



Last months of life of people with intellectual disabilities: A UK population-based study of death and dying in intellectual disability community services

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Abstract

Background: Population-based data are presented on the nature of dying in intellectual disability services.

Methods: A retrospective survey was conducted over 18 months with a sample of UK-based intellectual disability service providers that supported over 12,000. Core data were obtained for 222 deaths within this population. For 158 (71%) deaths, respondents returned a supplemented and modified version of VOICES-SF.

Results: The observed death was 12.2 deaths per 1,000 people supported per year, but just over a third deaths had been deaths anticipated by care staff. Mortality patterns, place of usual care and availability of external support exerted considerable influence over outcomes at the end of life.

Conclusion: Death is not a common event in intellectual disability services. A major disadvantage experienced by people with intellectual disabilities was that their deaths were relatively unanticipated. People with intellectual disabilities living in supported living settings, even when their dying was anticipated, experienced poorer outcomes.

KEYWORDS

care settings, end of life care, intellectual disability, mortality, place of death

1 | INTRODUCTION

The extent to which people with intellectual disabilities have access to good quality end-of-life care is recognized as an important public health imperative given their increasing longevity and an allied growing incidence of life-limiting illnesses such as cancer and dementia (Coppus, 2013; Evenhuis, Henderson, Beange, Lennox, & Chicoine, 2001; Haveman et al., 2011). There exist concerns that the suboptimal quality of health care provided to this population (Heslop et al.,

2013) may extend to end-of-life care provision (Tuffrey-Wijne et al., 2015). However, the evidence base concerning the scale of need for such care, and the extent to which such need is recognized and met effectively, is limited by a lack of population-based research (Moro, Savage, & Gehlert, 2017; Stancliffe, Wiese, & Read, 2017; Tuffrey-Wijne et al., 2016). For the most part, the major research contribution in this field has come from qualitative research which has provided many valuable insights concerning the delivery of care at the individual level. There are several challenges for population-based

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research in this area (Todd, Brandford, Worth, Shearn, & Bernal, 2019). Intellectual disability is not always identified on death certificates making it difficult to identify large or representative samples of deaths within this population (Dunwoodie Stirton & Heslop, 2018). An alternative approach, found in several studies designed primarily to identify premature and avoidable deaths of people with intellectual disabilities rather than examine end-of-life care, has obtained data on large numbers of deaths (Heslop & Glover, 2015; LeDeR, 2018) but, given the method for identifying deaths, these have not been able either to describe the living population within which deaths occurred or to determine whether all deaths within that population were reported. In an exploratory study of deaths with a defined population, Todd et al. (2019) were able to identify deaths within a population of just over 2,000 people with intellectual disabilities. The death rate within this population was estimated to be 13.1 deaths per 1,000 people per year, and hence, the study only yielded 66 deaths over a two-year period. Some of these deaths may have been ones where no end-of-life care was needed, further limiting the power of statistical analysis to identify factors affecting end-of-life care outcomes. Thus, a sizeable population would be needed to address these concerns. Furthermore, no intellectual disability in this field has used a validated measure of end-of-life care (Tuffrey-Wijne et al., 2016). The study reported here sought to respond to these challenges to provide the first population-based account of the last months of life of people with intellectual disabilities. It recruited a large number of intellectual disability service providers across the UK so as to be able to define the supported population and examine a large number of deaths regardless of cause of death, using a validated and intellectual disability-sensitive and supplemented version of VOICES-SF (Hunt, Richardson, Darlington, & Addington-Hall, 2017).

1.1 | Background

This paper examines the care provided in the last months of life to adults with intellectual disabilities who had been living in social care settings exclusively for adults with intellectual disabilities in the UK. Our reasons for this focus were twofold. Firstly, it permitted a determination of the frequency and types of death experienced by people with intellectual disabilities and the outcomes of care at the end of life within a defined population. Secondly, these are settings where many adults will live and, for many, settings where they will experience dying. Although not all adults with intellectual disabilities live in such settings, many do and more so with increasing age. In Scotland, for example, almost 70% of people with intellectual disabilities aged between 16 and 34 years lived with a family carer. For those aged 35–54 years, it was 35% and for those aged over 54 years, it was 16% (SCLD, 2016). Many of the remainder will live in intellectual disability social care settings, settings that have been the focus for a long lineage and high volume of research (e.g. Felce & Perry 2007; Felce et al., 2008; Flynn et al., 2018; Kozma, Mansell, & Beadle-Brown, 2009; Stancliffe, Lakin, & Prouty, 2005). These are settings, therefore,

where adults with intellectual disabilities both live and die. In a study of the deaths of 247 people with intellectual disabilities in England, Heslop et al. (2013) report that the majority of decedents (64%) had been living in a residential care setting at the time of death. Almost 75% of those deaths were of people who had lived in an intellectual disability setting (Heslop private communication). Thus, close to half of the deaths of adults with intellectual disabilities in England were of those who had been living in an intellectual disability setting. We acknowledge that people with intellectual disabilities will live and die in many other settings and that the findings from this study will have limited generalizability to other populations of people with intellectual disabilities. However, the settings of interest here are likely the last places of care for a significant and substantial proportion of adults with intellectual disabilities in the UK.

