

Evaluating quality of life in adults with profound learning difficulties resettled from hospital to supported living in the community

Journal of Intellectual Disabilities
16(4) 247–263
© The Author(s) 2012
Reprints and permission:
sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/1744629512463840
jid.sagepub.com



David Sines

Buckinghamshire New University, UK

Elaine Hogard

Lakehead University, Canada

Roger Ellis

University of Ulster, UK, University of Chester, UK, and Buckinghamshire New University, UK

Abstract

This article describes a longitudinal evaluation of the quality of life of service users with profound learning difficulties who were resettled from hospital accommodation to supported housing in the community. The Trident approach was used for the design of the evaluation with data gathered regarding outcomes, process and stakeholder perspectives. Using a specially designed tool, quality of life was measured in seven domains for 39 service users in the hospital as a base line and at six months, twelve months and eighteen months in supported housing. A statistically significant improvement in quality of life overall and in each of the seven domains was found. Questionnaire surveys of parents/next of kin and support staff confirmed these findings as did a number of qualitative case studies.

Keywords

evaluation, learning disability, quality of life, resettlement, supported housing

Date accepted: 10/9/2012.

Corresponding author:

David Sines, Buckinghamshire New University, 106 Oxford Road, Uxbridge UB8 1NA, UK.

Email: david.sines@bucks.ac.uk

Introduction

This article evaluates the quality of life (QoL) changes experienced by 39 adults with profound learning difficulties who were resettled from Orchard Hill Hospital to supported living in the community and reports the results. A longitudinal, repeated audit measure was applied on four occasions over 18 months using a specially developed instrument together with qualitative vignettes of individual lives and surveys of stakeholder views.

Brief reviews on the international movement towards deinstitutionalization for those with severe learning disability and the evidence regarding its effects are provided. The concept of QoL and its measurement is briefly reviewed in its application to those with learning disability. The evaluation is then described with regard to design and methods, the instrument used, results, discussion and conclusions.

International policy and practice in deinstitutionalization

Deinstitutionalization, that is the replacement of institutions by services in the community, has been described as probably the most important change in the policy and pattern of service provision for learning disability in the last 50 years (Mansell, 1996). From early initiatives in the UK (Tizard, 1960) and Sweden (Grunewald, 1997), the policy has been pursued, notably in North America, Scandinavia, Britain and Australia. Mansell (2006) describes the process as beginning typically with the replacement of hospital institutions with relatively large residential homes. These larger models are then superseded by group homes in which seven or eight people needing high levels of support live together with the help of a resident staff. Beadle-Brown et al. (2007) report the process of closing hospital-based provision as nearly complete in England, Scandinavia, the United States, Australia and Ireland, just beginning in many countries in eastern Europe, and, with a vague hope, further afield in, for example, Taiwan.

Orchard hill resettlement

The resettlement of service users from Orchard Hill Hospital to supported living in the community was a difficult and protracted process. This reflected conflict between the strongly held views regarding the best support for the service users, the consequences of a national scandal regarding abusive practices and the transfer of responsibility for commissioning from health care to social services.

A decision to close Orchard Hill was taken by the Health Authority in 1999. A significant cause of delay was the challenges brought by parents and relatives of three patients, who were supported by the specialists in the Hospital. Ultimately, the challenges were unsuccessful, and agreement was reached to close the hospital.

In 2007, the Health Care Commission inspection into the Sutton and Merton Primary Care Trust's (PCT) Learning Disability Services identified the institutional abuse arising out of the models of care in operation and recommended that the people be moved to new community placements, based on assessed need, as soon as possible but no later than 2009.

The number of long-term service users at Orchard Hill had reduced from 189 in 1990/1991 to 89 by January 2007. This fall in numbers had been brought about mainly by people being resettled into community settings, and partly by the death of few people. The remaining service users at Orchard Hill were generally young, between 30 and 50 years old, and most of them had complex social care and health needs, whilst older and more able people have been relocated previously.

The rate of resettlements into the community settings accelerated, and there were 80 people remaining by the end of April 2007. During 2007–2008, 79 of the 99 patients were transferred to other accommodation.

In August 2008, a communiqué announced that the Orchard Hill, the last long-stay hospital in England for people with learning disabilities, was due to close at the end of April 2009, which was 5 years after the original government deadline for all long-stay hospitals to close.

Advantages and disadvantages of resettlement

In a review of published studies on the effects of deinstitutionalization, Watts et al. (2006) found both advantages and risks for service users following a move out of the hospital and their review confirmed the seminal work of Emerson and Hatton (1994) in which mixed effects were also found. In the most recently published review, Chowdhury and Benson (2011) found that relocation had a generally positive impact on the QoFL of service users. However, many of the studies identified that improvements were most prominent shortly after the move and plateaued after a year. In addition, service users continued to have low levels of community integration, and there was some evidence that health care might not be adequately met in the community. A limited use of standardized measures and also a lack in subjective assessments of QoFL were found. More detailed studies of factors that are critical in affecting QoFL were advocated.

QoFL and its measurement

QoFL is not a simple construct. It covers relatively objective external factors, such as the physical environment, and also less tangible features, such as satisfaction with that environment, and even more complex feelings, such as autonomy and choice. Given this complexity, measurement also poses problems, and these are exacerbated when those whose QoFL is being studied have learning disabilities. Usually, a key indicator in QoFL measures is the views of those concerned. If these views are not accessible, a proxy view has to be created through close observation of behaviour and circumstances.

