "old age" were given, and in others, no data were provided. Where a cause of death was given and coded, just over one third of deaths were reported to be from respiratory causes and 6 (24.0%) were attributed to cardiovascular disease. The most common place of death was the care setting in which the person lived ( $n = 22, 62.9\%$ ). This was comparable across both groups, 61.5% (RCH) and 63.6% (NH).

TABLE 5 Mortality characteristics and place of death of decedents in NH and RCH

	RCH N = 13	NH N = 22	All N = 35
<b>Gender</b>			
Male	7 53.8%	8 38.1%	15 44.1%
Female	6 46.2%	13 61.9%	19 55.9%
Missing	0	1	1
<b>Age</b>			
<50 years	0 0%	0 0%	0 0%
50–59 years	0 0%	1 4.8%	1 2.9%
60–69 years	4 30.8%	7 33.3%	11 32.3%
70–79 years	5 38.5%	10 47.6%	15 44.1%
80–89 years	4 30.8%	3 14.3%	7 20.6%
Missing	0	1	1
<b>Cause of death</b>			
Respiratory illness	1 10.0%	8 53.3%	9 36.0%
Cancer	2 20.0%	1 6.7%	3 12.0%
CVD	4 40.0%	2 13.3%	6 24.0%
Other	3 30.0%	4 26.7%	7 28.0%
Not established	3	7	10
Dying with dementia	2 28.6%	3 25.0%	5 26.3%
<b>Place of death</b>			
Care setting	8 61.5%	14 63.6%	22 62.9%
Hospital	5 38.5%	8 36.4%	13 37.1%
Missing	0	0	0

## 4 | DISCUSSION

This paper offers a description of mortality and the need for EoLC among adults living in generic care settings, a population that is important but difficult to locate. Although it is not possible, in the UK at least, to determine the size of this population, the age structure and rates of death reported for the sample described here suggest that generic settings are important, if unrecognised last places of care for many older adults with intellectual disabilities. This is not reflected in the current literature concerning EoLC and people with intellectual disabilities. The mortality rates reported in each of the two types of generic care settings studied here were considerably higher than those reported for adults in intellectual disability settings (Todd et al., 2020). The SQ was used to estimate potential need for EoLC in the study sample. Our finding, that almost one in four adults in this sample had a potential need for EoLC, would be unlikely to be matched in a population of adults in intellectual disability care settings who are younger and have a lower risk of death in the immediate future; and where death is often not anticipated for long (Todd et al., 2020). Current concerns about issues of access and quality of EoLC in relation to people with intellectual disabilities, see, for example, (NHS England, P, 2018; Tuffrey-Wijne & McLaughlin, 2015) must be extended to include people with intellectual disabilities living in generic care settings. The role of generic care homes as important providers of EoLC and need for continuing service development in this regard is increasingly recognised (Teggi, 2018). However, we cannot assume, without further research, that people with intellectual disabilities will benefit from any overall uplift in service quality in this sector. The need for more research here is clear.

Our paper highlights how much is still unknown about this population who are amongst the oldest old people with intellectual disabilities. In this paper, we considered issues of death and dying. However, our data also suggest that despite the age of this population, research interest should not be confined to mortality. The majority of people with intellectual disabilities in this study were reported to be in good health, and staff projections concerning their immediate futures highlighted stability, and sometimes improvement, rather than decline in health. Research into the meaning, nature and implications of prolonged ageing for people with intellectual disabilities (McKenzie et al., 2017) should also include these settings where so many of the oldest people with intellectual disabilities live. Though mortality and the need for EoLC are important, the quality of the lives spent in these settings are equally important and under-researched. As (Bigby et al., 2008; Thompson et al., 2004) have argued, this is a population whose right to a full, varied and active life might be thwarted by ageism, and by popular but misleading stereotypes of care homes.

Regardless of whether the research focus is quality of life or dying within these settings, our experiences in finding this population suggest that any future research in this area is likely to be challenging given the multiplicity of providers and complexity of funding arrangements. Older people with intellectual disabilities are a relatively small population dispersed across numerous care settings.

The Competition and Markets Authority (Authority, 2017) estimated that there are around 11,300 care homes for older people in UK, homes that are managed by as many as 5500 different providers. In this study, of those settings willing to consider participation, around two thirds reported they did not support anyone with an intellectual disability. In those that did, there was an average of just over two people with intellectual disabilities living in either Registered Care Homes or Nursing Homes, with average resident population of 24 and 47, respectively. Nor can we expect to identify this whole population relying solely on the knowledge of Intellectual Disability professionals and teams. Our data suggest their contact diminishes over time, so that many those who have lived longest in the settings, including some of the oldest old, would continue to be hidden. There were also multiple pathways to their current residential placement, including movement between generic settings, which might further limit the utility of relying on the knowledge of intellectual disability professionals or commissioners' knowledge to identify this population. Indeed, these pathways themselves would be a useful focus for future research. One possible line of development here is for reciprocal and collaborative relationships between researchers with an interest in EoLC in intellectual disability and generic care homes.