Good end-of-life care can be seen as an extension of good supportive care. Nonetheless, death and dying seem to present challenges to staff in intellectual disability services. Internationally, there is a growing volume of qualitative research that has highlighted many of the issues that may have a detrimental impact upon individual experience and quality of care at the end of life, for example inadequate staff preparedness, lack of inter-agency collaboration, low levels of timely advance care planning and the limited involvement of the person with intellectual disabilities in decision making at the end-of-life care (Bekkema, Veer, Wagemans, Hertogh, & Francke, 2014; Bekkema, Veer, Wagemans, Hertogh, & Francke, 2015; Bekkema, Veer, Hertogh, & Francke, 2016; Botsford, 2004; D'Haene et al., 2010; Forrester-Jones et al., 2017; Grindrod & Rumbold 2017; Lord, Field, & Smith, 2017; McCarron, McCallion, Fahey-McCarthy, Connaire, 2010, 2011; McKenzie, Mirfin-Veitch, Conder, & Brandford, 2017; Ryan, McEvoy, Guerin, & Dodd, 2010; Todd, 2013; Todd & Read, 2010; Tuffrey-Wijne, Bernal, & Hollins, 2010; Tuffrey-Wijne, Rose, Grant, & Wijne, 2017; Voss et al., 2019; Wagemans, Schroyen Stein Lantman-de-Valk, Tuffrey-Wijne, Widdershoven, & Curfs, 2010; Wagemans et al., 2013; Wiese, Stancliffe, Balandin, Howarth, & Dew, 2012; Wiese, Stancliffe, Read, Jeltel, & Clayton, 2015). This body of research points to a need for intellectual disability services to be better prepared and resourced to deal with death and dying. However, little is known about the rate of death within intellectual disability services, the types of deaths that intellectual disability services typically encounter and the outcomes at the end of life, regardless of cause of death, for those supported within them. Research has also typically focused on people with intellectual disabilities who have had cancer (Tuffrey-Wijne, 2016) and to a lesser extent dementia (Hatzidimitriadou & Milne, 2005; McCarron et al., 2011). Such a focus stems from the cancer origins of modern palliative care and because the dying trajectory associated with cancer is understood well enough to better plan service interventions (Clark, 2007). However, the end-of-life care needs of people dying from other illnesses where end-of-life care might make a valuable contribution are less well understood, even within the wider population (Addington-Hall & Hunt, 2012; Rosenwax & McNamara, 2006). Furthermore, models of care developed from cancer studies may not be readily transferable to meet the needs of those dying from

other illnesses (Murray, & Sheikh, 2008). In an intellectual disability context, a focus on cancer deaths further marginalizes the deaths of many people with intellectual disabilities given that the prevalence of death from cancer is much lower than in the general population (Hosking et al., 2016). Thus, an understanding of the end-of-life care needs of the majority of people with intellectual disabilities who die is less well understood. Thus, this paper focuses on outcomes at the end of life for people with intellectual disabilities regardless of cause of death.

The place where people with intellectual disabilities die is a key outcome addressed here. Although not the only important measure of end of care (Gomes, Calanzani, Gysels, Hall, & Higginson, 2013), place of death informs policy in developed countries and is considered important for individuals and their families (Bone et al., 2016; Grande & Ewing, 2009; Howell et al., 2017; Wright et al., 2010). The direction of service reform has been the movement of death from hospital to community settings. Deaths within hospitals are viewed as incompatible with individual wishes, offering poorer outcomes, and with using higher and potentially inappropriate resources (Hatziandreu, Archontakis, & Daly, 2019). Given a general view that hospitals are less than ideal places of care for people with intellectual disabilities (Glover, Fox, & Hatton, 2016; Iacano, Bigby, Unsworth, Douglas, & Fitzpatrick, 2014; Tuffrey-Wijne et al., 2013; Webber, Bowers, & Bigby, 2010), concerns over place of death for people with intellectual disabilities may have even greater resonance. Staff in intellectual disability services have been reported to be sympathetic to the idea that people should be supported to die in place (Ryan, Guerin, Dodd, & McEvoy, 2011; Todd, 2013; Wagemans et al., 2010; Wiese et al., 2012, 2013) but the extent to which such aspirations are realized and what might determine this are not known. There are few empirical studies of place of death of people with intellectual disabilities, and these offer contradictory findings that are, in part, related to the different sampling strategies used. Wagemans et al. (2010) report, in a study of 47 deaths of people with intellectual disabilities in residential services in the Netherlands, that 35 (74%) of decedents died within the intellectual disability setting within which they had lived. Only 10 (21.3%) died within a hospital setting. However, this study was based in a large intellectual disability setting where people were supported by physicians and nursing staff. This would not be considered typical in many countries where the preferred model of care is for smaller, more dispersed community-based settings staffed by social care rather than healthcare staff (Bigby and Beadle-Brown, 2006). This distinction in place of residence seems important. Bekkema et al. (2015) in a study of staff that had supported people with intellectual disabilities in the Netherlands suggest that place of death may be influenced by the residential status of the dying. They indicate that people with intellectual disabilities were less likely to have received end-of-life care in the setting in which they had lived if they had lived in group homes (68.6%) or lived alone or with families (55.6%) than if they lived in larger residential settings (88.0%). Todd et al. (2019) report that most deaths of people living in intellectual disability group homes provided by a large intellectual disability Australasian

service were deaths that occurred within hospitals and that people living in smaller group homes were more at risk of hospital death than those living in larger settings. However, this latter study was based on only 66 deaths within a single provider. Although data were not provided separately for the place of death for people living in intellectual disability services, Heslop et al. (2013) reported that just under half of decedents with intellectual disabilities died in hospitals (46%). This compared to 54% of the wider English population. Yet, more recently in England, the Learning Disabilities Mortality Review (LeDeR) (2018), based on a review of 1,244 deaths of people with intellectual disabilities in England, reported that 60% of people with intellectual disabilities died in hospital. The discrepancy in levels of hospital-based deaths is interesting and may be due, potentially, to differences in the populations from which deaths were identified in both studies. The discrepancy in levels of hospital-based deaths is interesting and may be due to both studies relying on the voluntary reporting of deaths within undefined populations. Given this, and the scope for variability in place of death by place of residence, it seems important to be able to describe the population within which deaths occur.