The concept of QoFL and the means to measure it have been the focus of much recent research (Cummins, 1996; Skea, 2008). Skea (2008) identifies three areas of concern in the measurement of QoFL in service users with learning disability. These include conceptual issues regarding the nature of QoFL, methodological problems in equating subjective and objective measures as well as challenges in linking research with service utility. Hatton (1998) offers a radical critique of QoFL as a concept and basis for assessment and concludes that the subjective measurements should be abandoned as posing insuperable methodological problems and that ‘the quality of life approach, which claims to liberate people from a medical model, may paradoxically serve to extend the license of services to exert control over all facets of a person’s life’.

Verdugo et al. (2005) suggested that ideally the measurement of QoFL should be characterized by:

1. recognition of its multidimensional nature, involving core domains and indicators;
2. the use of both subjective and objective measures;
3. the use of multivariate research designs to evaluate the ways in which both the personal characteristics and the environmental factors relate to the assessed QoFL of the person;
4. a systems perspective that captures environmental influences at a micro-, meso- and macro-level and
5. the involvement, if possible, of those with learning disabilities in the design and implementation of QoFL assessment, research and evaluation.

In compiling and structuring instruments, there is a good agreement within the literature that the measurement of QoFL should be based on both domains and indicators (Felce, 2007; Verdugo et al., 2005). Domains are the areas considered significant in QoFL and indicators are the observable features within these domains that can be measured. Thus, domains are the subdivisions of the overall notion of QoFL and each domain provides a focus on a particular aspect of personal well-being. Taken together, the agreed domains signify the range over which the QoFL construct extends.

The 11 most common domains used within the QoFL assessments are summarised by Verdugo et al. (2005) as follows:

- Physical well-being,
- material well-being,
- interpersonal relations and social inclusion,
- personal development,
- self-determination,
- emotional well-being,
- rights,
- environment,
- family relationships,
- recreation and leisure activities and
- safety/security.

Felce (2007) in an elision of Verdugo suggested six domains, which are:

- Physical well-being,
- material well-being,
- social well-being: interpersonal relationships and community involvement,
- productive well-being: personal development, choice and occupation,
- emotional well-being and
- civic well-being.

Cummins (1997) covered similar but not identical ground with six domains, such as:

- safety/health,
- material well-being,
- intimacy: close relationships with family and friends,
- place in society: activities with people outside the home,
- productivity: achievement in life and
- emotional well-being.

He renames physical well-being as safety/health, focuses social well-being as intimacy on one hand and place in society on the other and, presumably, subsumes civic well-being in place in society.

Schallock et al. (2004) again covered similar ground but with some additional suggestions:

- physical well-being,
- material well-being,

- interpersonal relationships,
- social inclusion,
- personal development,
- self-determination,
- emotional well-being and
- rights.

His significant additions include notions of rights and self-determination, whilst personal development replaces productivity and achievement.

Indicators are the measurable elements within a domain that are taken as evidence that the person's well-being reaches an appropriate standard.

Verdugo et al. (2005) emphasizes the pervasive distinction between subjective and objective measures. In principle, objective indicators are accessible to public observation, whereas subjective indicators are accessible only to the concerned individuals or have to be inferred publicly from more objective measures. Objective measures have involved the use of audit tools, questionnaires and interviews alongside other approaches, such as ethnographic studies, direct behavioural observation, discrepancy analysis and multidimensional scales (Keith, 2001).

Nine tools were reviewed in detail and included, which are as follows:

- Evaluation of Quality of Life Instrument (Nota et al., 2006),
- The Life Experiences Checklist (Ager, 1998),
- Lifestyle Satisfaction Survey (Krapu et al., 2006),
- Index of Participation in Domestic Life (Stancliffe et al., 2010),
- Life Satisfaction Index (White, 2007),
- The Comprehensive Quality of Life Scale – Intellectual/Cognitive Disability (Cummins, 1997),
- Quality of Life Questionnaire (Schalock and Keith, 1993),
- The Mood, Interest and Pleasure Questionnaire (Ross and Oliver, 2003) and
- Measure of Independence and Choice (Grierson, 2006).

From these, four tools were selected, including items that were clearly relevant to the chosen domains, and had demonstrated validity and reliability. Each contained objective measures.

The first was *The Comprehensive Quality of Life Scale – Intellectual/Cognitive Disability* of Cummins (1997). Items are scored by subjective and objective means. Subjective questions are asked to service users or their proxy respondents. Objective scoring looks at publicly identifiable indicators of the item. No correlation was found between the subjective and the objective measures in this tool, and when available, the proxy measures were not found to correlate with service user responses. However, a correlation of objective data gathered across all the measures was found. Such results led the researchers to conclude that the objective responses may be 'the only feasible way forward' when service user views are not obtainable or if there are questions surrounding the use of proxies (Perry, 2002).

The second tool was the *Quality of Life Questionnaire* of Schalock and Keith (1993). This questionnaire includes 40 criterion-referenced items and focuses on four QoL domains: satisfaction, competence/productivity, empowerment/independence and social belonging/community integration. The scale has been well evaluated by researchers (Plimley, 2007).

The third tool was *The Mood, Interest and Pleasure Questionnaire* of Ross and Oliver (2003). This is based on an informed observer questionnaire and purports to measure levels of mood, interest and pleasure, by asking informants to rate operationally defined observable behaviours. It aims to access the important but relatively hidden personal experience and feelings of the population.

