Introduction

People with intellectual disabilities (ID) generally die earlier than those without ID (Public Health England, 2014). Health care improvements however, mean that individuals with ID, and in particular, those with mild ID and Down syndrome are now living closer to the ages of those in the general population (Emerson & Hatton, 2008; Tuffrey-Wijne, McLaughlin, Curfs et al., 2016; World Health Organisation, 2011;). Living longer is accompanied by age associated diseases such as cancer (Tuffrey-Wigne, 2015), respiratory disease, and coronary heart disease (Plichart, Barberger-Gateau, Tzourio et al., 2010; Winter, Echteld, & Evenhuis, 2013). Adults with Down syndrome in particular, also have an increased risk of Alzheimer's disease at an earlier age than the general population (Stancliffe, Larson, Engler, Taub, Fortune, & Bershadsky, 2012) and whilst results from cross-sectional and longitudinal studies show variability in terms of age of onset, Ballard, Mobley, Hardy, Williams, and Corbett's (2016) review of epidemiological studies indicate a prevalence rate of 40% for those over 50 years old increasing to 50% for those over 60 years old. There is therefore often a period of decline which is more prolonged for people with ID than it might have been twenty or so years ago. Declines in physical mobility, restricted transport and access to social activities, as well as the death of family and friends also means that those who enter this time of decline may have small social networks, and/or perceived lack of social support (Forrester-Jones, 2014) though hither-to there has been no research charting this. Mindful of social inclusion philosophy, it may be argued that understanding and meeting the health and social care needs of declining and terminally ill older people with ID requires additional specialist support (Bigby, Bowers, & Webber, 2011; Bischoff, Sudore, Miao, et al., 2013; Janicki & Dalton, 2000); with palliative care becoming appropriate but with new challenges associated with ID. Nevertheless, service provision currently appears to be

fragmented with little choice, (Bigby et al., 2011; Hatzidimitriadou & Milne, 2005) or support for individuals to make their own decisions about the type of palliative and end-of-life care they would prefer (Kirdendall, Linton, & Farris, 2016) and many older people with ID who are close to the end of their lives receive non-specialist, inappropriate care by inadequately trained staff (Bekkema et al., 2014; Ellison & Rosielle 2008; Thompson et al., 2004). Recognition of this has until recently however, been largely neglected in service provision (Mencap, 2012) and research (Wiese et al., 2012). Whilst policy and research around improving the quality of palliative and end-of-life care for people with ID in residential and nursing homes (National Health and Medical Research Council, 2005; NEoLC, 2010) has mirrored growing concern about the appropriateness of hospital as the place of death for the general population (Tuffrey-Wijne et al., 2015), little has been published about possible *specialist* care homes for people with ID who are dying.

The *aim* of this research was therefore to explore the organisational context of a specialist palliative and end-of-life care home (i.e., to our knowledge the only one in the UK) to see how it related to the quality of life of people with ID who were approaching the end of their lives. We also wished to identify the care costs. The *objective* was to gain insights into the particular phenomenon of a specialist service, and to assess whether it provided a positive environment for people who lived and worked there.

Method

Setting

The voluntary sector purpose built residence, pseudonym Leesdown House (LH), located in the South of England was a specialist, high dependency registered nursing home for older people with ID with multiple needs including dementia and terminal illnesses. Opened in May 2010, its mission was to ensure that each individual was valued, and enjoyed

a happy and lively environment whilst receiving the best possible nursing and palliative care. At the time of the study, the home had 15 residents (i.e., maximum capacity). There was a relatively stable (i.e., in terms of staff turnover) support staff group (i.e., 25 whole time equivalent). Six support staff were on duty in the morning, five during the afternoon and evening, and a nurse with two support staff overnight. During the day, either the manager or the deputy manager was on duty plus a cleaner, an estate worker, and kitchen staff. LH also had an on-site specialist activity centre, with three 'activity staff' working from 10am to 5pm weekdays. At the time of the study, a sensory garden and vegetable plot had recently been planted and fund-raising for a new sensory room was underway. The entrance hall to LH was designed as an informal seating area with a CD player and books, and there was also a lounge/dining area and a couple of 'sun rooms'. Residents could use any part of the home at any time. Spatially low density with a high staff ratio, LH was believed to be the first specialised establishment offering end-of-life care in the UK.

Design

A single instrumental case study design was used in line with Yin's (2014) rationale. As common when using an instrumental single case-study design (Flick, 2008) a mixed-methods approach was used to record different perspectives, which were then triangulated to reveal alternative meanings (Stake, 2003). For residents where assent from consultees was obtained, interviews about residents were conducted with 2 staff members (1 support worker, 1 activity instructor) to increase data reliability and help reduce proxy bias. The interviews asked about each resident's social support networks, choice, and quality of life. Four separate 60 minute focus groups with staff were facilitated to explore staff experiences of working at LH. Data collection took place during 2014/15.

Participants

Using a purposive sampling strategy, consultee assent was received for 9 (7 females: 2 males) of the 15 residents. Consultee assent was refused for 4 individuals, 1 resident died and 1 arrived at LH too close to the project start for staff to provide informed opinions about them. No data was collected to compare participants to non-participants. The Home Manager (HM) and 15 of the 40 staff were randomly selected and invited to participate; 14 staff consented to participate.

The mean age of the nine resident participants was 53 yrs (range 24-68; *SD* = 13.68). Their mean age on entering LH was 49 yrs. All of the participants had multiple medical diagnoses in addition to ID; 6 individuals also had dementia, 8 also had physical disabilities, and 1 also had mental health problems. All of the participants were also deemed to be either terminally ill and/or entering the latter/last stages of their lives, and they had lived at LH for between 5 and 48 months (*M* = 25.89; *SD* = 15.46) having previously lived in residential care homes (*n* = 5) or with their families (*n* = 3) or in supported living (*n* = 1). All were White British and single. One participant had an educational qualification and had previously been employed. Of the 14 staff participants, 12 were female, and all were White British. Ages ranged from 20 to 63yrs (*M*= 39.71; *SD* = 13.19). Five had a Health and Social Care Qualification, three had a higher education qualification, four had completed school/college and two had no qualifications. All had worked as carers for older adults with ID for at least 5 years.