It is not surprising that place of death varies among adults with intellectual disabilities. There is growing evidence within the wider population that place of death is likely to be determined by an interaction between a number of factors, for example cause of death, and individual and environmental factors (Costa et al., 2016; Gomes et al., 2013; Gomes, McCrone, Hall, Koffman, & Higginson, 2010). Cancer, as a cause of death, is often used to compare place of death across countries and across illness types (Cohen et al., 2015, 2017; Harding et al., 2018; Wachterman et al., 2016). The historical association between cancer and the development of palliative care has tended to imply that people dying from cancer are more likely to die within the settings in which they had lived than those dying from other causes. The prevalence of cancer within the intellectual disability population is lower than in the general population (Glover & Ayub 2011; Heslop et al., 2013), although it may be underdiagnosed (Tuffrey-Wijne, Hogg and Curfs, 2007). There is also a higher level of sudden or unexpected death within people with intellectual disabilities (Heslop et al., 2013; Hunt et al., 2019). Planning for dying in place is likely to be more problematic if death is less expected. The timely identification of dying is considered necessary to plan effective end-of-life care interventions (Gold Standards Framework, 2011) but this may be more difficult for people with intellectual disabilities given their mortality profile (Vrijmoeth et al., 2018). Consequently, fewer deaths of people with intellectual disabilities may be anticipated and identified as deaths with an associated need for end-of-life care. The extent to which these factors shape outcomes at the end of life for people with intellectual disabilities is unknown. In this paper, we examine the impact the extent to which a death had been has upon place of death and other outcomes.

This paper reports a cross-sectional, population-based study of mortality and care at the end of life for people with intellectual disabilities living in community-based intellectual disability settings. It seeks to build upon the limited evidence about the nature of death

and dying in intellectual disability services and the extent to which people with intellectual disabilities are supported to die in the settings in which they had lived. It also seeks to determine the factors that might influence place of death. The factors examined here are place of care, cause of death, anticipation of death, end-of-life care planning and support from external services.

2 | METHODOLOGY

Data for this study were obtained from a large sample of UK-based intellectual disability service providers. A retrospective cross-sectional survey design to identify both deaths within this population and also potential respondents for more detailed follow-up of reported deaths was implemented. Data were only sought for people living in non-nursing care settings that were exclusively for people with intellectual disabilities. Data were collected at three intervals every six months. Providers were asked to describe the population they supported in terms of age, gender and type of setting provided. Deaths that occurred within the previous 6 months of data collection were reported to us at three time periods over 18 months. Core data were obtained at phase 1 for each reported death, and then, at phase 2, detailed follow-up data for each reported death were sought from a named respondent, who had known the decedent, using an intellectual disability-sensitive and supplemented version of VOICES-SF (Hunt et al., 2017).

2.1 | Recruitment and population

The overwhelming majority of people with intellectual disabilities in care settings in England, and to a slightly lesser or greater extent in the other countries of the UK, live in settings managed by the non-statutory sector (Hatton, Glover & Ermerson, 2016). Thus, non-statutory providers were identified as potential participants through several routes including the knowledge of the collaborators, consultations with commissioners and through different professional networks and websites. Eighty such service providers across the UK were contacted and to be eligible for the study they had to provide or manage social care settings exclusively for people with intellectual disabilities. Thirty-eight (47.5%) providers met the eligibility criteria and agreed to participate in the study. They were asked to provide information on the populations they supported in either registered care homes (RCHs) or supported living (SL) settings. RCHs were settings that provided accommodation, board and personal care but where service users did not have a tenancy. SL settings were settings where people with intellectual disabilities were tenants in a home that was provided by a registered social landlord and where the support staff were managed by the participating providers. Thirty-six providers were able to provide such data. They supported 12,425 people with intellectual disabilities in one or other of these two setting types: 8,596 (69.2%) in SL settings and 3,829 (30.8%) in RCH. They managed

547 RCHs with an average size of 7.0 residents and 2,606 SL settings with an average size of 3.3 residents. The majority of service providers (58%) supported between 201 and 500 people with intellectual disabilities. Eight (21%) supported fewer than 50 people with intellectual disabilities in total. Every region in the UK had an intellectual disability setting that was managed by one of the participating services. The majority of the people with intellectual disabilities they supported lived in a setting in England ($n = 10,135$; 81.6%), 8.8% ($n = 1,089$) lived in Wales, 7.8% ($n = 969$) lived in Scotland and 1.9% ($n = 232$) lived in Northern Ireland.

An exploratory study by *N* (Todd et al., 2019) described the challenges in conducting a population-based study of death and dying in intellectual disability services. It reported a low level of death within such settings (11.3 deaths per 1,000 people supported per year). Thus, in order to yield a large number of deaths for statistical analysis, a considerably large population was required. Using place of death as the basis for our sample size calculation, and based on a proportion of 68% of people with intellectual disabilities dying in hospital, we calculated that a sample size of 182 decedents would be required to provide 80.0% power at $\alpha = 0.05$ (two-tailed) to detect a significant difference from the general population proportion of 58% dying in hospital. Assuming the death rates above, we estimated that it would be necessary to recruit services that provided support to approximately 11,000 people with intellectual disabilities to capture the requisite sample of 182 decedents. To allow for potential dropout, we extended the data collection period from 12 to 18 months. Over the course of the study, none of the 38 services dropped out of the study and data were obtained on 222 deaths.

2.2 | Procedure and materials

The study was divided into two phases. Phase 1 involved asking service providers to identify deaths that occurred over an 18-month period in three 6 monthly waves of data collection. This commenced in July 2013 and ended in December 2014. For each death reported, the service providers completed a core data questionnaire that included, among other things: the age of death, gender, health conditions, cause and place of death. It was not expected that respondents would have access to death certificates and so data were obtained on cause of death as perceived and reported by care staff. Respondents were asked to provide as much data on cause of death as they could so that cause of death could be coded and later confirmed by phase 2 respondents. Over this 18-month period, 222 deaths were identified by the service providers. One additional death was noted but not included in the study since it was subject to coronial review. Services confirmed these were all the deaths that had occurred within their services within the time period.

For each death identified in phase 1, service providers were asked to provide the contact details of a member of staff who knew the deceased person well and could participate in phase 2 of the study. This phase aimed to collect data on the perspectives of staff on the care the decedent received in the last months of their life.

