Introduction
The aim of this report is to review the evidence from research about shared-life communities for people with a learning disability. It will summarise the results from the small number of academic studies which have attempted to measure the quality of life of people with a learning disability living in such communities.

Shared-life communities in context
Shared-life communities for people with a learning disability in the UK date from the middle of the 20th Century, with most set up by the parents of people with a learning disability. A key motive was to achieve a more fulfilling way of life than that provided by the large mental handicap hospitals which were the dominant type of publicly-funded residential care for people with a learning disability until the 1980s. The shared-life communities that resulted from these initiatives were diverse in organisation and location, but most were in rural settings, and some were organised as ‘villages’ with a cluster of small homes, workplaces, and educational and recreational facilities. This model of settlement was the product of several factors. Many parents were concerned that people with a learning disability were at risk of violence or exploitation in ordinary urban society, and would lead lives that were isolated and unstimulating. The creation of village communities and shared-life networks was also part of the movement to create egalitarian communities, seen elsewhere in the establishment of kibbutzim and communes. This idealism can be seen in the two largest organisations of shared-life communities in the UK (Camphill and L’Arche). These promote an egalitarian pattern of organisation in place of the usual hierarchical separation between staff and clients found in most services for people with a learning disability. In place of salaried support workers, ‘co-workers’ (Camphill) and ‘assistants’ (L’Arche) are motivated by a personal calling to work alongside people with a learning disability, sharing their homes and family life.

Although shared-life communities were set up as alternatives to the residential hospitals, few former patients moved from the hospitals to shared-life communities as part of the
resettlement programmes that began in the 1980s. This is probably because of the circumstances that led to hospital closure. A series of public enquiries into residential hospitals from 1969 onwards revealed systematic abuse, severe neglect and a minimal quality of life for their residents. These inquiries usually concluded that the causes of these problems were inadequate levels of staffing and funding, distant and ineffective leadership, and the social isolation of the institutions producing an inward-looking culture in which abuse was tolerated and kept from public view. Earlier academic research had also described the impoverished lives of patients in large residential hospitals, subject to a routinised way of life and stripped of the capacity or opportunity to express their individuality, even to the extent of not owning their own clothes or personal possessions of any kind.

The discrediting of large residential hospitals occurred at a time when an alternative way of life for disabled people was being developed in Scandinavia. This aimed to provide disabled people with a way of life as similar as possible to that of the rest of the population, facilitated where required by environmental adaptation and specialist public services. The application of this policy of ‘normalisation’ to people with a learning disability favoured conversions of ordinary domestic property to provide small residential care homes staffed by a team of support workers. This became the dominant form of accommodation for people with a learning disability resettled from hospital. There has subsequently been a move towards ‘supported living’ schemes, in which three residents or fewer are tenants or owners of their own houses and are supported by a rota of visiting staff. Some resettlement programmes also included clusters of small units managed by the NHS, often on the site of a former hospital in which land had been sold for private residential development. These NHS clusters tended to specialise in admitting people with a learning disability who have additional health problems, especially mental disorders and behavioural problems. There has been a substantial reduction in recent years in the number of NHS beds, which has led to difficulties in finding appropriate placements for people with mental disorders and/or severe behavioural problems. This has resulted in an increase in long-term hospital care provided by not-for-profit agencies and by private firms.

Research studies of shared-life communities
There have been few recent studies of the quality of life experienced by people with a learning disability living in shared-life communities or which compare the lives of their residents with those of people with a learning disability in other types of accommodation. Most research has instead compared the quality of life of people with a learning disability before and after resettlement from hospitals and similar large institutions. Very few people in this group moved to shared-life communities, and this type of accommodation therefore rarely appears in the subsequent reviews of the research into the outcomes of resettlement. However, one large comparative study which included shared-life communities was completed in the 1990s by a research team led by Professor Eric Emerson at the former Hester Adrian Research Centre (HARC) at the University of
Manchester\textsuperscript{10}. The research aimed to compare outcomes for residents in three categories of accommodation. Using the terminology of the researchers, these were:

1. ‘Village communities’. This sample comprised 86 long-term residents in three shared-life communities in the UK. These involved clusters of homes and were all managed by charitable organisations. The villages in the sample had between 18 and 179 residents on each site and seven or eight residents in each home. The minimum figure of 18 residents/site shows that this category included some rather small ‘villages’.