The fourth tool was the objective measure developed by Grierson in his unpublished MSc dissertation (Grierson, 2006) to assess choice and independence in service users with learning disabilities.

Design and methods

The design of the evaluation was structured using the trident programme evaluation method (Ellis and Hogard, 2006) that focuses evaluation questions and data gathering on outcomes, process and stakeholder perspectives.

The principal intended outcome for the resettlement was to achieve an improvement in the QoFL of the service users. The evaluation used a design of repeated measure (Frison and Pocock, 1992), where the same measure is used with the same subjects at different points of time. This design, with data collected in a longitudinal time frame, allows the assessment of change over a period of time. It also allows two different conditions for the subjects to be compared. In this study, a comparison was made between the results when the subjects were in Orchard Hill Hospital and when they were in supported housing in the community. The measure was used on three occasions after resettlement, that is, at 6, 12 and 18 months.

Another indication of quality of life outcomes was provided in the stories or vignettes that the care staff was encouraged to produce, regarding individual service users.

Third, the views of care staff and parents/next of kin regarding the QoFL of the service users were solicited using questionnaires based on the domains of the audit tool.

The audit instrument was developed in accord with the following four main design principles:

- It should reflect, through its domains, the priorities for social care in *Our Health, Our Care, Our Say* (Department of Health, 2006).
- It should be valid and reliable, and to achieve this, use, where ever possible, the items from established measures in relationship to its domains.
- It should be based on objective rather than subjective indicators.
- It should be practicable and feasible for administration by care staff with a close knowledge of the service users and verification by social needs staff, managers, advocates and relatives.

The instrument was developed with the support of a steering group consisting of senior social services staff, nominated experts, advocates, parents and next of kin of service users as well as the evaluators. Given the severe learning disabilities of the service users, it was not practicable to have a service user member, but the advocates on the group maintained a robust and committed position on behalf of the service users.

The instrument was piloted with a group of support staff in a different facility, and this led to the minor modification of certain items to improve intelligibility and reliability.

The validity of the instrument was addressed in several ways. First, a number of items were derived from instruments whose validity and reliability had already been demonstrated.

Second, the instrument had high-face validity as judged by the members of steering group and care staff. Third, the instrument had good construct validity in that it reflected the priorities of DHSS guidelines. Fourth, the concurrent validity of the instrument was demonstrated by the correlation of its results with qualitative vignettes and surveys of the views of care staff and relatives.

Seven domains were chosen for the instrument reflecting the literature and DHSS guidelines, including 'valuing people now'; and 'our health, our care, our say'.

- Domain 1: quality and location of housing;
- Domain 2: care planning and governance;
- Domain 3: physical well-being;
- Domain 4: social interaction and leisure activities;
- Domain 5: autonomy and choice;
- Domain 6: relationships;
- Domain 7: psychological well-being.

In deciding the indicators and the questions for these domains, items were drawn, particularly, from The Comprehensive Quality of Life Scale – Intellectual/Cognitive Disability (Cummins, 1997), The Mood, Interest and Pleasure Questionnaire (Ross and Oliver, 2003) and the work of Grierson (1996) on choice and autonomy. In addition, the questionnaire benefited from the comments and suggestions of members of the evaluation steering group.

Wherever possible, questions were constructed with a scale of possible responses with one to be ticked by the respondent. Scoring was then based on 5 for the *most favourable* and 1 for the *least favourable* condition in the choices. The final version of the scale included 50 questions with, wherever possible, quantified alternatives to be ticked.

Given that the audit tool could not be completed by the individual service users, consideration was given to various alternatives, including completion by a carer, an advocate, a parent or a next of kin. It was decided that a primary carer would be in the best position to answer the questions in the tool, provided they were in regular sustained contact with the individual. The issue then became ensuring the validity and reliability of the responses of the carer. It was decided that each completed audit would be checked by both the manager of the carer and by an independent social services needs assessor. Opportunities were also provided for an advocate and relative to sign off the audit, if they wished.

Training was provided in the completion of the tool for two senior carers who were then responsible for training the primary carers. The tool was piloted through two audits: first of 10 residents in a comparable provision and then of 29 residents in the Orchard Hill programme. The results of these pilots were discussed at the Steering Group to produce the final version which is copyrighted as the Quality of Life Questionnaire V.3 for Assessing Quality of Life in Individuals with Learning Disabilities (Ellis et al., 2008).

The audit of the QoL of 39 residents was undertaken on four occasions:

- whilst resident at Orchard Hill,
- 6 months after resettlement,
- 12 months after resettlement and
- 18 months after resettlement.

The initial audit was undertaken in November 2008 and provided a baseline against which the subsequent audits could be compared. Whilst recognizing that this retrospective method is open to

criticism, we are satisfied by its validity and reliability through the triangulation of the judgments involved. Steps were taken to ensure that the audits were completed from January 2006 by carers who were familiar with the residents and their circumstances in Orchard Hill. All of the audits, including the retrospective audit, were carried out by front line staff with the support from their service managers; advocates and carers were involved wherever possible. The retrospective audits were further quality assured by senior staff who had worked at Orchard Hill since 2005.

Subsequently, the audit tool was modified in the light of experience and review by the steering group, and the final version of the tool was used for the retrospective audit and the subsequent audits. The 6-, 12- and 18-month audits were dated from the baseline of November 2008 and were thus completed for May 2009, November 2009 and May 2010, respectively.