The questionnaire consisted of a version of VOICES-SF (Hunt et al., 2017). This measures experience of end-of-life care and is well tested and widely used. For example, it was used to obtain data on 49,000 deaths in England and Wales between 2011 and 2014 (ONS, 2016). It was minimally adapted for this study so that it could be used by carers in intellectual disability settings. A supplementary questionnaire obtained additional data on the support needs of decedents in key activities of daily living; the presence and nature of personal and end-of-life care planning; and some details about the setting in which the person lived, for example number of residents supported and numbers of staff working in the setting. At phase 2, a total of 188 questionnaires were sent out, representing 85% of the deaths identified in phase 1. It was not possible to send questionnaires for 34 deaths since staff teams had disbanded or no contact details had been provided. Of the 188 questionnaires sent, 158 were completed and returned, which represents a response rate of 84% of those sent and a follow-up rate of 71.2% for the 222 deaths initially identified. The majority of respondents completing the questionnaire identified themselves as working in the service setting where the decedent had lived ($n = 144$, 91.1%). They reported having either a managerial role within the same setting ($n = 38$, 24.0%); the decedent's keyworker ($n = 18$, 11.4%) or simply noted that they had worked within the setting with the decedent without specifying their role ($n = 88$, 55.7%). Fourteen respondents (8.9%) noted that they had a managerial role across several settings. Four respondents (2.5%) did not provide any information on their relationship to the decedent.

2.3 | Analysis

Statistical analysis was performed to investigate patterns among the responses received. *t* tests were used to examine differences between groups in terms of normally distributed scale variables in the data set. Associations between categorical variables were explored using chi-square tests (or Fisher's exact test where expected counts were small). Analysis was conducted using IBM SPSS Statistics (version 24).

3 | RESULTS

3.1 | Description of settings and population

Thirty-six of the participating providers provided data on the number of people with intellectual disabilities living in registered care home (RCH) ($n = 3,829$) or supported living (SL) settings ($n = 8,596$). Thirty-four were able to provide data on the gender and age of the populations they supported across both types of settings. There were more men (56.3%, 6,718) than women (43.7%, 5,222) in both setting types, 2,081 men (56.4%) in RCH and 4,637 (56.2%) in SL settings. There was no significant difference in gender across both settings ($\chi^2 = 0.11$, $p = .74$). Table 1 shows the age distribution of the population supported across the two types of settings. The age

TABLE 1 Age distribution of supported population across types of setting provided by 34 participating service providers

Setting type	RCHs			SL settings		
	N	%	cum %	N	%	cum %
<20 years	87	2.4	2.4	216	2.6	2.6
20–29 years	421	11.4	13.8	1,201	14.6	17.2
30–39 years	541	14.7	28.5	1,179	14.3	31.5
40–49 years	858	23.3	51.8	1,840	22.3	53.8
50–59 years	917	24.9	76.7	2,025	24.6	78.3
60–69 years	598	16.2	92.9	1,242	15.1	93.4
70–79 yrs	213	5.8	98.7	420	5.1	98.5
80–89 years	38	1.0	99.7	103	1.2	99.7
90+	9	0.2	99.9	15	0.2	99.9
All	3,682			8,241		

distribution was similar between RCH and SL settings. More than three-quarters of people in either setting were aged 60 or less. The proportions of people supported in either setting declined dramatically beyond this age. The supported population could be described as largely middle-aged. There were, however, more people aged less than 40 years living in SL (31.5%) than in RCH (28.5%) settings ($\chi^2 = 10.73$, $p < .01$). There was no significant difference in the proportions of people aged 70 years or older in the two populations, 7.0% in RCH and 6.5% in SL ($\chi^2 = 1.07$, $p = .30$).

In the settings where decedents had lived, RCHs had more residents per setting (8.7 residents) than SL settings (3.2 residents) ($t = 5.80$; $p < .01$). Staff were present at all times when residents were in the settings in all RCHs and in 93.5% of SL settings. When all residents were present in those settings, there were more staff working in RCHs (average 3.7 staff) compared to SL settings (2.1 staff) ($t = 4.20$, $p < .01$). Although RCH settings had more staff and more residents, SL settings were more intensively staffed, with 1.72 residents per staff member compared to 2.29 in RCHs ($t = 2.90$, $p < .01$).

The overwhelming majority of decedents had been single (99.5%). Where ethnicity was given ($n = 193$), 97.4% were reported to have been White British. Epilepsy was reported for 39.8% of decedents, 22.6% were reported to have had Down syndrome (DS), and 9.2% were reported to have had autism. In addition, 35% were reported to have had challenging behaviour. Almost a quarter of decedents (23.7%) were reported to have been living with dementia. Decedents with DS were more likely to have had dementia (67.4%) than those who did not have DS (9.5%) ($\chi^2 = 58.5$; $p < .01$).

3.2 | Rate of death in intellectual disability settings

Although data were collected for 18 months, only data, from phase 1 and for the first full year, were used to estimate annual rate of death. There were 153 deaths in that year for those services that provided data on the population they supported. There was an overall death

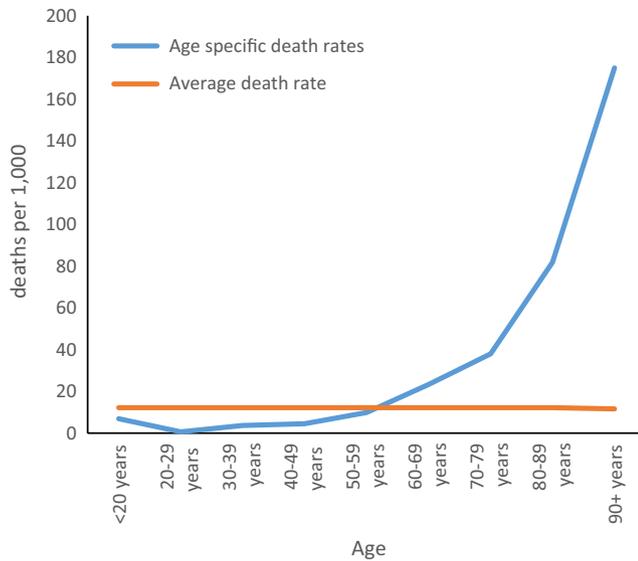


FIGURE 1 Age-specific annual death rates per 1,000 people with intellectual disabilities supported