Materials and Measures

Quantitative measures.

1. Resident background information interview;
2. DEMQOL-Proxy (Smith et al., 2005): a 31 item scale to measure health related quality of life of residents including individual's feelings/mood, memory concerns, and worries/concerns they had around aspects of their everyday lives over the previous week. Internal reliability analyses produced the following cronbach alpha – $\alpha = 0.79$ (acceptable, according to George & Mallary, 2003).
3. The Resident Choice Scale (Hatton et al., 2004): a 26-item scale, to assess opportunities for self-determination in residential settings in a range of areas of life (e.g. where they ate, who they lived with). Internal reliability analyses produced the following cronbach alpha - $\alpha = 0.85$ (good).
4. Social Network Guide (SNG). This instrument was developed from a previous ethnography of people with mental illness (Forrester-Jones & Grant, 1997). Adapted from Tracy and Abell (1994), it maps the structural size, membership, density (i.e., the proportion of network members who are interconnected; Brugha et al., 1993, p. 124), interactional (i.e., reciprocity, frequency, duration, and closeness) and supportive (i.e., companionships and decision-making) components of individual's networks. A fuller version of the SNG (Forrester-Jones et al., 2006, 2012; Bhardwaj et al., *in press*) is published elsewhere (Forrester-Jones & Broadhurst, 2007).

The above instruments were administered by interview with key staff who knew the participant well.

Qualitative methods.

1. For the focus groups, open-ended questions were developed from previous literature to explore staff roles and experiences of working at LH;

2. Informal participant observation was carried out by one of the authors to note the general levels of activity in the home on a number of consecutive days by one of the authors.

Costs estimation method.

A short pre-specified topic guide was used in the interview (November 2014) with the HM who was closely involved with all aspects of running the home. The interview covered funding, staffing and other inputs, services provided on-site, and the level of off-site services used by residents (i.e., not individually identified) over the past year (Beecham, 1995). These data, combined with a commentary from the Chair of Trustees, information from publicly available documents (e.g., CQC Review, Charity Commission submissions, and a compendium of nationally-applicable unit costs) allowed the full costs of care at LH care to be estimated (Beecham, 2000; Curtis, 2013).

Procedure

Personal and/or nominated consultees were sent information sheets and asked to sign assent forms; agreeing that the person with ID would participate in the research if they had capacity to do so. Staff were also given information sheets and asked to sign a consent form regarding their participation, and for interviews/focus groups to be digitally recorded. Staff were assured that participation or non-participation would not affect their employment or standing within the organisation. Staff work patterns meant we organised four focus groups with smaller numbers than hoped and one focus group was facilitated in the evening at the convenience of its members. We convened four single professional focus groups where possible to stimulate discussion with the potential for between group comparisons (emphasising quality rather than quantity) (Barbour, 2005). Thus one focus group consisted of 4 nurses (N); one had 3 support workers (SW); one had 2 support workers (SW), and one had 4 activity co-ordinators (AC) and 1 housekeeper (H). The HM was interviewed

separately to avoid staff feeling inhibited during their own focus groups. The interview questions with the HM were the same as those for the focus groups.

Analyses

Quantitative data on residents' quality of life, choice, and social networks were subjected to non-parametric descriptive analysis using SPSS v22. Network density, the proportion of network members who are interconnected, was calculated using the formula:

$$D = \frac{\Sigma N}{P\,(p - 1)}$$

where D represents density (range 0–1.00), p the total number of members of the 'social network' and N the number of contacts known by each member of it summed across all members (Brugha et al., 1993, p. 124).

Focus group interviews were transcribed verbatim and analysed using Braun and Clarke's (2006) 6 step thematic analysis process: familiarisation with the data (e.g., multiple reading of the transcripts); generating initial codes across the entire data set; searching for themes among codes whilst gathering quotes relevant to each potential theme; reviewing themes by checking if the identified themes worked in relation to the coded extracts and entire data set defining and naming themes; and finally writing the report.

The raw transcribed data was independently coded and categorised by one of the authors. Independent checks of the initial coding were performed by three of the other authors to aid accuracy and reliability. All potential themes were then discussed at length between these four authors until agreement of themes was reached (Charmaz, 2000). Three identified themes (presented below) were named, which represented staff views about working in the

study environment. Vivid and compelling quotes were selected from the data set to represent the themes (Braun and Clarke, 2006). By triangulating the data sets including content analysis of coding mission statements and field notes from informal participant observation and thematic analysis of interviews, a level of data corroboration and theoretical saturation of the phenomena was reached with no new relevant insights emerging (Bryman, 2001). We acknowledge however, that caution is required when claiming saturation in any small scale study (See Wray et al., 2007).

Ethical Approval and Considerations

The research was approved by the National Research Ethics Service (NHS) (REC reference 14/LO/0048). All of the residents with ID lacked capacity to consent to the research under the Mental Capacity Act (2005) criteria and so personal and/or nominated consultees were identified. Data were anonymised and active dialogue with the research participants was maintained to avoid concerns around privacy within this small-scale case study context (Stake, 2003). Feedback (which was aggregated and de-identified to protect anonymity within this small-scale study) was provided to LH via an accessible and interactive feedback session to which all participants were invited. A poster of the findings was displayed in the home in an accessible format.

Results

Resident Quality of Life

The sample had good health related quality of life as measured by the DEMQOL-Proxy (M = 112.44; SD = 4.47) where the range of total score was between 107 and 120. Individual overall quality of life ratings over the previous week ranged from fair to very good for all of the residents (M = 3.00; SD = 0.87). Staff had relatively few concerns regarding residents' mood, memory, or aspects of residents' day to day lives (see Tables 1, 2, & 3).

Insert Tables 1, 2 & 3 here

Resident Choice

Overall, residents appeared to have a high level of choice in their day to day living in terms of arrangements around meals and personal appearance, leisure activities (i.e., residents could express their preferences), personal possessions, household routines, and relationships (ie., residents had the final say) (see Table 4). Individuals seemed to have relatively little say however in the overall appearance of the residence (e.g., residents had no choice regarding communal areas), major home decisions (e.g., residents had no choice of moving home if they wanted to), and little to no choice in recruitment of staff or other staff issues (see Table 4).