2. ‘Residential campuses’. This term was used by the researchers to denote redeveloped NHS hospital sites in which the main buildings had been replaced by smaller housing units, usually accommodating substantially fewer residents than in the original hospital. The sample comprised 133 long-term residents living in five sites, with between 14 and 20 residents/site, and 7-10 residents/home. Although ‘residential campuses’ resembled some ‘village communities’ in grouping a number of homes on a single site, they differed in organisation and management. ‘Residential campuses’ were managed by the NHS, usually staffed by employees transferred from the hospital they replaced. To prevent confusion, this report will use the term ‘NHS residential campuses’.

3. ‘Dispersed housing schemes’. This sample included 281 long-term residents in ten schemes managed either by independent agencies or the NHS. There was a maximum of eight residents/home. For some analyses, the researchers further divided dispersed housing schemes into two categories: small staffed houses (termed ‘group homes’ in the study); and supported living schemes with a maximum of three residents/home.

The samples in each category were not chosen at random, but were instead selected from units considered examples of best practice. This probably had the effect of reducing the range of outcomes in each sample compared with the actual diversity in each category of accommodation in society as a whole.

The HARC study collected a wide range of data, using a set of questionnaires and interview schedules which had been developed from those used in earlier studies of residential and hospital care for people with a learning disability. Data collected included:

1. The social and physical environment. Researchers completed a series of observational measures of the physical environment of each residence, and interviewed managers about institutional practices and individualised care planning.
2. **Residents’ characteristics.** Researchers used postal questionnaires and interviews with keyworkers to collect data on the personal characteristics of each resident in the samples, their adaptive behaviour, social network and community involvement, health, choices in daily life, services received, and behavioural and psychiatric disorders.

3. **Residents’ views.** These were gathered using semi-structured interviews carried out by the researchers, and based on those used in earlier HARC studies.

4. **The views of closest relatives of residents.** This information was collected by postal questionnaire.

5. **Estimated costs.** This attempted to estimate the capital and revenue costs of each type of accommodation for each resident, including costs of other health and social services received.

The results from these questionnaires showed that the three samples of residents in the HARC study had similar characteristics, except that:

- Almost none (2%) of the residents in village communities had been resettled from hospital, compared with three-quarters (75%) of those in NHS residential campuses and half (50%) of those in dispersed housing.

- A third (34%) of residents in village communities had Downs Syndrome, compared with 5% in NHS residential campuses and 12% in dispersed housing.

- The sample of residents in NHS residential campuses was the most disabled, while that in village communities was the least disabled. For instance, 10% of residents in the latter were frequently incontinent, compared with 20% in dispersed housing, and 29% in residential campuses.

- Challenging behaviour was most common among the sample living in NHS residential campuses, but there was little variation between the three samples in the prevalence of mental illness or autism.

The main results of the study in terms of quality of life were:

1. **Physical environment.** The most homely accommodation was found in the village communities and in dispersed housing.

2. **Staffing.** There were wide variations between the samples in the numbers and qualifications of the staff. Village communities had lower staffing levels than the other samples, and only 49% of staff had qualifications (mainly NVQ or City and
Guilds). In NHS residential campuses, 95% of the staff had nursing qualifications, while in dispersed housing 80% were qualified (mainly nursing and NVQ/City and Guilds).