TABLE 2 Reported cause by death by setting

Cause of death	Setting type		All (%)
	RCHs	SL settings	
Cancer	14 (17.3)	16 (15.7)	30 (16.3)
Dementia	10 (12.3)	4 (3.9)	14 (7.6)
Cardiovascular illness	17 (21.0)	19 (18.6)	36 (19.7)
Respiratory illness	18 (22.2)	39 (38.2)	57 (31.1)
Aspiration Pneumonia	10 (12.3)	9 (8.8)	19 (10.4)
Other	12 (14.8)	15 (18.5)	27 (14.7)
Could not be determined or coded (n)	15	10	25

rate of 12.3 deaths per 1,000 residents per year. Although there was variation with gender (men, 13.4 and women 9.5 deaths per 1,000 people residents per year), this was not significant ($\chi^2 = 3.12, p = .08$). The death rate did vary significantly by setting. The annual death rate was almost twice as high in RCH settings (17.7 deaths per 1,000 residents per year) than in SL settings (8.8 deaths per 1,000 people supported per year) ($\chi^2 = 20.9, p < .01$). As Figure 1 shows, the probability of death increased exponentially with age. The figure shows a relatively low annual rate of death and well below the average of 12.3 deaths per 1,000 until the age of 60 years. It then rises exponentially for each decade thereafter, from 23.3 deaths per 1,000 people per year for those aged 60–69 years to 175.0 for people aged over 90 years.

For all deaths, the mean age at death was 61.2 years ($SD = 14.0$; min 18.0, max 97.0) and 61.0 years ($SD = 13.3$, min 34.0, max = 97.0) for men and 61.3 years ($SD = 14.9$, min 34.0, max 97.0) for women ($t = 0.61, p = .87$). The average age of death in RCH was 62.7 ($SD = 13.7$, min 25.0, max 97.0) and 60.0 years ($SD = 14.2$, min 18.0, max 95.0) in SL settings ($t = 1.38, p = .17$). A quarter of deaths had

occurred before the age of 53 years, and the highest proportion of deaths were of those aged 50–59 years (25.4%). Decedents with DS or epilepsy were more likely to have died at a younger age. Few decedents with DS had lived beyond 69 years of age (6.6%) compared to people with intellectual disabilities who did not have DS (30.5%) ($\chi^2 = 10.5; p < .01$). Many people with DS also had epilepsy (51.1%) compared to people who did not have DS (36.4%), a finding that underlines the association between dementia and epilepsy in people with DS (Lott et al., 2012). The mean age of death for those non-DS decedents with epilepsy was 57.4 years of age compared to 64.0 years for non-DS decedents without epilepsy ($t = 2.6, p < .05$). More decedents in RCHs had either DS or non-DS epilepsy (60.0%) than in SL settings (43.8%) ($\chi^2 = 5.1; p < .05$).

Cause of death, as perceived by staff, was obtained for 183 deaths (see Table 2). Deaths attributed to respiratory illnesses formed the largest number of deaths ($n = 57, 31.1\%$). A further 19 (10.4%) were reported to be from aspiration pneumonia. Fewer than one in six deaths (16.3%) were reported to be from cancer and half as many again from dementia (7.6%). Thus, deaths from cancer and dementia, the two illnesses most associated with a need for end-of-life care within the general population, were reported for only about a quarter of all deaths within this population ($n = 44, 23.9\%$). There was no significant difference in the proportions of these deaths across RCH and SL settings ($\chi^2 = 1.96, p = .16$). For those who were reported to have been living with dementia, only 14 (34.1%) were reported to have died from dementia. Ten people (24.4%) living with dementia were reported to have died from a respiratory illness and five (12.2%) from aspiration pneumonia.

3.3 | Place of death

Place of death was obtained for 202 decedents. The majority (96.0%, $n = 194$) had either died in the care setting in which they had lived ($n = 94, 46.5\%$) or in hospital ($n = 100, 49.5\%$). Of the eight other deaths, 4 occurred in a hospice, 3 in another care setting and 1 at the family home. There was no difference in the probability of dying within the care setting for those aged under 50 years (39.0%) and those aged over 70 years (46.2%) ($\chi^2 = 0.23, p = .63$). Men (43.8%) were no more likely to die in the care setting than women (50.1%) ($\chi^2 = 0.66, p = .42$). Although more decedents died in the care setting than in hospital if they lived in RCH settings (54.5%) than if they lived in a SL settings (43.4%), this difference was not significant ($\chi^2 = 1.97, p = .16$). People dying from cancer or who had lived with dementia were more likely to die in the care setting (65.9%) than people dying from all other causes (39.3%) ($\chi^2 = 8.52, p < .01$).

3.4 | Anticipation of death

The provision of end-of-life care implies that a death had been expected, and data, in the second phase of the study, were obtained on how long, if at all, staff had anticipated that the decedent might

die. Such data were obtained for 146 decedents. Staff reported that they had not anticipated death for the majority of decedents ($n = 79$, 54.1%). In another 13 instances (8.9%), they had anticipated the death for less than three months. For 54 (37.0%) deaths, staff anticipated the death for three months or more. The deaths that staff had anticipated for 3 months or more ($n = 54$) were compared with all other deaths ($n = 92$): that is, the “most” and “least anticipated deaths.” Deaths from cancer or deaths associated with dementia were more common in the most anticipated deaths ($n = 16$, 76.2% and $n = 21$, 67.7%, respectively). Deaths from cardiovascular causes were more likely to be among the less anticipated deaths ($n = 19$, 79.2%), as were all causes of death from a respiratory illness in decedents who did not have dementia ($n = 33$, 76.7%).

