PSSRU

Personal Social Services Research Unit

A case study: the costs of residential care for people with intellectual disability and dementia

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Contents

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Abstract

Background People with intellectual disabilities have a shorter life expectancy but health care improvements mean that they are living longer, with the associated health difficulties. Research into ways of supporting people with intellectual disabilities who are ageing and need end of life care is short supply, and few services are provided.

Method This research is a single case study that included observations, interviews with standardised questionnaires and focus groups for staff. This Discussion Paper focuses on estimating the comprehensive costs of a specialised residential facility using a standard, well-established approach.

Results At £1,422 per resident week (2013 prices) our estimated cost for supporting residents at Leesdown House are likely to be slightly higher that the placement fees paid by local health trusts and social services departments. Any difference would allow the service to build up a small 'cushion' of funds on which to rely during periods of lower occupancy. Additional services and volunteer costs account for a further £55 per resident week.

Conclusion Cost information alone should never drive care policy. However, the resources absorbed by Leesdown House generated positive results for residents' quality of life and opportunities to make choices for themselves. This service may provide a solution to the gap in specialist service provision.

Key words

Intellectual disability, end of life care, residential services, costs.

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Introduction

Overarching improvements in health care mean that people with intellectual disabilities are living longer. This has also brought an increase in the prevalence of age-related health care needs, including dementia (Cooper et al., 1997; Holland, 2000) and the need for end of life care. Understanding and meeting the resulting health and social care needs will require additional resources to provide the high levels of specialist support required (Janicki & Dalton, 2000). Leesdown House (pseudonym) is one of the very few specialist services for older people with intellectual disabilities. It is a purpose built nursing home, managed within a single purpose voluntary sector organisation – the Foundation – situated on the edge of a market town in Kent. The Foundation's underlying philosophy is that residents should be valued, treated as individuals, and enjoy a happy and lively environment. They should be able to end their days in comfortable surroundings, secure in the knowledge that they will receive the best possible nursing and palliative care.

Leesdown House (LH) provides high dependency nursing and care for 15 residents and opened in May 2010. Between December 2012 and November 2013, occupancy rose from 10 residents to 15, with a concomitant increase in staff (25 whole time equivalent). In November 2014, when the costs research began, LH had a relatively stable support staff group with two new permanent nursing staff due to start in early 2015. LH is a registered nursing home so a nurse is always on duty. Six support staff are on duty in the morning and five during the afternoon and evening. A nurse is on duty overnight with two support staff. During the day, either the manager or the deputy manager is on duty plus a cleaner, a handy man, and kitchen staff. The on-site nursing staff provide most of the training although training can also be purchased through the LH budget.

Since opening, the site has developed and currently includes an on-site specialist activity centre. Only residents use this facility and although it is available whenever the residents want to use it, the three activity centre staff work from 10am to 5pm. Other improvements to the site have included the creation of a sensory garden and vegetable plot, improvements to the entrance and gates, and new laundry and storage facilities. Currently, funds are being raised for a sensory room, with the the aim of starting building it in 2015.

Research aims

This case study aimed to map the philosophy, organisation and running of Leesdown House, and investigate the quality of care and residents' quality of life using a single instrumental case study design (Forrester-Jones et al., 2017). Ethical permission was obtained from National Health Service Ethics Service, reference 14/LO/0048. The aims for the cost component reported here are as follows.

- to identify the funding streams
- to identify the comprehensive costs associated with care provided to LH residents, which include on-site supports, other health and social care services, and care time inputs from volunteers or family and friends

- to identify whether there are any major variations in the resources used to support residents
- to compare the costs of care at LH with other care locations for people with intellectual disabilities and complex health care needs
- to set these data alongside findings from other parts of the study on philosophy, organisation and residents' quality of life.