The responsibility for the completion of the audits rested with the new care home providers, all of whom were subject to overview by the Head of Provision for Learning Disabilities and Mental Health Services. Problems were not reported in the completion of the audits and on the few occasions when there were missing sheets this was quickly rectified.

In addition to the quantitative data gathered using the instrument, qualitative data were gathered through inviting care staff to produce vignettes of success stories in the lives of service users. Respondents were encouraged to describe the behaviours, which they believed to represent the improvement in the QoL of service users following their resettlement.

The process of resettlement was explored through interviews with senior staff in the responsible social services department. The process followed was described by Hogard (2007). The interviews began by asking for a chronological account of the resettlement process. Respondents were then asked to identify particular successes and, if any, failures in the process. They were then asked to identify lessons learned. A process description was subsequently produced to identify key features. This description was then verified by the respondents and is included below.

Stakeholder perspectives were sampled using two questionnaires designed to replicate the seven domains of the audit tool and to invite direct comparisons of life for the service users in Orchard Hill and supported accommodation. Similar questionnaires were devised for support staff and parents/next of kin. They covered the seven domains of the audit tool and asked whether they believed that the life of the service users had improved, deteriorated or remained much the same following resettlement.

The service users

All the 39 service users who were resettled from Orchard Hill Hospital to supported housing (34) or residential accommodation (5) had profound learning disabilities and many had additional disabilities, including autism, Down's syndrome, epilepsy and various physical disabilities, including sensory impairment. The genders were almost equal with 20 females and 19 males. The average age was 51 years with a range from 41 to 68 years and a SD of 5.68. Of the 39 service users, the majority (31) was described as having no spoken language with seven having severely limited language and one very limited language. Most had lived in Orchard Hill Hospital since early childhood until middle age.

Results

In this section, the results of the four audits completed for these service users are presented together with a brief summary of the 'good news' vignettes and the surveys of care staff and parents/relatives. A summary description of the process of resettlement is given.

Table 1. Summary of the results at four audit points

Name	Quality and location of housing	Care planning and governance	Physical well-being	Social interaction and leisure act	Autonomy and choice	Relationships	Psychological well-being	Quality of life
Retrospect to January 2006								
Maximum	30	45	35	74	65	30	25	304
Mean	17.33	0.08	17.28	21.92	24.26	8.28	17.26	106.28
SD	5.21	0.48	3.62	8.26	11.24	6.26	2.55	25.02
Percentage	58	2	57	30	37	28	69	35
6 months								
Mean	25.58	39.08	19.15	32.18	53.87	12.74	19.87	192.26
SD	1.94	12.06	5.36	13.53	6.52	6.56	3.47	40.96
Percentage	85	76	55	43	83	42	79	63
12 months								
Mean	24.58	39.92	20.33	28.51	54.28	10.92	20.31	192.95
SD	3.53	4.62	4.10	12.72	6.21	6.17	2.69	27.46
Percentage	82	78	58	39	84	36	81.24	63
18 months								
Mean	28.11	36.26	20.6	32.59	56.62	13.62	20.03	206.95
SD	2.53	5.28	3.54	10.31	6.74	6.78	2.42	24.24
Percentage	93.7	80.6	58.9	44	87	45.4	81.2	68

QofL audit

For each of the four audits, Table 1 shows the overall results for the group of 39 residents and the results for each of the seven domains that made up the QofL tool. Overall and for each domain, an average (mean) score is shown together with the maximum possible score. The achieved score is also shown as a percentage of the maximum possible score. The SD of each score is shown, this being an indicator of the spread or dispersion of scores.

Comparisons were made and tested for statistical significance for an overall QofL score for all the 39 residents at the retrospective baseline and at 18 months. Comparisons were also made for each of the seven domains. A *t* test was used to test for significant difference between baseline and 18-month audits, and a significant difference was found for overall QofL and for each of the domains. A *t* test calculates the probability of the difference in scores occurring by chance as opposed to indicating a significant difference. The differences from the overall QofL comparison and the comparisons for the seven domains were all significant at <0.0001 level. The two-tailed *p* value in each case was <0.0001. By conventional criteria, this difference is considered to be highly statistically significant with only a 1 in 10,000 chance that it occurred by chance.

A comparison was also made with the five service users who were resettled in a care home and with the 34 who were resettled into supported living accommodation. No significant difference was found.

The purpose of the audit tool was to detect differences between QofL at Orchard Hill and in supported accommodation in the community. The simplest indicator of QofL for individuals and hence the group is the overall QofL score out of a possible 304. This score is arrived at by summing the scores in the seven domains for each completed audit. Figure 1 shows an average (mean) calculated from all the 39 completed audits. The SD for the scores is shown and this gives an indication of the spread of scores between the 39 individuals. Finally, the mean is computed as a percentage of the maximum score possible in each domain and overall.

The most significant single finding is that this average QofL score was 106.28 for residents when at Orchard Hill rising to 192.26 after 6 months in supported accommodation, a level which is maintained for 12 months (192.95) and which then rises to 206.95 after 18 months. This represents an improvement, in percentage of possible score, from 35% to 68%. This is shown in Figure 1 as the percentage of possible maximum at each audit. On the basis of these results, it is clear that the overall QofL for the 39 residents improves after their resettlement into supported accommodation. As stated above, there was no significant difference in the QofL scores for the five service users in a care home and the 34 in supported living.