End-of-life care plans were in place for 82.7% of decedents whose deaths were more anticipated compared to 47.2% of deaths that were less anticipated ($\chi^2 = 15.83$, $p < .01$). Across all deaths, these plans had involved either care staff in the setting (73.6%) or families (71.3%). These rates of involvement were similar for more and less anticipated deaths. However, for anticipated deaths there was more contribution from the individual decedent (38.6%, $n = 17$) when death had been anticipated compared to less anticipated deaths (4.6%, $n = 2$) ($\chi^2 = 12.78$, $p < .01$). Professionals from outside the setting (77.3%) were reported to be more involved in planning than for less anticipated deaths (34.9%) ($\chi^2 = 8.4$, $p < .01$). The data indicate that the most and least anticipated deaths represented very different types of deaths. Anticipated deaths were more likely to involve cancer or dementia-related deaths, a higher level of end-of-life care planning and with greater involvement in planning end-of-life care from decedents with intellectual disabilities and non-intellectual disability professionals. There were no significant differences between the distribution of more and less anticipated deaths across setting types ($\chi^2 < 0.01$, $p = .89$), for gender ($\chi^2 = 0.4$, $p = .53$) or in age at death ($t = 1.42$, $p = .16$). However, the deaths of people aged 70 years and older were less anticipated ($n = 9$, 22.0%) that those

who were younger ($n = 45$, 41.3%) ($\chi^2 = 4.03$, $p < .05$). The deaths of people with Down syndrome were almost twice as likely to be categorized as more expected deaths ($n = 18$, 58.1%) than those of other people with intellectual disabilities ($n = 35$, 30.1%) ($\chi^2 = 6.73$, $p < .01$).

Table 3 presents data on outcomes at the end of life in relation to the extent to which staff had anticipated the death as outlined above. Dying in the care setting was more likely for the most anticipated deaths ($n = 38$, 71.7%) than for the least anticipated deaths ($n = 31$, 34.1%) ($\chi^2 = 18.74$, $p < .01$). This was only replicated in RCH settings ($\chi^2 = 22.41$, $p < .01$). It was not found in SL settings ($\chi^2 = 1.58$, $p = .21$). For the least anticipated deaths, the most likely place of death was a hospital setting ($n = 60$, 65.9%). There was no difference in the proportion who died in hospital between the two types of care settings for such deaths ($\chi^2 = 0.05$, $p = .82$). Regardless of whether the death had been anticipated or not, and regardless of place of death, the majority of respondents considered the actual place of death as the most appropriate place of death. The only exceptions to this were anticipated deaths that had occurred in a hospital. There were 14 such deaths, and in only 8 (57.1%) did respondents feel that the place of death was appropriate. Thirteen of those deaths were decedents that had lived in SL settings and just over half ($n = 7$, 53.8%) felt that that place of death was appropriate.

Finally, respondents rated the extent to which they had felt supported by external services in the last 3 months of life. The data show that among the most anticipated deaths, deaths that occurred within the care setting were more likely to be associated with staff perceptions indicating sufficient support from external services ($n = 29$, 80.6%) compared to anticipated deaths that occurred in hospitals ($n = 6$, 42.8%) (Fisher's exact $p < .05$). In SL settings, the most anticipated deaths that occurred within the care setting were more likely to be associated with sufficient support from external sources (84.6%) than those equally anticipated deaths that occurred in hospitals (46.2%) (Fisher's exact $p < .05$).

TABLE 3 Outcomes at the end of life by setting and extent to which death had been anticipated

	RCHs (%)		SL settings (%)		All (%)	Settings (%)
	Most anticipated deaths	Least anticipated deaths	Most anticipated deaths	Least anticipated deaths		
Place of death						
Care setting	24 (92.3)	15 (34.1)	14 (51.8)	16 (34.0)	38 (71.7)	31 (34.1)
Hospital	1 (3.8)	29 (65.9)	13 (48.1)	31 (66.0)	14 (26.4)	60 (65.9)
Other	1 (3.8)	0 (0)	0 (0)	0 (0)	1 (1.9)	0 (0)
Place of death was considered appropriate						
Home deaths	24 (100)	13 (100)	13 (100)	14 (93.3)	37 (100)	27 (96.4)
Hospital deaths	1 (100)	21 (80.8)	7 (53.8)	16 (80)	8 (57.1)	37 (80.4)
External support was considered sufficient						
Home deaths	18 (78.3)	3 (60.0)	11 (84.6)	8 (80.0)	29 (80.6)	11 (73.3)
Hospital deaths	0 (0.0)	13 (59.1)	6 (46.2)	10 (66.7)	6 (42.8)	23 (62.2)

4 | DISCUSSION

The study reported here sought to strengthen the evidence base concerning care at the end of life to people with intellectual disabilities, regardless of cause of death, by utilizing both a population-based approach and an intellectual disability-sensitive and supplemented version of a widely used end-of-life care measure (Dieckmann, Giovis, & Offergeld, 2015; VOICES-SF, Hunt et al., 2017). Death among adults with intellectual disabilities in these social care settings was a relatively rare event, although people with intellectual disabilities have higher mortality rates than the general population (Dieckmann et al., 2015; Florio and Troller, 2015; Glover, Williams, Heslop, Oyinlola, & Grey, 2017; Hosking et al., 2016). Intellectual disability services may not regularly be dealing with death but it was almost twice as likely in RCHs than in SL settings. As we discuss below, the exceptional nature of death in these services poses its own unique challenges for services and researchers. If death was not common, a death that staff had anticipated was less common still. Many of the deaths experienced by adults with intellectual disabilities, and more so than in the wider population (Hunt et al., 2019), were sudden or less expected deaths. The data also suggest that the low level of anticipation of dying is a major disadvantage for adults with intellectual disabilities at the end of their life. When death was anticipated, there was a significantly greater chance that the individual was supported to die within the care setting. This was not found in SL settings, a point we return to below. That the risk of a hospital death was moderated by place of usual care underlines the importance of end-of-life care research in intellectual disabilities to focus on the range of settings where people with intellectual disabilities live. Before we examine these findings in greater detail, we think it helpful that they are located within an appreciation of the strengths and weaknesses of the study.