Insert Table 4 here

Social Networks

Size, density, and network membership.

The mean network size was 10 members (*SD* = 6; range 3 to 20) and network members were primarily staff and family. Without staff, residents' social networks were very small (see Figure 1). The mean density was high, ranging from 0.80 to 1.00 (*M* = 0.93; *SD* = 0.08).

Insert Figure 1 here

Social support.

Table 5 gives a breakdown of the types of support reported by participants showing whether or not they were provided by all network members. Of those contacts who did

provide support, staff made up the highest percentage in all support types with family carers as the second main providers of each support type.

Interactional features of social networks.

Residents were reported to have contact (i.e. having some kind of interaction such as a 'chat' which was more than simply saying hello) on a weekly basis with staff in the main. This was an expected finding given that staff were on duty somewhere in the building all the time. Interestingly, only 14% of weekly contacts were with other residents, suggesting that a daily routine of all residents sitting in one room (i.e., a characteristic of many residential/care homes) was not the norm at LH. Participant observation confirmed that residents spent time in several locations within LH.

Staff were proportionately more likely to be regarded as residents' 'best' friends after family members. Whilst it was reported that over half (57%) of the total number of reciprocal relationships were with family members, less than a quarter (23%) of reciprocal relationships were with staff. Staff and family members were also those whom participants felt "close" to and rated as their "best" relationships.

Staff Views

Thematic analysis categorised staff views (i.e., opinions and views did not diverge significantly between different staff roles) into three overarching themes:

Theme 1: Specialised unique service.

Staff talked about the *uniqueness* of LH in relation to their previous experiences of working in the NHS or larger care homes:

> *"I think that's the thing with us being a unique home, isn't it, is that … there is nothing else it compares to"* (AI)

Care aspects that made LH 'unique' could be categorised into three sub-themes. Together these led to a fourth - a '*variation on palliative care'*.

(i) Holistic philosophical approach.

Staff reported that LH offered an "*holistic philosophical approach*" to care, explaining this was mainly due to the small number of residents which allowed more individual staff-client time:

> "*…if somebody, for instance, is dying we will go and sit with them because they're never ever left on their own when it's at the end. We will sit with them and if we sit there for 2 hours it's not a problem."* (AI)

The 'holistic' care at LH was described as including activities and therapies in addition to a range of clinical and social care:

> *I like the therapies that are coming in as well, reflexology and, uh, alternative.* (N)

> *"that clinical aspect of the home is what makes us quite unique and makes the difference between what we do and what the* [nursing] *home down the road does… we're a lot smaller we have a lot more specialised care because of the type of clientele that we take on…so I think it's very different to an elderly care nursing home*" (Manager)

(ii) Person centred approach/individualised care.

Staff unanimously reported that LH provided a person centred approach, incorporating dignity, knowing people well, and compassion/empathy, especially when

residents lacked communication skills. There was also a sense that staff were doing their best to offer choice and independence within the home right up to the end of residents' lives:

> *"…to be there for them all the time, give them the choice, the respect, the dignity, if they want to do something. Help them achieve it rather than, you know 'you can't do that'"* (SW)

(iii) Informalised formal care.

Despite the tendency of staff to use distant pronouns such as 'them', 'that one', 'ours', to refer to the residents, the focus groups highlighted a homely social environment in which the care context reflected supportive, family relationships:

> *"We're all very fond of the residents and we form an attachment with them"* (N)

> "*It's more homely than the very large care homes that you get, which do become quite institutionalised"* (SW)

(iv) Variation on palliative care.

Whereas people without ID who have a terminal illness may enter a hospice near to or at the end of their lives, LH recognised that this could be more difficult for people with ID who may cope less well with environment changes. Staff agreed that LH had developed into a service which embodied the 'unknown time factor' of serious clinical conditions, with residents entering LH shortly after a diagnosis of terminal illness:

> *"It* [LH] *was initially a kind of hospice, but, um because you spend a relatively short period of time in a hospice, what became apparent is that people with [ID] do not want to be moved, um, like you or I would…umm, so, to move somebody, when they technically needed that hospice care just didn't work. So we…get them in a lot earlier*

um, like when they have [a] *diagnosis of dementia or something that's going to limit their life, rather than waiting right at the last minute like in a main stream hospice"* (Manager)

A proportion of staff reported that they did not think LH could be strictly defined as an 'end-of-life' home. Rather, staff aimed to ensure that residents received the best quality of life possible right up until 'the last days'. In some cases, the care was seen as compensating for an individual's previous negative experiences:

"…we are here to make sure that their last days are their best and while they're with us we make them as comfortable and as happy as we can...they come with such bad histories, don't they? It's like… at least while they're with us we can try and make up for what they've been through" (AI)

Quality of life then was key to care provision even where death was a 'possibility' rather than a 'certainty':

"I would say 'give them bit more of a normal life' that's probably the wrong word but yeah just enjoy their lives, taking them out and about …people may think 'they've only got a couple of weeks left', well it's not a couple of weeks in bed…make it the best day ever. I know it sounds really horrible like, [but] *its bonus that they're still here you know and you think 'they might be [here at] Christmas' and if they [are] really ill and they're still here you just think keep carrying on because you just don't know"* (AI)

Over half of the staff felt the type of service offered by LH should be more widely available for people with ID:

"*There definitely needs to be more places like this. You can't put somebody with Down* [syndrome] *and dementia on a hospital ward where the nurses go and see them maybe for 3 seconds every 2 hours, you know….They need to have one to one when they're really poorly. So I don't feel hospitals are the place for them"* (AI)

Theme 2: Positive organisational environment.

This second theme related to how the home was organised and included (i) "*supportive management"*, which led to (ii) "*perceptions of a positive job role"*:

(i) Supportive management.