Methods

Data collection

Data for the costs study were collected in November 2014 during a semi-structured interview with the LH manager using a pre-specified topic guide (see Appendix I) but allowing the discussion to range freely. The first part of the topic guide focused on funding streams and commissioning arrangements and the second concerned other resources that came into the home in the form of additional professional help, volunteers and Trustees, and whether there was any large formal care input from family members.[1] Together, both sections allow us to estimate the full costs of the support that LH residents receive, and identify who funds that care. The third broad question was about the way resources were used within the nursing home; not just staffing rotas and activities but also whether some residents received more staff support than others. The final part of the topic guide was more discursive, and asked the manager to identify any other types of care location where people with similar needs might be living. The Chair of the Trustees provided additional information on Trustees' time inputs to LH and the Foundation.

We also looked at publicly available information such as the Foundation's website, the recent CQC Review of LH, data submitted to the Charity Commission website, and we searched for research studies reporting costs for similar client groups.

Estimating costs

Collecting these descriptive data about LH is the first of four stages that allow 'bottom-up' cost estimation (Beecham, 2000). The second stage is easier as it requires us to identify the activities undertaken in the service and a unit of activity. The most relevant units for residential services such as LH is 'per resident year' or 'per resident week' although for inpatient care 'per day' or 'per episode' would be more appropriate, as would 'per hour' for off-site therapists; such units of measurement should match the way people use services. The following definitions are relevant.

> A residential/nursing facility is one that has overnight beds for more than one person. Residents may attend off-site activities but on-site staff supervise all other normal daily activities (for example, eating, sleeping or leisure activities). Within the facility, 24-hour waking staff cover is provided or there are waking staff during the day and sleeping-in or on-call staff at night.

[1] Informed by a short-form of the Client Service Receipt Inventory (CSRI; Beecham, 1995) which provides a list of potential services the residents might use and a systematic means of recording use of these inputs over a specified period.

> A person is deemed a resident each night they slept there, or had a bed reserved for them. The unit of activity is, therefore, the number of occupied places for each day/week during the relevant financial period; average or typical numbers can be used. When a place is reserved for a resident but the person is temporarily staying elsewhere (perhaps in hospital, or at home for the weekend), this should still be counted as an occupied bed-day. (Adapted from Beecham, 2000, p80.)

The third stage of the process is to attach a cost to each of the service components. There can be several complications to this process. The first is obtaining the relevant expenditure data; for LH we used the accounts submitted to the Charity Commission for November 2013. Another challenge is when non-residents use on-site services; in this case, the finance data would need to be adjusted to remove any costs associated with the increased 'output' measure. (In fact, at LH only residents use the on-site services.) We must also make sure the results approximate *long-run marginal opportunity costs*. This approach, based in economic theory, aims to estimate the full cost of providing the service, not least to inform commissioners in the face of increasing demands for such services. The alternative would be a cost based on the assumption that however many people need the service in the future, they can be 'squeezed into' the existing capacity. Full costs should include not just staff and other revenue costs but also any overheads, and the costs accruing for any buildings and equipment.[2]

The fourth stage of this cost estimation model is, therefore, to arrive at a unit cost by totalling the cost of all the service components and dividing that figure by the number of units of activity.

One further item to discuss in this methods section is the identification of costs associated with the alternative locations for care. Our search did not identify any cost research on similar services. Instead, we have taken unit costs from the well-established PSSRU annual volumes of *The Unit Costs of Health and Social Care*,[3] in which unit costs for around 200 health and social care service are estimated according to the principles of *long-run marginal opportunity costs.* We have also used data from this volume to attach a cost to the off-site services that provide additional health and social care for Leesdown House residents. All costs are shown at 2013 prices.

Findings

Funding care at Leesdown House

Local councils and health trusts fund services at LH though individual placement contracts. There are no private fee-paying residents. The placing agency transfers the full contract price to LH so the manager has no information about whether people's social security benefits are reduced at source to (part-)pay for care; many residents' finances are overseen by a relative or guardian. Residents at LH also have their own personal money for shopping, commonly around £25 per week.