4.1 | Strengths and limitations

The study responded successfully to the challenges for research in this field identified by Todd et al., (2019). These included the need to recruit a large number of services to yield sufficient deaths for robust analysis. Services across the UK were recruited and retained over the 18-month study and they supported over 12,000 people with intellectual disabilities. In addition, it was possible to describe this population. The geographical spread of services across the UK and the numbers they supported indicate grounds for the generalisability of findings. The mortality profile of decedents was consistent with other studies (Heslop et al., 2013). The study also incorporated VOICES-SF, a measure of quality of care at the end of life within the wider population (ONS, 2016). A high response rate was achieved and the data obtained within six months after death. A paper comparing the deaths and the quality of care at the end of life for this sample with that in the wider population in England and Wales has been published elsewhere (Hunt et al., 2019).

Although the data provide a generalizable and robust account of care at the end of life for people with intellectual disabilities, there are three major limitations. Firstly, data were obtained only from social care providers whilst people with intellectual disabilities live in a range of settings. Our rationale for this focus was outlined in the introduction. Many younger adults will live within the family home, and the need for further study of the nature and impact of their death and dying cannot be understated (Reilly, Huws, Hastings, & Vaughan, 2008; Todd, 2007). People with intellectual disabilities may also live and die within a range of other settings, for example services for older adults and in forensic and psychiatric settings. Our finding that outcomes at the end of life are influenced by place of usual care underlines the need for more research across the range of settings where people with intellectual disabilities live. Secondly, one of our key study inclusion criterion was that a decedent had to be in receipt of support from participating services at the time of death. Thus, the findings relate only to people with intellectual disabilities that services had been able to support up to the moment of death, regardless of their place of death. Although this meant that those who died in hospital were still included in the study, there is every possibility that some people may have left the care of the intellectual disability service before death. Indeed, the findings strongly suggest a possibility that other care settings may be playing a major but unrecognized role in supporting older adults with intellectual disabilities at the end of their lives. The age distribution of the living cohort highlighted that relatively few older people with intellectual disabilities were being supported by participating services. Only 1.5% of the living cohort were aged 70 years of age or older. Although, in part, this may be attributable to premature mortality (Heslop et al., 2013), the low rates of death for younger people within this cohort suggest this is not the only answer. Another probable factor here is that people with intellectual disabilities may be moved out of intellectual disability-specific services as they age (Bigby, Webber, McKenzie-Green, & Bowers, 2008; Thompson, Ryrie, & Wright, 2004). This may also be happening with increasing ill health and frailty. If this is the case, then this too might have had some influence over the low proportion of anticipated deaths reported here for this population. The deaths of the oldest adults in this population were the most probable. Yet, they were also the least anticipated, suggesting they had been healthy survivors. The role services for older adults play in supporting people with intellectual disabilities at the end of life is relatively less well known (see, e.g., Webber, Bowers, & Bigby, 2014), as is the extent to which movement out of intellectual disability services involves an end-of-life care dimension. These areas are worthy of future study. Finally, our data relate to the appropriateness of place of death from the perspective of staff and not the person with intellectual disabilities. As a retrospective survey, the approach is defensible. Data were obtained on the extent to which the person with an intellectual disability had anticipated their own death and had a preferred place of death. These have been reported elsewhere (Hunt et al., 2019).

4.2 | Principal findings

The findings add to our understanding of the scale and nature of the challenges facing intellectual disability services in delivering good quality of care at the end of life. The first is the relatively low rate of death within this population. A single and large provider may only experience 2–3 deaths per year, and within any single care setting, there might only be one death every 10 years. An anticipated death is rarer still. This makes intellectual disability care settings distinct from other care home settings where the death rate is much higher (Kinley et al., 2014). Death and dying are less common events than is sometimes suggested in the intellectual disability literature and make it difficult for services and researchers to respond proactively to the types of challenges associated with death in intellectual disability settings that were outlined in the introduction. However, our findings suggest a rationale for three general areas for development. The relatively low occurrence of death when added to the even lower level of expected death may imply that staff and co-residents, as well as relatives, may experience more complex bereavement since they had not been prepared for an individual's death. Such deaths can be significantly and uniquely traumatic for those that witness or live through them (Keyes et al., 2014) and underline that an important aspect of end-of-life care is the level of care provided after death (NICE, 2011). In terms of preparation for dying, there may be some rationale to develop policies and practices for older people with intellectual disabilities, given their deaths were the most probable but also, paradoxically the least anticipated. The end-of-life care training needs of staff supporting older people with intellectual disabilities have previously been flagged as important (Northway, Jenkins, & andHolland-Hart, D., 2017; Schepens, van Puyenbrock, and Maes, 2019) and are reinforced here. Services might also prioritize developing end-of-life care approaches for adults with Down syndrome given the high prevalence of early-onset dementia, a life-limiting illness, within this population (Coppus et al., 2006). Indeed, this group may represent a subpopulation of people with intellectual disabilities with perhaps the greatest anticipated need for end-of-life care and one that researchers with an interest in evaluating and understanding end-of-life care provision to people with intellectual disabilities, and especially in a prospective fashion might pay considerably more attention to (McCallion et al., 2017).

The level of hospital death reported here was commensurate with that reported in the wider population (Hunt et al., 2019) but higher than that reported for other populations of people in care homes more generally (Kinley et al., 2014). However, it seems that the desire of care staff to support people with intellectual disabilities to die in the places that they have lived for years, if not decades, (see, e.g., Ryan et al., 2011; Todd, 2013; Wiese, Dew, Stancliffe, Howarth, & Balandin, 2013) was largely being realized when dying was anticipated and supported by external professionals, in particular from a range of nurses (Northway et al., 2018). When the death had not been anticipated, death was more likely to occur within a hospital setting. Yet, dying in a hospital may not be indicative of failed or weak end-of-life care interventions and more related to the mortality profile of people with intellectual disabilities. Many of the deaths