It should also be noted that all the seven domains show improvement, although some significantly show more improvement than the others. Table 2 shows, in rank order, the improvement in percentage terms (achieved score out of possible score) for each domain.

Care planning and governance showed the most dramatic improvement reaching a high percentage from a very low base line. This reflects the fact that the standards now set by the social services for care planning, which were not in place and being met at Orchard Hill, are now established and being followed (Figure 2).

Autonomy and choice showed the next largest improvement, which is exactly what might have been hoped for when residents moved from the relatively controlled environment of hospital to the more autonomous and personalized environment of the supported housing. At a descriptive and qualitative level, there are dramatic differences between the restrictive regime at Orchard Hill described in the commission report and the more independent and individual life for the service

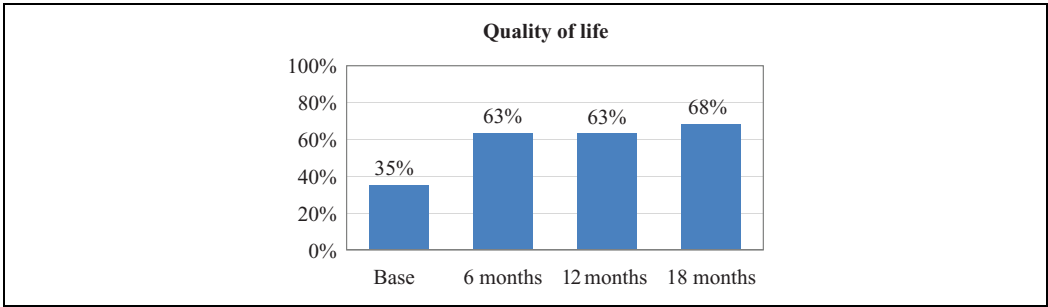


Figure 1. Overall quality of life score shown as a percentage of maximum possible.

Table 2. Percentage of improvement for seven domains in rank order

Domain	Baseline (%)	18 months (%)	Improvement (%)
Care planning and governance	2	80.6	78
Autonomy and choice	37	87	50
Quality and location of housing	58	93.7	35.7
Relationships	28	45.4	17.4
Social interaction and leisure	30	44	14
Psychological well-being	69	81.2	12.2
Physical well-being	57	58.9	1.9

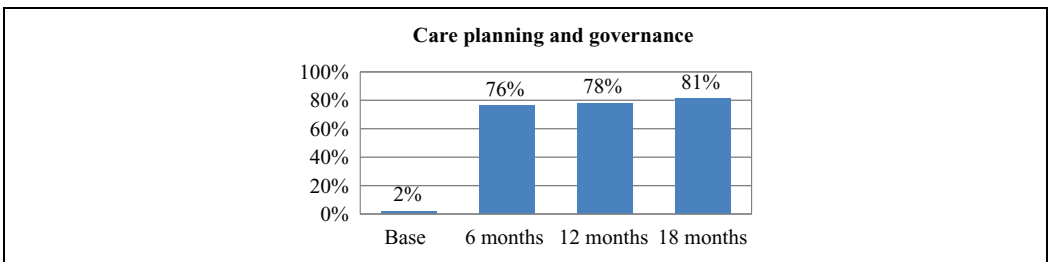


Figure 2. Percentage of possible maximum for care planning and governance.

users in the supported housing. This is reflected in the range of choice detected by the audit tool (Figure 3).

As would have been expected, the *quality and location of housing* also improves significantly in the new purpose built housing (Figure 4).

The two key social domains, *relationships and social interaction and leisure*, show improvement, but are still at a relatively low percentage (<50%) of what might be achieved. These are both areas that would benefit from further attention to maximize the potential advantages of living in the community. A risk identified in the literature is that sheltered housing might actually restrict social interaction compared with the range of interactions available in an institutionalized setting with the number of service users and care staff (Figures 5 and 6).

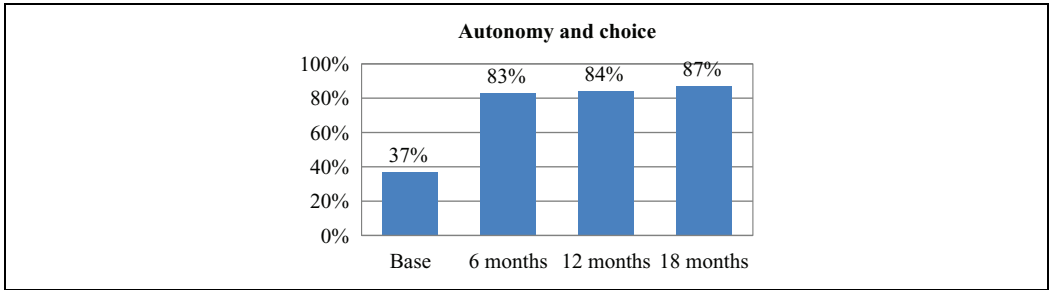


Figure 3. Percentage of possible maximum for autonomy and choice.