Staff praised the current management style as approachable, professional, and responsive to the needs of staff, including a willingness to organise training:

"they bring in extras…if you want to [do] *end of life or dementia courses, you know, those ones aren't mandatory but you get the choice but you will find that most people do take them up*" (AI)

"You know, we would like challenging behaviour, um, training … and they will get it in for us, you know, they are good like that" (AI)

Staff views concerning the quality and necessity of good management were mirrored by what the manager said about their own role:

"*I needed to be somebody that knew the residents, knew the staff, had good communication, good liaison with other professionals, um, really had the heart of, um, what the whole ethos behind LH was. So the training I book now tends to be shaped around what the staff want, what the needs of the residents are… I won't have left any day without seeing all of the residents…to gauge how they are that day;*

whether they look a bit off colour, whether they look happy, whether they look sad, whether they're concerned about anything" (Manager)

Staff were generally less positive when discussing the role of the service trustees, reporting that some trustees appeared to lack understanding of the needs of the service, and in some cases, the residents:

"…sometimes I think the trustees don't understand what actually goes on here…and some of the trustees are people that are just names to us, you know, we know a couple that actually sort of come now and again but majority of them are just people" (AI)

(ii) A positive job role.

Staff reported that their role was 'more than just a job', that they experienced genuine enjoyment and job satisfaction, and that they would, could and should go the 'extra mile' to improve residents' quality of the life:

"I think it's rather inspirational. There's plenty of staff who come in on their days off to take them out and stuff and I don't think you'd see that anywhere else" (AI)

There were tensions within the team. Nurses generally reported more pressure in terms of their clinical responsibility compared to that expressed by support staff. In particular, nurses felt frustrated that they were unable to attend clinical appointments with residents:

"I suppose the one disadvantage is because generally we're the only nurse on duty we can't actually physically leave the building so if somebody is going for an appointment we can't actually escort them. It would be a support worker that does that, and so obviously you rely on the feedback from the support worker…they

[support workers] actually get quite anxious about going as well sometimes, worried about it" (N)

Theme 3: Unpredictable emotional challenges.

Staff also reported challenging aspects of their roles including working with LH residents who were experiencing a deterioration of skills and emotional distress:

"*The randomness of the situations [laughs] ...we have one particular lady* [with dementia] *who constantly wants to go out. She doesn't remember she's already been out earlier in the day"* (SW)

Activity instructors and support staff identified being challenged by the emotional impact of death. Despite their sadness, some staff were able to find positive aspects regarding their role in supporting a person physically and emotionally who was dying:

"*Privilege is a complete and utter perfect word for it, [to be with someone when they die]"* (SW)

"*I think I've been struggling with that* [death] *a bit lately and…It's almost like building up your own resilience [to death], isn't it."* (AI)

The Costs of Supporting LH Residents

The comprehensive costs of supporting LH residents include those accruing both within LH and for services provided off-site. The costs shown below approximate their *long-run marginal opportunity value* are expressed at 2013 prices, in line with the available expenditure accounts for LH.

The costs of care within LH.

To estimate the cost per resident year at LH, information from the available expenditure accounts (December 2012 to November 2013), the manager interview, and the

Chair of Trustees were combined with occupancy data for the same period. At 2013 prices, the total costs of providing on-site support were £837,438 per annum. This includes the costs of resident care, administration and management, governance and fund-raising, as well as the annuitized value of buildings, vehicles and equipment. There was an overall occupancy rate of 80% (n = 12 residents) over the year, therefore the average on-site cost per resident per year was £69,786, or £1,342 per week (i.e., 52 weeks). There has been no previous cost estimates for the type of service LH provides. Curtis (2013) reports the costs of a staffed home for people with learning disabilities to be between £906 and £1,186 per resident week.

Costs associated with LH trustee and volunteer time.

To help ensure good governance, the organisation providing LH had two patrons, ten Trustees and a Trustee Chair, two special advisors and six vice-presidents. Some provided help on-site (i.e., 18 hours each week) and others attended Trustee's Meetings or helped raise additional funds. Many local groups supported LH with donations 'in kind'. Three volunteers also worked a couple of hours each per week. Staff often took residents for trips during their own time and while the manager reported that this really benefited residents, she could not quantify the resulting *additional* staff hours. Similarly, no cost could be estimated for time family and friends spent at LH.

While none of these people were reimbursed for their LH-related time, an 'opportunity cost' could be estimated, recognising that they were foregoing extra work hours or leisure activities. Table 6 lists the approximate number of hours they spent at LH and the cost of this time when valued at the minimum wage (i.e., £6.31 from April 2013). For example, the manager met with the Trustee Chair every week for approximately an hour; 52 hours per annum were valued at £328.12 (first row, Table 6).

Insert Table 6 here

Whilst a total of £9,200 per year does not represent the full costs of involving the specific personnel as trustees, or the loss of their 'productive time' to GDP, the calculation recognises that volunteer inputs carry a cost – even if that input is 'free' to LH.

Costs associated with use of off-site services.

Table 7 shows the input to LH from the local health and social care services and the cost over a year.

Insert Table 7 here

Inpatient hospital care was rarely used but carried a high unit cost of over £3,000 per episode (i.e., penultimate column). By contrast, some commonly used services, such as the GP or the community therapists, had a relatively low total cost per year, despite higher frequency of contact. Hospital outpatient services were the most frequently used service and the foot practitioner saw each person monthly. The only community-based social care service visiting LH was resident's care managers.

The cost of all off-site service inputs to LH over a typical year were £32,763 (Table 3), LH had operated at full occupancy over the previous year and thus the average cost per person is an additional £2,227 per year.

The total cost of support at LH.

Table 8 summarises the total costs of care at LH, including accommodation and hotel costs, on-site nursing and support staff, trustee and volunteer time and use of off-site services: £73,883 per resident year, or £1,420 per resident week.