described here were relatively unexpected deaths. At the time of hospital admission, if death was not anticipated, in-patient investigation or treatment may have been entirely appropriate. The study, then, suggests that although place of death can be an important indicator of quality of care at the end of life, it needs to be used with care for people with intellectual disabilities. Since few deaths of people with intellectual disabilities may have been anticipated, place of death may obscure more than it reveals about the nature of end-of-life care. There is some concern over the quality of hospital care for people with intellectual disabilities (Glover et al., 2016; Iacano et al., 2014; Webber et al., 2010). This may have added resonance at the end of life when one considers that for the wider population hospital-based end-of-life care is considered to be limited by an environment not designed to deal with dying or death and associated with poorer symptom control and burden, and less positive decision making and communication with health professionals (Robinson, Gott, & Ingleton, 2014). Yet, Hunt et al. (2019) report that support staff rate hospital care at the end of life positively, although significantly less favourably than community-based care. In this study, staff certainly tended to have greater disaffection over place of death when it was an anticipated death that occurred within a hospital. Such deaths were much more associated with decedents that had lived in SL settings, a point we return to below.

Since end-of-life care implies that dying is anticipated, and anticipated in a timely fashion, a major disadvantage for people with intellectual disabilities at the end of life may be dying a less anticipated death. The data suggest that for people who had experienced an anticipated death there was greater individual awareness of dying, more support from external care services; and a greater likelihood of dying in their place of usual care. Less anticipated deaths were largely deaths from causes other than cancer and not related to dementia. However, this does not imply that people who die from other causes do not have end-of-life care needs or may not benefit from end-of-life care interventions. The identification of dying in individuals who do not have malignant conditions has been highlighted as a concern within the wider population (Ellis, Winslow, & Noble, 2016; Murray, Kendall, Boyd, & Sheikh, 2005; Teggi, 2018) and for people with intellectual disabilities (Vrijmoeth et al., 2018). Within intellectual disabilities, it may be a larger problem compounded by the added complications of communication problems between healthcare professionals, carers and the person with intellectual disabilities, and/or delays or errors in diagnosis and treatment (Bernal & Tuffrey-Wijne, 2008; Regnard et al., 2007; Heslop et al., 2013; Tuffrey-Wijne et al., 2010). In a further analysis of data, we aim to address the nature and outcomes of unexpected deaths of people with intellectual disabilities in more detail. There exists evidence of improved identification of need in the general population when an anticipatory model of need for end-of-life care is used rather than one whose sole focus is the accurate prognostication of death (Kennedy et al., 2014; Teggi, 2018; Thoosen et al., 2016; Urquhart et al., 2018). There is an urgent need for more research on how a need for end-of-life care in people with intellectual disabilities is suspected, anticipated and determined.

Although the extent to which death might have been anticipated seems critical in improving care at the end of life for people with intellectual disabilities, environmental factors, such as usual place of care, also seem important (Todd et al., 2019; Wagemans et al., 2013). There was considerable variability across the two setting types discussed here that underlines again the need for more research on care at the end of life across the range of settings where adults with intellectual disabilities are supported. Here, there were major differences in mortality and end-of-life outcomes across the two setting types. The death rate in SL setting was half that of RCHs. This could be attributed here to the higher proportion of younger people in SL settings and with fewer deaths associated with epilepsy and Down syndrome, two factors associated with premature mortality in people with intellectual disabilities (O'Leary, Hughes-McCormack, Dunn, & Cooper, 2018; Robertson, Hatton, Emerson, & Baines, 2015; Torr, Strydom, Patti, & Jokinen, 2010). However, the prevalence of anticipated death was comparable across both settings, although outcomes at the end life varied. This suggests that SL settings may be less capable of supporting people with intellectual disabilities with complex health conditions (Bigby & Beadle-Brown 2018). There may be other reasons. The lower level of death within SL settings may imply a more limited bank of experience in supporting people with intellectual disabilities at the end of life. There may also be differences in exposure of staff to training and development activities across these setting types. There were also major differences between the two types of settings in terms of numbers of staff and intensity of staffing. Although SL settings had higher staff: resident ratios, they had fewer staff on shift at any one time than RCHs. Finally, there was evidence of less support from external professionals within SL settings when death was anticipated. Developing links and collaborative partnerships with external services seems key for the delivery of effective end-of-life care for people with intellectual disabilities (Tuffrey-Wijne & Davidson, 2018) and there may be obstacles to their use in SL settings. No data were obtained on the physical features or designs of these settings (e.g. whether the setting had upstairs or downstairs bedrooms). These could further impede or facilitate supporting people to die in place. In addition, there may be other important differences between the populations of people with intellectual disabilities supported across these two setting types, for example in their degree of disability or needs for support that might also be factors here. If SL settings are the preferred service option for people with intellectual disabilities, given that they are associated with improved quality of life (Bigby & Beadle-Brown 2018), then the extent to which they have the capacity to support people to and at the end of life represents a new and important area for further research.

5 | CONCLUSION

Intellectual disability services are places of living and dying. This study reiterates that the agenda to improve quality of care and experience of people in intellectual disability services must embrace a notion of

care "to the end of life." A failure to do so may ultimately lead only to poor experiences and unnecessary disadvantage at the end of life. Death appears not to be a common event within intellectual disability services but as this population continues to age, and if "ageing in place" becomes increasingly successful, death will only come to have a greater presence. The data here suggest that services can respond successfully to the needs of people with intellectual disabilities at the end of life if dying is recognized in a timely manner and external support is in place. There are areas though where future service development and resources, and research might enable more people with intellectual disabilities to be supported well at the end of life. These involve improving the ability to recognize that death might be likely and determining the challenges that SL settings face in supporting people whose deaths are anticipated. The benefits may not only be felt by individuals with intellectual disabilities who are dying but also those who care for and about them. If there can be developments in end-of-life care provision that successfully meet the needs of a population who seem more likely to experience complex dying whilst living in types of residences that are themselves complex, at least to people outside of intellectual disabilities, then one might reasonably expect that this leads to wider developments in end-of-life care that benefit all.

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ETHICS

The study was approved by the LSE Faculty Ethics Committee at the University of South Wales.

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