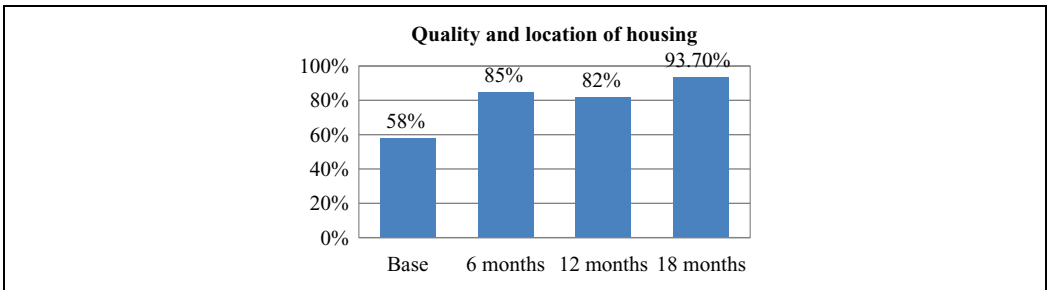


Figure 4. Percentage of possible maximum for quality and location of housing.

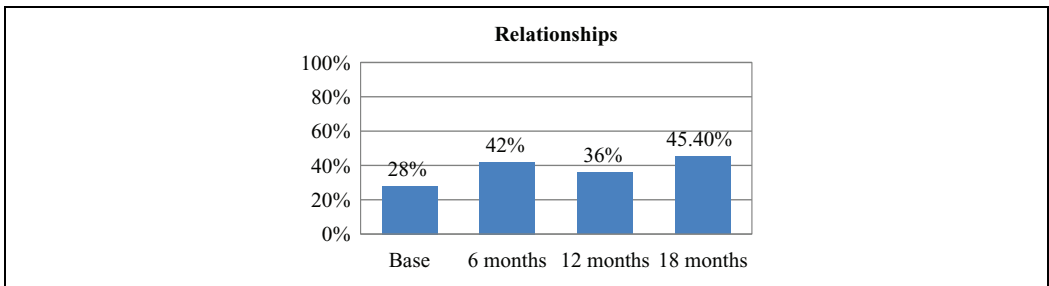


Figure 5. Percentage of possible maximum for relationships.

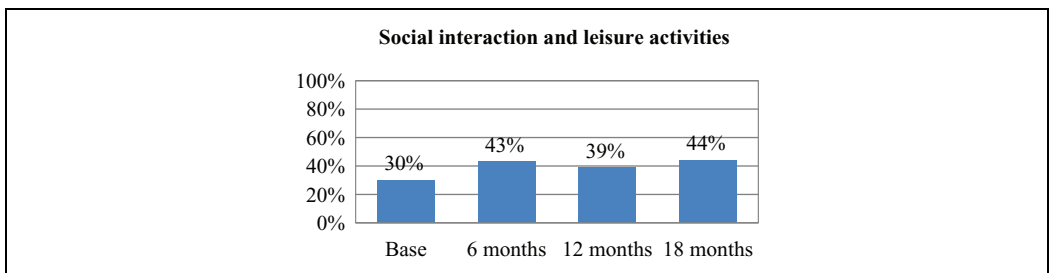


Figure 6. Percentage of possible maximum for social interaction and leisure activities.

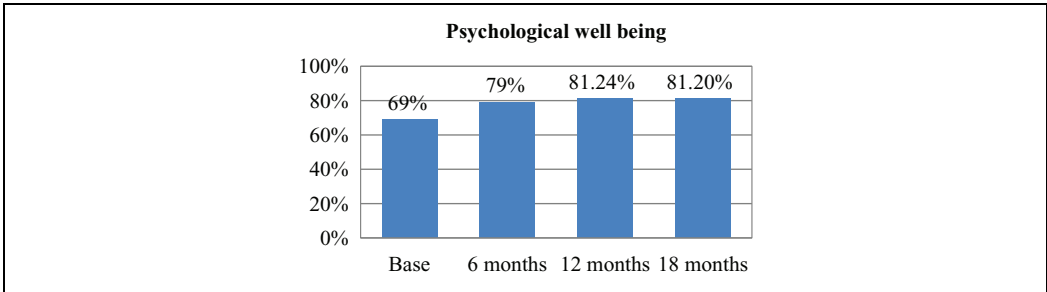


Figure 7. Percentage of maximum possible for psychological well-being.

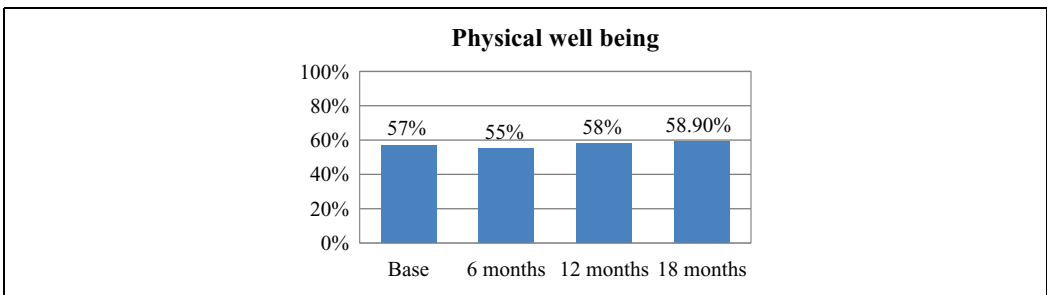


Figure 8. Percentage of possible maximum for physical well-being.

Psychological well-being, which was relatively high in Orchard Hill, has nevertheless improved and maintained a fairly steady level since the beginning of the resettlement. This domain was measured through observations of behaviour and appearance from which feelings could be inferred (Figure 7).