Insert Table 8 here

Discussion

Whilst single case studies are critiqued for their lack of generalisability (Sarantakos, 2005), Yin (2014) highlights how they can act as an exploratory tool. This in-depth exploration of a single service illuminated how its philosophy and practice shaped the family-type culture and how resources were used to provide care. Government policy (DoH , 2001) clearly states that people with ID may be '*misplaced in older people's homes living alongside much older and more incapacitated people'*. Thompson et al.,'s (2004) investigation of the circumstances of those who reside in generic services for older people in the UK found that out of 2,570 residential and nursing homes sampled, 215 people with ID were living in 150 homes, where staff were unlikely to be trained in caring for them. There are 19,770 care homes in the UK, thus there may be at least 20,000 people with ID in care homes (see www.oscar-research.co.uk) which do not offer specialist care for those with terminal illnesses or end-of-life care. LH appears to offer a solution to this gap in service provision, not least because the positive results for resident QoL and choice are markedly different from findings in studies of older people with ID living in ordinary residential/nursing homes (Nikmat et al., 2015). In Nikmat et al.,'s study of 49 older people with dementia, those who were living at home experienced higher QoL, activities of daily living, and social connectedness compared with those living in institutional care. Moreover, unlike some residences (Cook et al., 2014) LH appeared to operate in a genuinely 'homely' fashion, with very few limits and routines placed on residents, in a manner consistent with social identity research (Monteleone & Forrester-Jones, 2017). However, while the pattern of LH residents' social support was very similar to that found in other studies of people with ID (Forrester-Jones et al., 2006; White and Forrester-Jones, 2017) their mean network size was very small. There is more work to be done here to facilitate this aspect of individuals' lives.

Whilst there is growing knowledge regarding care home practices for those who are ageing, end-of-life care is more complex and less well understood (Hunter & Levett-Jones, 2010; Hasson & Arnetz, 2011). We also know that care home staff have a range of understandings and experiences of what is involved in caring for people who are dying, that they often underestimate end-of-life care requirements, and report varying levels of confidence about providing that support (Ryan et al., 2011). Our study found that in general, LH staff felt supported by management to provide end-of-life care in a sensitive way. They were honest about their stress and sadness associated with end-of-life care, but were broadly positive, using words such as 'privilege', corroborating previous studies (Wiese et al., 2012).

Costs

By taking careful account of all resources 'consumed' in situations where residents' quality of life is shown to be good, the costs of replicating good quality care become clear. In this study, we have included the costs of the physical space, the day activity service, the staff team (i.e., including volunteers), the leadership and management input, as well as access to off-site services. The average cost per resident week was £1,420, 94% of which covered accommodation and support provided at LH. At around £1,750 per week, placement fees paid by the local health trusts and social services departments were slightly higher than the estimated cost. In part, this is due to the differences between usual accounting practices and the cost estimation process used here, which is informed by economic theory. In part, this gap also represents good financial management by a small voluntary sector organisation that has no large 'cushion' of funds on which to rely during periods of lower occupancy: when beds are empty, there is no income. Moreover, as placement consistency is closely linked to improved quality of life, so to ensure the continued existence of the service, it is important that the organisation can meet short-term financial commitments and that there is a fund to carry the service over lean times. On its own, cost information should never drive policy or

provision - interest should lie in what can be achieved with those resources by way of quality of care and the residents' quality of life, rather than how much the service costs.

Limitations

The study was too small for the results to be generalisable but this was not the purpose of the research. The service itself is unusual – possibly the only one of its kind in the UK – in that it provides continuing and end-of-life care for a small but increasing population of older people with ID who are terminally ill. The single case study design was intended to gain insights into this 'particular phenomenon'. More specifically, the research aimed to find out whether this care model provided a positive environment for the people who live and work there, and at what cost. Data concerning individuals with ID was collected via staff interviews and this invariably poses questions around data reliability. We interviewed 2 staff members (i.e., 1 support worker, 1 activity instructor) in order to help reduce proxy bias. Whilst the question of whether such methods ever truly represent the position of the person about whom the proxy is reporting we asked interviewees to provide their 'opinion' of what the resident with ID would say if they did have capacity to guard against staff simply giving their own answers about residents' experiences. Despite the inherent difficulties with such methods, it is important to include participants who lack capacity in research otherwise their situations will never be reported.

Although the data collection methods had the full support of the management and leadership team, we could not collect information on all residents. Consultee assent could only be obtained for 9 of the 15 residents, but they had lived at LH for between 5 months and four years so represented a good range of resident experiences. Staff were randomly selected to be invited to participate and the researchers did not observe anything at LH to lead them to think the staff participants did not represent the full staff complement.

Conclusion

Whilst the philosophical debates around ‘specialist’ care will continue, this study has indicated that there may be an argument for the type of service described here in order to fill a gap in palliative and end-of-life care for people with ID.

References

Ballard, C., Mobley, W., Hardy, J., Williams, G., Corbett, A. (2016). Dementia in Down's Syndrome, *The Lancet*, 15, 622-636.

Beecham, J. (1995). Collecting and estimating costs. In M. Knapp (Eds.), The economic evaluation of mental health care (pp. 157-174). Arena: Aldershot.

Beecham, J. (2000). Unit costs: Not exactly child's play. London: Department of Health. Retrieved from http://www.pssru.ac.uk/archive/pdf/B062.pdf

Bhardwaj, A.K., Forrester-Jones, R., and Murphy, G. (in press). Social networks of adults with an intellectual disability from south asian and white communities in the uk: A comparison. Journal of Applied Research in Intellectual Disabilities.

Bigby, C., Bowers, B., & Webber, R. (2011). Planning and decision making about the future care of older group home residents and transition to residential aged care. Journal of Intellectual Disability Research, 55, 777-789.

Bischoff, K.E., Sudore, R., Miao, Y., Boscardin, W.J., & Smith, A. K. (2013). Advance care planning and the quality of end-of-life care in older adults. Journal of the American Geriatrics Society, 61, 209-214.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77-101. doi: 10.1191/1478088706qp063oa.

Cook, G., Thompson, J., & Reed, J. (2014). Re-conceptualising the status of residents in a care home: older people wanting to 'live with care. Ageing and Society, 35(8), 1587-1613. doi: http://dx.doi.org/10.1017/S0144686X14000397.

Curtis, L. (2013). Unit Costs of Health and Social Care. Canterbury: PSSRU, University of Kent.

Department of Health. (2001). Valuing People: A New Strategy for Learning Disability for the 21st Century . London: Deaprtment of Health.