[2] The ACEVO recommendations for 'full cost recovery' take a similar approach, although implemented slightly differently, when costing for contracts. See for example, http://www.thinknpc.org/publications/full-cost-recovery-2/

[3] The 2013 volume used here can be found here http://www.pssru.ac.uk/publication-details.php?id=4578

Leesdown House has 15 places and a current waiting list of three people. When a person is referred, the manager goes to their current home to assess whether the person can be cared for at LH. The assessment also includes identifying any additional care hours needed. Residents might, for example, need extra staff support hours for personal care or eating. For 2012-2013, the basic rate was £1,342 with the 'additional care hours' component accounting for a further £558, giving a total of £1,740. If a resident's needs increase over time, the contract price can be re-negotiated with the funder. If a resident dies, LH has a fully funded 'overlap' week when they prepare the room for the next resident.

There are other small variations in the level of care provided within LH, perhaps when a resident is unwell, or for trips, but these are usually covered through management of the staff rota and staff deployment on that day, rather than employing additional staff.

On-site costs at Leesdown House

Stage 1: Describe the elements of the service
The description of the service at LH shown above was taken from the interview with the manager of LH and data submitted to the Charity Commission.

Stage 2: Identify the activities and a unit of measurement
The November 2013 accounts span the period from December 2012 to the end of November 2013. There were 10 residents at beginning of this financial year, with full capacity reached in July. We have calculated the 2012-2013 annual occupancy as

- Full occupancy = 12months*15 residents = 180 resident-months
- Ten residents from December to June = 10 residents*7 months = 70 resident-months
- Fifteen residents from July to November = 15 residents*5 months = 75 resident-months.
- Total resident-months for the year = 70+75 = 145 resident-months.
- Occupancy for the period covered by the accounts = 145 / 180 resident-months = 80%.

Stage 3: Estimate the cost implications of the service elements
The publicly available annual accounts submitted to the Charity Commission provide a detailed breakdown of the 2012-2013 expenditure, disaggregated by budget heads such as staff, medical supplies, utilities etc. Expenditure on governance and support is also identified, and so too are values for capital items (land, buildings, equipment etc.). For our purposes, we have adjusted the data presented there. For example, our concern is with the running costs over the long-term, rather than with 'shorter-term' expenses such as loan repayments. We also treat capital costs slightly differently. Rather than identifying depreciation values, we estimate the annual return on the investment using a standard 60-year period for buildings,[4] which is annuitized at 3.5% in line with HM Treasury policy. This results in a slightly lower figure than shown in the accounts for loan interest payments and depreciation.

[4] A 10-year period for motor vehicles, furniture & fittings, and equipment

Stage 4: Calculate total and unit costs

At 2013 prices, the total costs of providing on-site support were £837,438 per annum (see Table 1). The occupancy rate was 80% for that year; that is, an average of 12 residents over the year, rather than the 15 places LH could provide when fully occupied. This means that the average on-site cost per resident per year was £69,786, or £1,342 per week (52 weeks).

Table 1 On-site costs at Leesdown House

Service component	**Expenditure per annum**
Care of residents	£711,651
Support	£24,032
Governance	£3,600
Fundraising	£1,866
Total running costs £734, 481	
Buildings, vehicles, equipment etc	£96,289
Total cost per annum	£837,438
Average cost per resident (n=12) per year	£69,786

Trustees and volunteers

To help ensure good governance, the Foundation has two patrons, ten Trustees and a Chair of Trustees, two special advisors and six vice-presidents, all identified on the Foundation's webpage. Eight Trustees attend the regular two-monthly Trustees Meetings and three Trustees are usually at LH for a total of 18 hours each week undertaking a wide range of activities:

- overseeing staff matters such as wages and employment issues;
- monitoring the quality of care through outcomes and, for example, ensuring meals are good and residents are happy;
- checking the building and organising large repairs;
- leading or supporting corporate or on-site fund-raising activities, which have funded all the recent improvements to the site;
- producing a Newsletter three times a year, maintaining the Friends' Group and organising events to spread the work of the Foundation; and
- overseeing the finances, both LH and residents' personal bank accounts, dealing with invoices and orders, producing monthly and annual accounts and budgets, and organising the annual audit.