Physical well-being has shown the smallest improvement, but this probably reflects both a good standard of physical care at Orchard Hill and fairly intractable conditions in the individuals. Since there were fears that a move from hospital to community might lead to a deterioration in physical and medical care, the maintenance of this standards was significant (Figure 8).

As a qualitative complement to the QoL audit, a number of ‘stories’ of individual service users were provided by care staff who were familiar with service users in Orchard Hill and their supported housing. A total of 18 such stories were collected; the excerpts given below provide heartening evidence of the improvement in their lives and behaviour through supported housing, personalization and choice. They are in striking contrast with the descriptions of patients’ lives in the Healthcare Commission Inspection Report (2007) on Orchard Hill.

The tenant was not only making a choice but it was being listened to and acted upon.

After a very few weeks in her new flat she looked relaxed, and greeted me quietly and appropriately.

She is obviously enjoying having her own space when she needs it and maybe this is helping her to be more sociable at other times.

One of the people we support, whilst selecting a lounge suite for their new home, went straight over to a suite unprompted and sat in the arm chair smiling and happy.

One person we support has purchased an MP3 player and they now enjoy relaxing in their own home and listening to music they have selected.

There is another service user whose outbursts of self-injury have decreased quite significantly after moving out of Orchard Hill.

Spontaneously, she took herself to the front of the crowd that had gathered for the opening event, and made a speech, welcoming everyone to her new home, her new flat.

The most liberating aspect of his move for him is that he has a garden where he can enjoy the sun, he has his own flat and belongings, can eat what he wants when he wants and he can walk into Cheam Village whenever he wants. He loves getting out and about and just smiles so much now.

The process part of the evaluation focussed on the approach and procurement procedures of the council and these bear careful study to identify how a resettlement associated with a clear excellent improvement in QoFL can be achieved so cost effectively. Fundamental to their approach was the design of a new model of supported living based on the individual needs of people as identified in their statutory assessment of needs. The council commissioned a model of social care in supported living in clusters of one bed flats where service users/citizens could gain new skills for more independent living. Economies of scale were achieved by sharing staff across day and night time support. Three care providers had already been procured by the PCT, and Sutton Council agreed an exemption from tendering to facilitate the transition from health to social care. The three social care providers had agreed to take NHS staff on TUPE (protected [Transfer of Undertakings (Protection of Employment) Regulations]) transfer and costed care plans were agreed on this basis with a new supported living service specification and hourly rate negotiation. The supported living service specification used the Reach ("Reach Standards of Supported Living" promulgated by Advance Support) standards to ensure personalization of care.

Stakeholder perspectives were solicited for the evaluation from parents/next of kin and care staff. To a large extent, their views supported the audit findings, although both the groups expressed concern about friendships and social relationships that achieved relatively less (although still significant) improvement when compared with other domains in the QoFL audit. This, we believe, is a major area for further development. The response rate of both the groups in the surveys was disappointing, which suggests that these are early days for them to have formed confident views and that they should be surveyed regularly as the resettlement matures.

Discussion and conclusions

The design of this evaluation research was based on the well-tried trident method (Ellis and Hogard, 2006) in which the focus of research questions and data gathering is on outcomes, process and stakeholder perspectives. This approach has integrated a number of data streams to provide a distinctively comprehensive evaluation of the resettlement compared with other reported evaluations (Chowdhury and Benson, 2011). The research combined a relatively objective audit with qualitative descriptions and questionnaire surveys of stakeholder views. Each of these methods has strengths and weaknesses but their combination provides a degree of complementarity.

With regard to outcomes, the main part of the study was the completion of the specially devised QofL audit at four points in time to assess whether the major outcome of an improvement in QofL for service users appeared to have been achieved. At the conclusion of this part of the research, it appeared clear from the QofL audit data that there was an appreciable improvement in QofL for all the 39 residents in their new supported accommodation and care home compared with Orchard Hill. These audit results were confirmed in both the qualitative vignettes of service users and the perceptions of care staff and parents/next of kin.

Comparing the baseline audit with the one obtained after 18 months shows highly significant results for QofL as a whole and for the seven domains through which it was measured. There are differences in the level of improvement between different domains and this would merit further study.

The research design cannot of course indicate unambiguous cause and effect between accommodation and QofL, but it is a not unreasonable conclusion that the resettlement from hospital to supported housing appears to be associated with this improvement in QofL.

The improvement in QofL found in this research should be considered in relationship with the costs of the supported accommodation, which compared more than favourably with costs elsewhere and for other forms of provision.

The results are consistent with those found in other studies in both the immediate improvement following resettlement and the relative plateauing over an 18-month period. The risks associated with resettlement were not apparent at this stage but would merit further auditing over a longer period. Whilst all the domains showed improvement, the relatively smaller improvement for social relationships suggests the need for further study, and this reflects the findings summarized in Chowdhury and Benson (2011) in which the community relationships had showed least improvement after resettlement.

The concentration on outcomes and on the process of commissioning in this evaluation study did not address the process whereby the outcomes are being achieved beyond a description of accommodation and support. Further study would be desirable to identify key variables associated with QofL outcomes.

After this study, Sutton Council has commissioned continued monitoring of the effectiveness, impact and acceptability of the relocation. In particular, this will include repeating the QofL audit, monitoring provision against known risk factors, developing more refined audit in key social areas and continuing surveys of stakeholder satisfaction. It is the intention that the project should be used as a basis for devising sustainable internal monitoring procedures.