Emerson E., & Hatton C., (2008). People with learning disabilities in England, Retrieved from http://www.lancaster.ac.uk/staff/emersone/FASSWeb/Emerson_08_PWLDinEngland.pdf (2008, accessed 23 June 2017).

Flick, U. (2008). Designing Qualitative Research. Sage.

Forrester-Jones, R. (2014). Loss and People with Autism, In Read, S. (Eds.) Supporting People with Intellectual Disabilities Experiencing Loss and Bereavement, (pp. 165 - 173). London: Jessica Kingsley Press

Forrester-Jones, R. & Broadstairs, S. (2007). Autism and Loss. London: Jessica Kingsley

Forrester-Jones, R., Carpenter, J., Coolen-Schrijner, P., Cambridge, P., Tate, A., Beecham, J., & ... Wooff, D. (2006). The social networks of people with intellectual disability living in the community 12 years after resettlement from long-stay hospitals. Journal of Applied Research in Intellectual Disabilities, 19(4), 285-295. doi: 10.1111/j.1468-3148.2006.00263.x.

Hartley D., Blumenthal T., Carrillo M., DiPaolo, G., Esralew, L., Gardiner, K., Granholm, A., Iqbal, K., Krams, M., Lemere, C., Lott, I., Mobley, W., Ness, S., Nixon, R., Potter, H., Reeves, R., Sabbagh, M., Silverman,W., Tycko, B., Whitten, M., Wisniewskiet, T. (2015). Down syndrome and Alzheimer’s disease: Common

pathways, common goals. Alzheimer's & Dementia : the Journal of the Alzheimer's Association, 11(6), 700-709. doi:10.1016/j.jalz.2014.10.007.

Hasson, H., & Arnetz, J. E. (2011). Care recipients' and family members' perceptions of quality of older people care: a comparison of home-based care and nursing homes. Journal of Clinical Nursing, 20(9-10), 1423-1435. doi: 10.1111/j.1365-2702.2010.03469.x.

Hatton, C., Emerson, E., Robertson, J., Gregory, N., Kessissoglou, S., & Walsh, P. N. (2004). The Resident Choice Scale: A measure to assess opportunities for self-determination in residential settings. Journal of Intellectual Disability Research, 48(2), 103-113. doi: 10.1111/j.1365-2788.2004.00499.x.

Hatzidimitriadou, E., & Milne, A. (2005). Planning ahead Meeting the needs of older people with intellectual disabilities in the United Kingdom. Dementia, 4(3), 341-359. doi: 10.1177/1471301205055027 .

Hollins, S., Attard, M., van Fraunhofer, N., McGuigan, S., & Sedgwick, P. (1998). Mortality in people with learning disability: Risk causes, and death certification findings in London. Developmental Medicine and Child Neurology, 40, 50-56.

Janicki, M. P., & Dalton, A. J. (2000). Prevalence of dementia and impact on intellectual disability services. Mental Retardation, 38(3), 276-288. doi: http://dx.doi.org/10.1352/0047-6765(2000)038<0276:PODAIO>2.0.CO;2.

MENCAP. (2012). Death by Indifference: 74 Deaths and Counting - A Progress Report 5 Years on. London: MENCAP.

Monteleone, R., & Forrester-Jones, R. (2017). "Disability Means, um, Dysfunctioning People": A Qualitative Analysis of the Meaning and Experience of Disability among

Adults with Intellectual Disabilities". Journal of Applied Research in Intellectual Disabilities, 30, 301-315.

National Health and Medical Research Council. (2005). Guidelines for a Palliative Approach in Residential Aged Care. Canberra: NHMRC.

NELoCP. (2010). The Route to Success in End of Life Care – Achieving Quality in Care Homes. NHS England.

Nikmat, A. W., Al-Mashoor, S. H., & Hashim, N. A. (2015). Quality of life in people with cognitive impairment: nursing homes versus home care. International Psychogeriatrics, 27(05), 815-824. doi: http://dx.doi.org/10.1017/S1041610214002609.

Ryan, K., Guerin, S., Dodd, P., & McEvoy, J. (2011). End-of-life care for people with intellectual disabilities: Paid carer perspectives. Journal of Applied Research in Intellectual Disabilities, 24(3), 199-207. doi: 10.1111/j.1468-3148.2010.00605.x.

Sarantakos, S. (2005). Social Research. (3rd ed.). Hampshire: Palgrave Macmillan.

Smith, S. C., Lamping, D. L., Banerjee, S., Harwood, R., Foley, B., Smith, P., & ... Knapp, M. (2005). Measurement of health-related quality of life for people with dementia: Development of a new instrument (DEMQOL) and an evaluation of current methodology. Health Technology Assessment (Winchester, England), 9(10), 1-93.

Stake, R. (2003). Case Studies. In N. Denzin, & Y. Lincoln, Strategies of Qualitative Inquiry (2nd ed., pp. 134-164). London: Sage.

Stancliffe, R.J.LK., Larson, S.A., Engler, j., Tuab, S., Fortune, J., & Bershadsky, J. (2012). Demongraphic characteristics, health conditions, and residential service user in adults

with Down syndrome in 25 U.S. states. Journal of Intellectual and Developmental Disabilities, 50, 92-108.

Thompson, D. J., Ryrie, I., & Wright, S. (2004). People with intellectual disabilities living in generic residential services for older people in the UK. Journal of Applied Research in Intellectual Disabilities, 17(2), 101-108.doi: 10.1111/j.1360-2322.2004.00187.x.

Todd, S. (2013). 'Being there': The experiences of staff in dealing with matters of dying and death in services for people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 26(3), 215-230. doi: 10.1111/jar.12024.

Tuffrey-Wijne, I. (2015). Cancer and intellectual disability. In: Wyatt, Debbie and Hulbert-Williams, Nicholas, (Eds.) Cancer and cancer care. London, U.K. : SAGE. pp. 143-158. ISBN 9781446256282

Tuffrey-Wijne1, I., McLaughlin, D., Curfs, L., Dusart, A., Hoenger, C., McEnhill, L., Read, S., Ryan, K., Satgé, D., Straßer, B., Westergård, B.E., Oliver, D. (2015). Defining consensus norms for palliative care of people with intellectual disabilities in Europe, using Delphi methods. *European Association of Palliative Care Palliative Medicine,* 30(5), 446-455. doi: https://doi.org/10.1177/0269216315600993

White, P. & Forrester-Jones, R. (submitted). Valuing e-inclusion: Social media and the social networks of adolescents with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*.