3. **Care practices.** Village communities were the most likely of the three categories of accommodation to involve residents in case planning, and to have defined procedures for planning and implementing support for residents. Their plans placed particular emphasis on acquiring educational and vocational skills. NHS residential campuses were least likely to involve residents in case planning or have effective procedures for planning care. Results from interviews using the Group Home Management Interview (designed to measure the extent to which units approximated the characteristics of a total institution) found that NHS residential campuses were the most institutional, with village communities and dispersed housing the least.

4. **Professional contacts.** Residents in village communities were those most likely to have regular health checks and sight and hearing checks, although residents in NHS residential campuses were more likely than others to be on regular anti-psychotic medication (even after controlling for varying levels of challenging behaviour between the different categories of unit). Residents in village communities were more likely to see a social worker and therapy services, while those in NHS residential campuses were more likely to see a psychiatrist and psychologist.

5. **Costs.** There were very wide variations in the total weekly costs of accommodation and associated care between and within each category. The range between maximum and minimum cost/resident/week (using prices at the time of the survey) were: £339-886 in village communities; £600-1285 in NHS residential campuses; and £455-1247 in dispersed housing. Needless to say, the equivalent costs at today’s prices would be higher. The cost/resident in village communities were higher for the less able residents, but no relationship between cost and severity of disability was found in the other two categories of accommodation. The researchers also compared the costs of care for groups of residents matched according to scores on the questionnaires measuring ‘challenging behaviour’ and mental disorders, and for degree of learning disability. For these samples, village communities were cheapest, and dispersed housing the most expensive.

6. **Quality of life.** This was measured by a series of indicators, the results of which are summarised in the table below. This shows the category or categories of accommodation which scored best under each heading.
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<thead>
<tr>
<th>Indicator</th>
<th>Best-performing group(s)</th>
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<tr>
<td>Individual choice</td>
<td>Village communities and dispersed housing</td>
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<tr>
<td>Family contact</td>
<td>Village communities</td>
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<td>Social networks</td>
<td>Village communities (contacts with staff and other people with learning disability)</td>
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<td></td>
<td>Dispersed housing (contacts with non-disabled people)</td>
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<tr>
<td>Physical activity</td>
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<td>Reduced risk of accidents and</td>
<td>Village communities</td>
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<td>assault</td>
<td>Dispersed housing (employment)</td>
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<td>Village communities (hours of scheduled activities)</td>
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<td>Dispersed housing (leisure activities)</td>
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<td></td>
<td>NHS residential campuses (day centres)</td>
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<td>Satisfaction of resident</td>
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The authors of the HARC study noted that dispersed housing and village communities offered a better quality of care and quality of life than NHS residential campuses. Dispersed housing and village communities, however, offered distinctive patterns of benefits, with dispersed housing providing more leisure activities and contacts with non-disabled people, while village communities provided more contact with families, more hours of activities, and greater personal safety. Professor Emerson and his colleagues concluded that:

“... given that dispersed housing schemes and village communities appear to be associated with different patterns of benefit, people with intellectual disabilities should be free to choose between these two options.”

One subsequent study has compared shared-life communities with other types of accommodation for people with a learning disability. This was completed in the Republic of Ireland by Fahey and her colleagues, and compared 29 residents in two Camphill communities with data from an earlier study by the same authors of 65 residents in community-based group homes and 60 in campus-type accommodation (also in the Republic of Ireland). The two Camphill communities included one of four houses located at a single site in a rural setting, and one comprising three adjacent houses in a small town with a fourth house on a farm two miles away. The research used similar methods to the HARC research, and found that residents in the Camphill communities had higher mean scores than residents in the other types of accommodation on the
questionnaires measuring adaptive behaviour, but had higher rates of challenging behaviour and mental health problems than residents in group homes. Camphill residents lived in smaller, more homely settings than the other residents, and were less likely than residents in campus settings to experience the rigid routines and block treatment characteristic of institutional life. Camphill residents were also less likely than residents in the other two categories of accommodation to experience ‘social distance’: a term designating the extent to which they live separate lives from the non-disabled people they live with (co-workers in Camphill and support staff in group homes and campuses). The research team also measured the extent of ‘reciprocity’ in relationships between residents and co-workers in the Camphill communities, and found that 71% of interactions involved exchanges of help and information, rather than the simple transmission of information from staff to residents.