In addition, many local groups support the Leesdown House and there are donations 'in kind', such as the marquee for the summer and Christmas fairs.

LH currently has three volunteers – two students and a retired nurse – who each work with residents for a couple of hours a week. The manager noted that the support staff are very motivated, often using part of their day off to take residents out for personal shopping, attend birthday or other

parties, or select and purchase presents for residents. The manager feels this input really benefits the residents, but found it very difficult to quantify it in terms of *additional* staff hours. We have not, therefore, been able to attach a cost to these important time inputs.

Relatives are actively encouraged to be involved in residents' lives. They can visit LH at any time, although a telephone call is often a useful way of making sure that a particular resident is at home. Residents' relatives are invited to birthday parties as well as other events such as the Fairs, and seasonal parties on Bonfire Night or Halloween. These visits are social; relatives are not expected to provide any formal care support.

While none of the volunteers or Trustees are reimbursed for their time, we have estimated an 'opportunity cost' for the amount of time they spend on LH-related activities. This approach recognises that volunteers, whatever their role, could be undertaking other tasks, leisure, education, or additional work hours instead of their LH-related activities. Table 2 lists the approximate number of hours and then shows the cost of these inputs when valued at the minimum wage payable for 2013 (as from October, £6.31). For example, the manager has a meeting with the Trustee Chair every week for about an hour; over a year, this is approximately 52 hours, valued at £328.12 using the minimum wage (first row, Table 2).

Of course, 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 in their usual employment. But the calculation allows us to recognise the fact that volunteer inputs, whether directly or indirectly supporting residents, carry a cost – even if that input is 'free' to the Foundation.

Table 2 Trustee and volunteer time and estimated costs

Activity	**Time**	**Total hours pa**	**Cost**
Weekly meeting	Trustee Chair, 1.0 hour 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	e15 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	Three 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

Additional off-site services

Table 3 shows the range of services used by residents at LH. These services are provided to individuals in response to their needs, although the Table shows the overarching profile for the whole establishment. The Table describes the level of input from the local health and social care services and the final two columns show the cost calculation over the year.

Inpatient hospital care is rarely used but carries a high unit cost of over £3,000 per episode (penultimate column, see also Appendix II). By contrast, some commonly used services – such as the GP or community therapists – have a relatively low total cost per year: their low unit cost offsets the greater frequency of contact. Hospital outpatient services are the most frequently used service, particularly the psychiatry, psychology, and wheelchair clinics. The foot practitioner is one of the most regular professional contacts as she visits LH every two weeks and sees half the residents each time. Each resident, therefore, sees the foot practitioner every month.

Perhaps surprisingly, given the residents' needs, there is only occasional input from community-based nursing services. However, LH is a registered nursing home so on-site staff provide most of the nursing care. For example, although many residents have seizures, the on-site nurses undertake the day-to-day clinical support associated with epilepsy.

The only community-based social care service used by residents is a care manager. Each resident's care manager visits once a year for the annual review: here we have assumed that each care manager reviews the arrangements for two residents at each visit. The length of the visit is somewhat dependent on how well the care manager knows LH and the residents but generally lasts between one and three hours. The manager reported that care manager visits between annual reviews were rare, happening 'only if something is not working very well'.

Some residents visit community professionals in their surgery, such as the GP or dentist although this becomes less common as their needs and frailty increase. One resident visited a hydrotherapy pool once every two weeks but has been unwell recently and unable to attend.

We estimate the total cost of the off-site service inputs over a typical year at nearly £33,000. Hospital services absorb more than two-thirds of that total (inpatient care 47%, outpatient services 22%). By contrast, the relatively frequent visits from the GP cost £2,834 per annum account for just 8% of the total off-site service costs. These data were collected for the year prior to interview (November 2014) when LH was operating at full capacity. Thus, assuming 15 residents over the year, the average cost per person represents an additional £2,227 per resident year, or £43 per resident week.