Wiese, M., Stancliffe, R. J., Balandin, S., Howarth, G., & Dew, A. (2012). End-of-life care and dying: issues raised by staff supporting older people with intellectual disability in community living services. *Journal of Applied Research in Intellectual Disabilities, 25(6)*, 571-583. doi: 10.1111/jar.12000.

World Health Organisation. (2011). *World Disability Report.* Retrieved from www.who.int/disabilities/world_report/2011/report.pdf

Yin, R. (2014). *Case Study Research - Design and Methods* (5th ed.). London: Sage Publications.

Table 1

Residents' mood over the previous seven days (*n*=9)

	Min	Max	M	SD
Cheerful*	2	4	2.89	.60
Worried/Anxious**	2	4	3.00	.87
Frustrated**	2	4	3.44	.88
Full of energy*	1	4	2.00	1.32
Sad**	3	4	3.89	.33
Content*	2	4	3.11	.78
Distressed**	2	4	3.22	.83
Lively*	1	4	1.89	1.05
Irritable**	1	4	3.33	1.00
Fed-up**	3	4	3.67	.50
That he/she has things to look forward to*	1	4	2.22	1.30

**1 = Not at all; 2 = A little; 3 = Quite a bit; 4= A lot*
***1=A lot; 2 = Quite a bit; 3 = A little; 4 = Not at all*

Table 2

Residents' memory over the previous seven days (*n* = 9)

	Min	Max	Mean	SD
His/her memory in general?	4	4	4.00	.000
Forgetting things that happened a long time ago?	4	4	4.00	.000
Forgetting things that happened recently?	4	4	4.00	.000
Forgetting people's names?	4	4	4.00	.000
Forgetting where he/she is?	3	4	3.89	.333
Forgetting what day it is?	4	4	4.00	.000
His/her thoughts being muddled?	3	4	3.89	.333
Difficulty making decisions?	4	4	4.00	.000
Difficulty making him/herself understood?	2	4	3.67	.707

**1=A lot; 2 = Quite a bit; 3 = A little; 4 = Not at all*

Table 3

Residents' aspects of their everyday lives (*n* = 9)

	Min	Max	Mean	SD
Keeping him/herself clean?	2	4	3.78	.667
Keeping him/herself looking nice?	2	4	3.11	.928
Getting what he/she wants from the shops?	1	4	3.56	1.014
Using money to pay for things?	4	4	4.00	.000
Looking after his/her finances?	4	4	4.00	.000
Things takings longer than they used to?	3	4	3.78	.441
Getting in touch with people?	3	4	3.78	.441
Not having enough company?	3	4	3.89	.333
Not being able to help other people?	3	4	3.89	.333
Not being able to play a useful part in things	3	4	3.78	.441
His/her physical health?	3	4	3.78	.441

**1=A lot; 2 = Quite a bit; 3 = A little; 4 = Not at all*

Table 4

Resident Choice Scale*

Area of Life	Min	Max	Mean	SD
Meals				
Time of evening meal	2	4	3.67	0.71
Content of evening meal	2	4	3.67	0.71
Where they eat	1	4	3.44	1.13
Household Appearance/ Possessions				
Furnishings in the home	1	4	1.78	1.09
Furnishings in the bedroom	4	4	4.00	0.00
Personal possessions	4	4	4.00	0.00
Keeping Pets	1	3	1.78	0.97
Personal Appearance				
Clothes they purchase	2	4	3.78	0.67
Clothes they wear each day	2	4	3.78	0.67
Haircut	3	4	3.78	0.44
Major Home Decisions				
Who they live with	1	1	1.00	0.00
Where they live	1	3	1.89	1.05
Moving home in the future	1	4	1.33	1.00
Household Routines				
Time they go to bed	4	4	4.00	0.00
Time spent in bathroom	4	4	4.00	0.00
Access to a private area	4	4	4.00	0.00
Household routines	1	4	2.11	1.27
Leisure and Relationships				
Activities in residence	3	4	3.89	0.33
Intimate relationships	4	4	4.00	0.00
Going out	2	4	3.22	0.83
Holidays	1	4	3.11	1.05
Staffing Issues				
Recruitment of Staff	1	3	2.22	0.83
Staff Performance Review	1	2	1.11	0.33
Firing of unsuitable Staff	1	2	1.22	0.44
Employment/Daytime Activity				
Employment	1	1	1.00	0.00
Activities Centre	3	4	3.89	0.33

**1= residents have no choice, 2=residents have little choice, 3=residents can express preferences, 4=residents have final say.*

Table 5

Social support and interactional behaviours provided by network members

Support type	Other residents	*Staff in LH	Visiting professionals	Volunteer/advocate	Retail (shops)	Partner/spouse	Family	Total
Personal	0	2 (6)	0	0	0	0	5 (16)	31
Domestic	1 (3)	31 (79)	0	0	0	0	7 (18)	39
Material	1 (2)	36 (59)	5 (8)	0	0	0	19 (31)	61
Decisions	0	40 (64)	4 (6)	0	1 (2)	0	17 (27)	62
Confiding	0	11 (52)	3 (14)	0	0	0	7 (33)	21
Companionship	7 (10)	33 (46)	2 (3)	2 (3)	2 (3)	2 (3)	23 (32)	71
Invisible	8 (10)	38 (47)	8 (10)	2 (2)	2 (2)	1 (1)	22 (27)	81
Critical	8 (20)	22 (56)	0	0	1 (2)	1 (2)	7 (18)	39
Interactional behaviours								
Reciprocity	3 (11)	6 (23)	0	0	0	2 (8)	15 (57)	26
Frequency								
Duration								
<1 years	8 (14)	38 (67)	6 (10)	2 (3)	2 (3)	1 (2)	0	57
>1 year	1 (3)	2 (7)	2 (7)	0	0	1 (3)	24 (80)	30
Closeness (very close/best friend)	9 (11)	37 (47)	4 (5)	2 (2)	1 (1)	2 (2)	24 (30)	79
Feelings about relationship								
(best)	1 (5)	7 (35)	0	0	0	1 (5)	11 (55)	20
(good)	4 (9)	26 (56)	1 (2)	2 (4)	1 (2)	1 (2)	11 (24)	46
(neutral)	4 (21)	5 (26)	7 (37)	0	1 (5)	0	2 (10)	19
(bad)	0	2 (100)	0	0	0	0	0	2