Funding

This research was supported by a grant from the London Borough of Sutton.

References

- Ager A (1998) *The BILD Life Experiences Checklist*. London: British Institute of Learning Disabilities.
- Beadle-Brown J, Mansell J and Kozma A (2007) Deinstitutionalization in intellectual disabilities. *Current Opinion in Psychiatry* 20: 437–442.
- Chowdhury M and Benson B (2011) Deinstitutionalisation and quality of life of individuals with intellectual disability: a review of the international literature. *Journal of Policy and Practice in Intellectual Disabilities* 8(4): 256–265.
- Cummins RA (1996) The domains of life satisfaction: an attempt to order the chaos. *Social Indicators Research* 38: 303–332.

- Cummins RA (1997) *Comprehensive Quality of Life Scale – Intellectual Disability: ComQol-15*. 5th ed. Melbourne: School of Psychology, Deakin University.
- Department of Health (2006) *Our Health Our Care Our Say*, London: Department of Health.
- Ellis R and Hogard E (2006) The trident: a three-pronged method for evaluating clinical, social and educational innovations. *Evaluation* 12(3): 372–383.
- Ellis R, Hogard E and Watts V (2008) *Quality of Life Questionnaire V.3 for Assessing Quality of Life in Individuals with Learning Disabilities*. Chester, UK: SHEU, University of Chester Press.
- Emerson E and Hatton C (1994) *The Impact of Relocation from Hospital to Community on the Quality of Life of People with Learning Disabilities*. London, HMSO.
- Felce (2007) *Quality of Life in Community Living Services: Issues of Objective and Subjective Measurement*. Cardiff: Welsh Centre for Learning disabilities, Cardiff University.
- Frison L and Pocock SJ (1992) Repeated measures in clinical trials: Analysis using mean summary statistics and its implications for design. *Statistics in Medicine* 11(13): 1685–1704.
- Grierson A (2006) *A stakeholder analysis of a quality of life for people with learning disabilities*. MSc Thesis, South Bank University.
- Grunewald K (1997) Effect of social and educational policies on the number of persons with mild mental retardation in Sweden. *Mental Retardation* 35(3): 218–220.
- Hatton C (1998) Who's quality of life is it anyway? Some problems with the emerging quality of life consensus. *Mental Retardation* 36(2): 104–115.
- Healthcare Commission (2007) *Investigation into the Service for People with Learning Disabilities Provided by Sutton and Merton Primary Care Trust*. London: Healthcare Commission.
- Hogard E (2007) Using Consultative Methods to Investigate Professional-Client Interaction as an Aspect of Process Evaluation. *American Journal of Evaluation* 28(3): 304–317.
- Keith KD (2001) International quality of life: current conceptual measurement and implementation issues. *International Review of Research in Mental Retardation* 24: 49–74.
- Krapu T, Meinke L, Kramer L, Friedman R and Voda J (2006) The life satisfaction survey (LSS): development of the instrument. In: Proceedings of the 4th international coach federation coaching research conference.
- Mansell J (1996) In: Mansell J and Ericsson K (eds) *Deinstitutionalisation and Community Living: An International Perspective*. London: Chapman and Hall.
- Mansell J (2006) Deinstitutionalisation and community living: Progress, problems and priorities. *Journal of Intellectual & Developmental Disability* 31: 65–76.
- Nota L, Soresi S and Perry J (2006) Quality of life in adults with an intellectual disability: the evaluation of quality of life instrument. *Journal of Intellectual Disability Research* 50(5): 371–385.
- Perry (2002) Subjective and objective quality of life: their interrelationship and determinants. ReFeR summary. Available at: <http://www.refer.nhs.uk>.
- Plimley LA (2007) A review of quality of life issues and people with autism spectrum disorders. *British Journal of Learning Disabilities* 35: 205–213.
- Ross E and Oliver C (2003) Preliminary analysis of the psychometric properties of the mood interest and pleasure questionnaire (MIPQ) for adults with severe and profound learning disabilities. *British Journal of Clinical Psychology* 42: 81–93.
- Schalock RL (2004) The concept of quality of life: what we know and do not know. *Journal of International Disability Research* 48(3): 203–216.
- Schalock R and Keith K (1993) Quality of life questionnaire. *Mental Retardation* 40(2): 157–165.
- Skea D (2008) Quality of life for adults with learning disabilities in private residential care: monitoring aspects of life experience over time. *Mental Health and Learning Disabilities Research and Practice* 5: 252–265.
- Stancliffe R, McVilly K, Radler G, Mountford L and Tomaszewski P (2010) Active support, participation and depression. *Journal of Applied Research in Intellectual Disabilities* 23(4): 312–321.
- Tizard J (1960) Residential care of mentally handicapped children. *British Medical Journal* 1: 1041–1046.
- Verdugo MA, Schalock RL, Keith KD and Stancliffe RJ (2005) Quality of life and its measurement: important principles and guidelines. *Journal of Intellectual Disability Research* 49:707–717.

- Watts V, Hogard E and Ellis R (2006) *Resettlement of Individuals with Learning Disabilities into Community Care: Advantages and Risks SHEU Occasional Papers No 7*. Chester, UK: University of Chester Press.
- White A (2007). A global projection of subjective well-being: a challenge to positive psychology? *Psychtalk* 56: 17–20.