Table 3 Additional off-site support services used by LH 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	All residents have a six-monthly check-up, mostly at LH	£18*15*2	£540
Optician	Visits every six months for residents' annual sight test, staying for about 2 hours	£20.90*15	£314
Physiotherapist, occupational or speech & language therapist	In total, 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	Visits every two weeks for 4.5 hours; assumes 30 minutes travel	£30*5*12*2	£3,600
Home Enteral Nutrition (HEN) team member	Visits once every six months for an hour to assess all residents who are fed this way; assumes 30 minutes travel	£42*1.5*2	£126
Dietician	As 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 three months to attend to a resident's additional health needs; assumes a 30-minute visit, plus 30 minutes travel	£42*1*4	£168
Care managers	Visit once a year per resident generally lasting between one and three hours; assumes one hour travel. We assume one care manager supports two residents.	£40*3*7.5	£900
		Total per annum	£33,408
		Average cost per resident (n=15) per annum	£2,227

The total cost of support at Leesdown House

Table 4 summarises the total costs of residence at Leesdown House including accommodation and hotel costs, on-site nursing care, volunteer time and use of off-site services.

Table 4 Total average cost of residence at Leesdown House

Cost component	Total cost per annum	Cost per resident per annum
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	£33,408	£2,227
Total	£1,108,895	£73,926

1. Adjusted to reflect 100% occupancy

Cost comparisons

Despite having only three people on their waiting list, demand for places at LH can be high. The manager told us that when a place becomes vacant, she gets many telephone calls about placing someone at LH. Sometimes these requests result in the person being placed on the waiting list but more often, their need is pressing so another placement is found. However, although there are one or two other small independent sector homes in Kent that provide nursing care for people with intellectual disabilities, none provide care specifically for people with intellectual disability and dementia and/or needing end of life care. We use LH residents' previous placement types as a basis of estimating the cost of alternative care locations:

- Mainstream nursing homes, where the nursing care may be excellent but needs related to the complex interaction between learning disability and dementia are not met
- Supported living, where deteriorating health – such as problems with mobility, eating, or dementia – means staff find it increasingly difficult to care for them
- Living with relatives, where deteriorating health – such as problems with mobility, eating, or dementia – means relatives find it increasingly difficult to care for them
- Mainstream residential home, where nursing care is not provided

In Table 5, we reproduce the nationally applicable unit costs for staffed accommodation cited in the *Unit Costs of Health and Social Care* (Curtis, 2013) and the source reference where relevant.

While the options shown in Table 5 tend to be less expensive than LH, it is worth re-iterating that none of these home types care specifically for older people with intellectual disability and their specialist support needs. They are unlikely to be able to meet fully the additional health or social care needs of this group. We should expect care and support costs to be higher where residents' needs are higher.

Table 5 The cost of care in alternative settings

Setting	Unit cost for on-site support only	Unit cost for on-site support, plus hospital, community and day care services
Accommodation and care for people with mild to moderate learning disabilities (Felce et al, 2005)		
Fully staffed living settings	£1,186 per resident week	£1,703 per resident week
Group home	£906 per resident week	£1,401 per resident week
Semi-independent living settings	£378 per resident week	£794 per resident week
Residential social care for adults with learning disabilities (Laing and Buisson, 2011)		
Four-bed house with 7.5 wte care staff and 1.0 wte manager (257 care hours per week, one waking and one sleeping-in night staff)	£1,580 per resident week	Not available
Eight-bed house with 12.4 wte care staff and 2 wte managers (427 care hours per week, one waking and one sleeping-in night staff)	£1,242 per resident week	Not available
Supported living for adults with learning disabilities (Laing and Buisson, 2011)		
Two-bed home with 94 hours staff support per week	Staff and management costs: £882	Not available
Three-bed home with 85.7 hours staff support per week	Staff and management costs: £884	Not available
Nursing homes for older people		
For-profit provider (fees plus resident's personal money)	£774 per resident week	Not available
Residential homes for older people		
For-profit provider (fees plus resident's personal money)	£532 per resident week	Not available
Local authority provided (includes resident's personal money)	£1,026 per resident week	Not available
Extra care housing for older people (Darton et al., 2011) Self-contained units with variable level of care and some communal areas		
Mean cost	£256 per resident week	£430 per resident week
Highest cost	£256 per resident week	£1,261 per resident week