Key: Values are given as n (%). *Staff includes key worker and ex-staff

Table 6

Trustee and volunteer time and estimated costs

Activity	Time	Total hours pa	Cost
Weekly meeting	Trustee Chair, 1.0 hours per week	52 hours pa	£328
Regular attendance at Trustee meetings	Eight members, 2.5 hours every 2 months	120 hours pa	£757
Annual meeting	15 members, 2.5 hours per annum	37.5 hours pa	£237
Regular trustee presence on-site	Three members, 6 hours per week	936 hours pa	£5,906
Volunteer time	3 people, 2 hours per week	312 hours pa	£1,969
Additional staff time	Impossible to identify these hours so we cannot estimate a value	Not available	£0
Donations in kind	Impossible to quantify	Not available	£0
	Total cost per year		£9,197
	Average cost per resident (n=15) per year		£613

Table 7

Additional off-site support services used by residents and their associated costs

Service	Use	Calculation	Cost
Hospital inpatient	Short stays 4-5 times a year, usually for general health issues and travelling to hospital by ambulance as an emergency.	(£3,283+£177)*4.5	£15,570
Hospital outpatient clinics	Used 4-5 times a month, for general health, psychiatric and psychology services, and the wheelchair clinic	£135*4.5*12	£7,290
Accident and Emergency Dept.	Staff members take residents to A&E; this happens once or twice a year	£117*1.5	£176
General practitioner	Visits once a week, staying for 15 minutes; unit cost includes travel	£218/4*52	£2,834
Dentist	Residents have a six-monthly check-up, mostly at LH	£18*15*2	£540
Optician	Visits every 6 months for annual sight tests, staying for about 2 hours	£29.90*15	£449
Physiotherapist, occupational or speech & language therapist	Community-based therapists visit around twice a month staying 1-3 hours to assess or treat residents; assumes 30 minutes travel	£30*2.5*12*2	£1,800
Foot practitioner /reflexologist	Every two weeks for 4.5 hours; assumes 30 minutes travel	£30*5*12*2	£3,600
Dietician	When advised by HEN team. Around twice a year for an hour; assumes 30 minutes travel	£30*1.5*2	£90
Community nurses	Visits once every 3 months to attend to a resident's additional health needs; assumes a 30-minute visit, plus 30 minutes travel	£42*1*4	£168
Home Enteral Nutrition (HEN) team member	Visits once every 6 months for an hour to assess or check residents who are fed this way; assumes 30 minutes travel	£42*1.5*2	£126
Care managers	Visits once a year per resident for their annual review, generally for 1-3 hours, assumes one hour travel	£40*3*1	£120
		Total per annum	£32,763
		Average cost per resident (n=15) per annum	£2,184

Table 8

Average total cost of residence at Leesdown House

Cost component	Total cost p.a.	Cost per resident p.a.
On-site costs	£1,046,790[1]	£69,786
Residents' personal money	£19,500	£1,300
Trustee and volunteer time	£9,197	£613
Off-site services	£32,763	£2,184
Total	£1,108,250	£73,883

1. Adjusted to reflect 100% occupancy
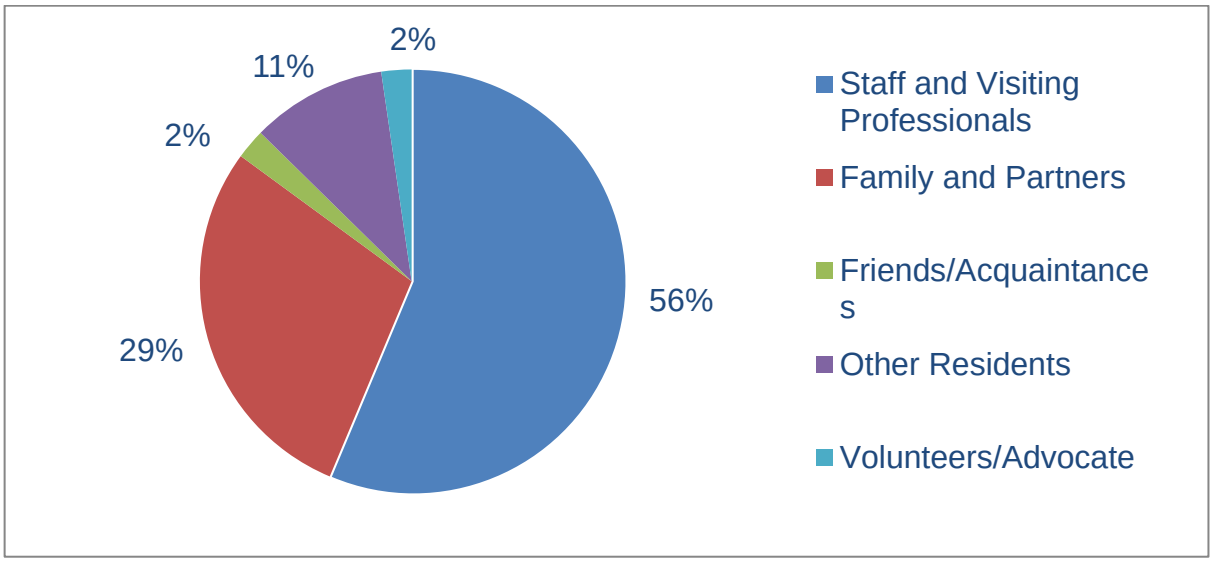
Figure 1. Social network membership