These two research studies show that people with a learning disability who live in shared-life communities have as good a quality of life as those in dispersed housing. In some respects (involvement of residents in case-planning, contacts with health and social care professionals, personal safety and social distance), shared-life communities perform better than dispersed housing. Shared-life communities also provide a better quality of life on almost all measures than the NHS-managed residential campuses, even though both characteristically comprise clusters of small houses dispersed across a shared landscape. This indicates that the size of a residence and its location is less important in determining quality of life than the pattern of social relationships within each residence.

A study of the social relationships in a shared-life community was completed by Randell and Cumella. They studied Botton Village, which is part of the Camphill Movement. At the time of the research, the Village had 300 community members (members with learning disabilities and co-workers) in over 30 households. Each household comprised an extended family of co-workers (often a family with children) and members with disabilities. Household tasks and meals were shared, and co-workers provided support as required. The researchers used a combination of participant observation and qualitative interviews with a sample of 15 residents. The interviewees had lived a median of 25 years in the Village, and all but one had lived in more than one household.

With the exception of one elderly resident who had retired, interviewees were all engaged in work (usually in three or four different workplaces each week). They appreciated the diverse range of employment and leisure opportunities, and regarded their work as a means of sustaining the daily life and economy of the village. Interviewees reported widespread participation in leisure activities, which included a range of activities which they were able to plan and organise themselves. They particularly valued their wide network of friendships with other residents, which in many cases were intense and mutually-supportive. Interviewees also expressed a strong sense of inclusion within a community, determined mainly by taking part in shared activities in a variety of roles,
their involvement in the management of the Village, and the events organised around the non-denominational church.

This study shows how shared-life communities facilitate a high quality of life for their residents with a learning disability:

1. **High levels of meaningful employment.** The lack of formal employment contracts in shared-life communities obviates the barriers to formal employment encountered by many people with a learning disability.\(^{14}\) As a result, residents are able to work full time in a range of unskilled and skilled work essential to the daily life and economy of the community, while also exercising choice over where they are able to work.

2. **Opportunities for friendship.** People with a learning disability typically make friends with other people with a learning disability\(^{15}\), although they often encounter obstacles in sustaining friendships when living in dispersed housing schemes because of the cost of transport and problems with communication\(^{16}\). By contrast, a shared-life communities provide a larger clustering of potential friends with the opportunity to meet in workplace and informal settings, while ease of communication enables friendships to be sustained.

3. **Long-term relationships.** Living in extended families in a long-term social relationship with co-workers/assistants enables both groups to become familiar with each others’ pattern of communication: an essential step if a person with a learning disability is to learn of the world and express choices about what they want to do in it.\(^{17}\) It also helps generate a sense of community in which they feel part of a readily available, supportive and dependable social structure.\(^{18}\).

**Implications**

The research summarised in this report has implications for the future of shared-life communities, and also raise questions about the future direction of public policy for people with a learning disability. A key finding is that shared-life communities can provide as good a quality of life as dispersed communities, but in some cases at lower cost. As noted by Professor Emerson and his colleagues, shared-life communities and dispersed housing schemes each have a distinctive profile of benefits, thereby providing an element of choice for people with a learning disability and their families.