Outcomes

The research included standardised measures of health-related quality of life (DEMQOL_Proxy), opportunities for self-determination (Resident Choice Scale) and social network size and membership (Social Network Guide). Health-related quality of life was good with individual ratings over the previous week ranging from fair to very good for all nine participating residents and staff had relatively few concerns about residents' mood or memory. Residents appeared to have a high

level of choice around day-today living matters (for example, meals, personal appearance, possessions, leisure activities) but less round major decisions about the whole establishment, moving home or recruiting staff. Social networks were small, comprising mainly family or staff. (More detailed findings can be found in Forrester-Jones et al., 2017).

Conclusion

In this short report, we have identified all the resources absorbed in providing care and support for Leesdown House residents. This includes all public sector contributions, as well as those from volunteers, Trustees, residents and their family and friends. All these resources go towards creating a positive environment for residents thus any replication of the model that hopes to achieve the same level of outcomes should be aware of all the inputs required. We found that the cost per resident week was £1,422. This includes £43 for support provided by off-site hospital and community health care services, and £12 for volunteer and Trustee inputs. This is the average cost per resident and is useful for planning purposes. We know that there is some variation around the level of care provided for residents, and that there is a small increase in the fee for some residents in line with their additional care needs. However, without a larger observational or time-use study that records staff activities in detail we cannot be precise about these variations.

Basic fees for residences at Leesdown House are £1,342 plus £558 where residents are eligible for the 'additional care hours' payment (2013 prices). Depending on how many residents are eligible for the additional payment, average fees may be higher than the cost we have estimated. In part, this would be due to the differences between the standard accounting practices adopted for the Leesdown House financial reporting and our cost estimation processes, which have been informed by economic theory. In part, any gap 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. It is therefore important for the continued existence of the service that there is a fund to meet their short-term financial commitments and carry them over lean times.

The final task was to look at the costs of care in similar care locations. This proved difficult, as there are few similar services and no prior cost research. Instead, the manager identified residents' living situations before they arrived at LH and we sought nationally applicable costs for these accommodation types. Commonly these were less expensive that care at LH, but the health and support needs of LH residents are much higher than found for most residents in those types of establishments.

On its own, cost information should never drive care policy or provision thus the final research aim for this small single-service cost study was to set the findings alongside other parts of the study on the residents' outcomes. Overall, the resources absorbed by Leesdown House generated positive results for residents' quality of life and opportunities to make choices for themselves. This service may provide a care model that fills the current gap in specialist service provision.

References

Beecham, J. (2000) *Unit Costs: Not Exactly Child's Play,* Department of Health, London http://www.pssru.ac.uk/archive/pdf/B062.pdf

Beecham, J. and Knapp, M. (2001) Costing psychiatric interventions, in G. Thornicroft (ed.) *Measuring Mental Health Needs,* Gaskell, 2nd edition, 200-224.

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

Cooper, S. (1997) Deficient health and social services for elderly people with learning disabilities, Journal of Intellectual Disabilities Research, 41, 4, 311.

Darton, R., Baumker, T., Callaghan L, and Netten A (2011) *The PSSRU evaluation of the extra care housing initiative: technical report*, Discussion Paper 2265/3, Personal Social Services Research Unit, University of Canterbury.

Felce, D., Perry, J., Robertson, J., Meek, A., Emerson, E., Knapp, M. (2008) Outcomes and costs of community living semi-independent living and fully staffed group homes, *American Journal of Mental Retardation,* 113, 87-101.