The relative risk of death within this population suggests that research, policy, and service development concerning ageing in this population, as for any other older population, must embrace rather than marginalise death and dying (Martin et al., 2015). Almost one in five of the sample here had died before follow-up 12 months later. Such a rate of death in the settings is close to 15 times higher than that reported in intellectual disability care settings (Todd et al., 2019, 2020). The levels of mortality in the current study are broadly comparable, if lower, to those reported for care homes in general (Fernandez & Forder, 2011; Shah et al., 2013; Tanuseputro, et al., 2015; Vossius et al., 2018). Although death might be distinct in intellectual disability and non-intellectual disability settings, there may be an important similarity in both. That is many of these deaths are from illnesses associated with uncertain dying trajectories and uncertainty that the end of life might be approaching (Teggi, 2018). People with intellectual disabilities of any age may, given their mortality profile, be at a high risk of missed opportunities for timely and effective EoLC interventions and hence experience disadvantaged dying (Bernal et al., 2021). Various tools have been developed to improve prognostication in these illnesses. One of these has been the SQ, either alone or in the context of a wider prognostic tool, for example the PIG (Thomas et al., 2016). We report here, as have others, for example (Downar et al., 2017) that the SQ may have limited predictive power in terms of death. It did not identify all those who eventually died. However, it did better at predicting survival. This implies that it may be useful in practice. In services for adults with intellectual disabilities where death is infrequent and typically not well anticipated (Bernal et al., 2021; Todd et al., 2020), it might prompt further and tentative discussion of potential need for end-of-life care. The SQ might also enable more focused, cost-effective and sensitive sampling in prospective EoLC care researcher in excluding a sizeable group of people who are unlikely to die in the near

future and whose deaths may never be foreseeable until death is imminent.

Previous research has focused on the extent to which generic care homes are appropriate places for adults with intellectual disabilities to live. It is also important to consider whether they are appropriate places for adults with intellectual disabilities to die. We did not collect data on the quality of EoLC and this remains an important focus for future research. Data were obtained on place of death, which has been widely used as a proxy measure of the quality of EoLC (Costa et al., 2016; Gomes et al., 2010), though its significance in people with intellectual disabilities, who are known to experience inequitable access to health care, is less clear (Bernal et al., 2021; Todd et al., 2020). Two thirds of decedents died in their usual place of care. This is higher than is reported for Intellectual Disability settings (Todd et al., 2020) and comparable to the proportion of care home residents more generally (Public Health England, 2019). However, further research should investigate more fully the quality of EoLC delivered to this population.

#### 4.1 | Limitations of the study

Many older people with intellectual disabilities live in non-intellectual disability care settings, and the sampling strategies used here were successful in finding a difficult to identify sample of people with intellectual disabilities dispersed across many settings. However, since the size of the total population of adults with intellectual disabilities living in generic care settings remains unknown the generalizability of the findings. We were not able to cross-check the quality of data supplied to us on the characteristics of individuals: including their intellectual disability. The characteristics of the study sample, in terms of age and gender, are broadly in keeping with that reported by others (Bigby et al., 2008; Thompson et al., 2004). The pattern of age-related illnesses matches that reported by others (McCarron, Swinburne, et al., 2011). It does not appear, therefore, to be an atypical sample for adults with intellectual disabilities. We restricted the number of people on whom we obtained data to three per setting, thus excluding 30 people with intellectual disabilities from our sample. This means that the average age and the death rate in our sample are likely to have been higher than among the total population of people with intellectual disabilities in these settings.

## 5 | CONCLUSION

The lives and deaths of this particular group of people are largely hidden from view in the intellectual disability and EoLC literatures. This limits a wider understanding of the mortality of people with intellectual disabilities, their need for EoLC and the quality of the care they receive at the end of their lives. Generic care settings are important last places of care for older adults with intellectual disabilities. To develop the evidence-base on ageing well and dying well with intellectual disabilities better ways of identifying this

population are needed. This is all the more pressing now given the huge impact COVID-19 has had upon those living in generic care homes (Oliver, 2020), a population that will include significant numbers of older adults with intellectual disabilities.

## ACKNOWLEDGEMENTS

This study was funded by the Dunhill Medical Trust, Research Grant R406/0215. The data that support the findings of this study are available on request from the corresponding author.

## DATA AVAILABILITY STATEMENT

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

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**How to cite this article:** 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;00:1–10. <https://doi.org/10.1111/jar.12891>