A further implication of the research is that the quality of life experienced by people with a learning disability is a product of the ethos and day-to-day organisation of a residential setting rather than its size or location\(^{19}\). Shared-life communities usually have strong religious and ethical foundations that have resulted in the recruitment of committed volunteers with a personal commitment to sharing their lives with disabled people. This
results in a greater sense of community and more egalitarian social relationships than are typically found in residential care, in which residents are subordinated to care staff who are employed and remunerated to carry out officially-specified duties during designated hours of work\textsuperscript{20}. Reductions in public finance and the power of government agencies as monopoly purchasers have the effect of reducing expenditure/client\textsuperscript{21}. Provider organisations respond by employing many of their staff (particularly those in day-to-day contact with their clients) on remuneration close to the minimum wage. This in turn makes it difficult to recruit or retain staff suitable for this type of work\textsuperscript{22}, but may also generate among staff an alienation characteristic of industrial process work. However, there has been to date very little research that has looked at how care staff in traditional residential services themselves interpret the demands of their day-to-day work\textsuperscript{23}.

The choice of residence is defined as a right of disabled people under the United Nations Convention on the Rights of Disabled People\textsuperscript{24}. Nevertheless, the choice of how and where to live has usually been denied to people with a learning disability. Instead, public policy has usually specified what pattern of life people with a learning disability ought to lead\textsuperscript{25}, and research has often discounted their expressed preferences\textsuperscript{26}. There has therefore been a policy in some local authorities of funding only supported housing schemes (in some cases only single person flats), irrespective of the wishes of the person with a learning disability and their family\textsuperscript{27}. This policy aims to promote an ‘ordinary life’, but fails to take account of the great diversity of ordinary life among the general population. An increasing number of unattached adults now choose to share houses, particularly in areas of high property values. Elsewhere, groups of elderly people prefer to live in ‘retirement communities’. There has been very little research on the housing preferences of people with a learning disability, but one recent study of older people with a learning disability found they preferred models of housing that provide an opportunity for people with a learning disability “to live in close proximity to their peers and in large groups in the community rather than in small, dispersed community housing”\textsuperscript{28}. It is probable, however, that people with a learning disability, just like the general population, do not all wish to live in the same way. Public agencies should therefore ensure that a diverse range of residential provision is available, and take account of this objective when they assess, commission, fund and regulate residential support for people with a learning disability.

Notes
1. This paper uses the term ‘shared-life community’ in place of ‘intentional community’, which has been used more frequently in the past. ‘Shared-life community’ is preferred because it highlights the distinctive feature of communities like Camphill and L’Arche, which is the systematic sharing of tasks and responsibilities between disabled and non-disabled members.


8. The number of inpatients in non-NHS beds for people with a learning disability has risen from 930 in 2006 to 1072 in 2010.


Schemes. All published by the Hester Adrian Research Centre, University of Manchester. Following the usual practice with a project of this size, summaries of different aspects of the research were subsequently published in several academic journals. However, this may give a misleading impression that many different studies were carried out rather than one.


18. A review of research on community integration, Cummins & Lau concluded that people with a learning disability need a ‘sense of community’ They propose that this is unlikely to be derived from encounters in the work, commercial or recreational environments used by the general community, but within families and among groups of other people with a learning disability. See Cummins R and Lau

19. A recent study of the quality of life of people with severe learning disability living in small units and in supported housing has found that activity levels were in some cases similar to those in larger units and even in the old mental handicap hospitals. Activity levels were unrelated to numbers of staff. The sample was selected from units judged ‘good’ by the managing agency. See: Beadle-Brown J, Leigh J, Whelton B, Richardson L, Beecham J, Baumker T and Bradshaw J (2015) Quality of life and quality of support for people with severe intellectual disability and complex needs. *Journal of Applied Research in Intellectual Disabilities*, early view.


24. Article 19 specifies that “a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement; b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community; c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.”


26. One example is in the measurement of ‘satisfaction’ among people with a learning disability and their families before and after resettlement. It has been found that levels of ‘satisfaction’ often remain constant, and this has been used to argue that placement should proceed despite opposition from people with a learning disability and their families. But ‘satisfaction’ probably resembles ‘self-rated quality of life’, in that it measures people’s overall sense of wellbeing rather than a specific preference between different living arrangements.