Forrester-Jones, R., Beecham, J. Barnoux, M., Oliver, D., Couch, E. and Bates, C. (2017) People with intellectual disabilities at the end of their lives: the case for specialist care, Journal of Applied Research in Intellectual Disability, 30, 6, 1138-1150.

Holland, A. (2000) Ageing and learning disability, *British Journal of Psychiatry*, 176, 26-31

Janicki, M. and Dalton, A. (2000) Prevalence of dementia and impact on intellectual disability services, *Mental Retardation*, 38, 3, 276-288

Laing and Buisson (2011) *Illustrative Cost Models in Learning Disabilities Social Care Provision*, Department of Health, London

Appendix I: Topic Guide for Manager's Interview

Aims

The first task is to identify the resources absorbed in the organisation and running of the Leesdown House (LH) including all funding sources, public sector grants or fees, as well as donations or funds raised. This may include additional health or social care services or personnel that visit LH to support residents or staff, and 'time' contributions from volunteers, family and friends, and for governance structures (such as council members and trustees). It is the total of all these resources that create a positive environment for residents and that will be needed for any replication of the model.

The second task is to explore the way these resources are used to provide the different functions of the establishment, perhaps end-of-life care, crisis care, respite care or convalescence. It may also be that some residents need more staff support than other residents. Finally, we will compare the costs associated with providing care at LH with data from existing literature, which are likely to cover different user groups.

Funding streams

- Individuals' direct payments and hosing benefits etc?
- Privately funded placements?
- Agency placements (CQC reports that LDF is monitored by the council): out of area placements?
- Assessed by that agency? (eg. by council as too high needs for support at home)
- If agency funded then what types of contracts (single, block etc); with varying prices (why)?
- Donations and fundraising – how spent?
- Expenditure – 2014 accounts? Or use year-end Nov 2013 submitted to Charity Commission?

Inputs

- Volunteer activities? What do they do and how many hours per week/month?
- Trustee time, including meetings and other activities?
- Inputs from community services; Routine? How funded? (CQC mention GP/medical, SALT team, dietician. Are these resident specific?)
- Use of hospital care

Outputs

- Variations in staff time
- Activity Centre: also open to non-residents, or those who are occasional residents?
- Occupancy

Alternative care locations

- Local facilities
- Previous placements
- And if they lived in their own homes?

Appendix II: Unit costs for off-site services used by Leesdown House residents

Unless otherwise stated, the table shows the cost per working hour for professionals and the source is *The Unit Costs of Health and Social Care 2013*.

Service	Unit cost	Comment
Hospital inpatient	£3,283	Elective; average cost per episode
Hospital outpatient clinic	£135	Weighted average of all outpatient procedures
Hospital A&E/Minor Injuries Unit	£114	Per attendance
Ambulance	£177	See, treat and refer
General Practitioner: surgery	£34 per contact	11.7 minutes
General Practitioner: home visit	£218 per hour of contact	Out of clinic surgery, includes travel
Speech and Language Therapist Occupational Therapist/Dietician Physiotherapist/Chiropodist	£30 per hour	
Community/District nurse	£42 per hour	
Social worker	£40	
Community Learning Disability Team	£36 per hour	CMHT per team member
Clinical psychologist	£59 per hour	
Psychiatrist	£94 per hour	Associate specialist
Pharmacist	£51 per hour	
Optician sight-test fee[1]	£20.90 per sight-test	
Dentist check-up[1]	£18 per check-up	NHS charge for Band 1 course of treatment

For the dentist and optician we have taken a conservative approach and used the basic sight-test or Band 1 course of treatment (check-up) fee. For dentists, the NHS Band 2 charge is £49 for fillings, root canal, extraction etc. and the Band 3 charge (for crowns, dentures and bridges) is £214. The fees payable to Optometrists and Ophthalmic Medical Practitioners for an NHS domiciliary visit is £36.82 for the first and second patients seen at one visit and £9.22 for the third and subsequent patients.