The impacts of deinstitutionalisation on the quality of life of individuals with intellectual disabilities

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Thesis submitted to the University of Leicester,
in partial fulfilment of the degree of Doctorate in Clinical Psychology
Declaration

I confirm that the research presented within this thesis, submitted for the partial fulfilment of a degree of Doctorate in Clinical Psychology, is my own original work. The exceptions to this are clearly stated within the body of the text but are summarised here. The research herein is an extension of a service evaluation completed in 2010 by Dr Kevin Baker and Dr Lyn Collins. The data from this previous study is used here as a baseline for longitudinal comparison with the currently collected data.
The impacts of deinstitutionalisation on the quality of life of a cohort of individuals with intellectual disabilities: A longitudinal mixed methods study

Rob Jones

Thesis abstract

Literature review
The systematic review aimed to examine the impact that deinstitutionalisation had on the community integration of service users with intellectual disabilities. Six electronic databases (PsycINFO, Medline, Scopus, Web of Science, CINAHL, and ASSIA) were searched and 12 studies met the inclusion criteria. Findings indicated that access to community facilities increased but integration did not. Frequency and quality of social relationships with staff, family, and peers was generally high post move but relationships with individuals unrelated to services remained infrequent. It is concluded that the focus of policy should move towards developing close personal relationships rather than community integration.

Research report
The empirical research project aimed to examine how deinstitutionalisation had impacted the quality of life of a cohort of 14 service users. The study formed the second half of a quantitative longitudinal study spanning eight years. A mixed methods approach was used. Eleven staff members who knew service users well completed outcome measures. Transcriptions of discussions alongside this were analysed using template analysis. Interviews were held with social workers who knew the remaining three. Six themes were created: Social relationships; community use; choice; emotional wellbeing; challenging behaviour; and adaptive behaviour.

The move to the community was experienced very differently by each service user. While it appeared that a number of gains were made for some service users, others experienced poor quality care and received few benefits. Relationships with staff appeared to be very important for some service users and these relationships appeared to impact all areas of quality of life.

It is concluded that for the move to the community to be successful, staff must be sensitive to the changing needs of service users throughout their lives.

Critical appraisal
The research process is critically appraised and reflected upon. Key decisional points are considered, and extended theory is discussed.
I would like to thank the individuals and services who kindly gave up their time to participate in the research. Listening to the passion and dedication they had for the people that they supported was genuinely uplifting.

Thanks to Dr Gareth Morgan and Dr Kevin Baker for their constant support and guidance, and especially for patiently reading through endless emails and manuscripts. Thanks as well to everyone at the university who has offered insights and support.

Finally, I'd like to thank my wife for putting up with me through the long nights and the frantic days that have characterised the last few months.
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- Article Body: 11610
- References: 2122

**Section C: Critical Appraisal**
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- References: 280

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Section A: Literature Review

A Critical Systematic Review of the Impact of Deinstitutionalisation has upon the Community Integration of Adults with Intellectual Disabilities in the UK

for submission to the British Journal of Clinical Psychology (see Appendix C)

Abstract

This paper reviews the UK based evidence of the impact that deinstitutionalisation has on the community integration of service users labelled with intellectual disabilities.

A systematic literature search was conducted using ASSIA, CINAHL, Medline, PsychINFO, Scopus and Web of Science. Search terms used included relevant government policies and synonyms for intellectual disability, community integration and deinstitutionalisation. A sample of 12 studies met the inclusion criteria and were retained for review.

Included papers broadly examined two main topics: Use of community facilities and social relationships. Findings suggested that moving into the community yielded greater use of community facilities, though this remained below that of non-disabled individuals. The most frequent types of community based activities appeared to be going to do food shopping and going out to pubs or cafes.

There was little evidence that community use led to service users having more meaningful contact with others. Frequency and quality of social relationships with staff, family, and peers was generally high post-move but relationships with individuals unrelated to services remained infrequent. Moving to the community also came with a loss of important friends or attachment figures in the forms of peers and key staff. Social isolation remained prevalent and various studies featured participants that reported having no friends.

It is concluded that moving into the community appears to increase community presence but generally fails to increase community integration. It is argued that policy needs to move beyond simplistic notions that community placements are inevitably better than hospital settings for all, and that consideration should be given to privileging development and maintenance of meaningful attachments and relationships over integration.
1. Background

The vision of normalisation contained within *Valuing People* (Department of Health, 2001) has continued to be a dominant paradigm in UK policies aimed at improving the lives of people labelled as intellectually disabled. Founded on normalisation-based principles (Nirje, 1969; Wolfensberger, 1972), the focus has ostensibly been on a move towards individualised and person centred care that empowers individuals to become consumers of support rather than passive recipients. The version of normalisation espoused by this and subsequent policies suggests that service users\(^1\) should be living lives more closely resembling non-disabled peers through community integration\(^2\) and participation (Jones *et al.*, 2016).

While such policies have supported shifts towards social model understandings of disability that locate problems for service users within society rather than individuals (e.g. Goodley, 2001), the implied imposition is that ‘normalcy’ is a concrete and proper way to live that all individuals should aspire to. At its ideological core, normalisation has been put forward as a vehicle for shifting the opinions of a majority who had typically ‘othered’ intellectually disabled people. However, in practice, it could be argued that the onus is placed upon devalued groups to conform to the expectations of others so that they better fit in. Ignoring the obvious truth that many individuals with intellectual disabilities lack the skills or desire to integrate, this actually maintains the status quo as the privileged, non-disabled majority are not required to make any concessions (Dalley, 1993). Additionally, while normalisation would

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1 Whilst a contentious term, ‘service users’ is used throughout this article to refer to individuals labelled as intellectually disabled who require staffed care.

2 Community integration is used throughout this article for the sake of clarity. This was chosen as the term appears to be the most widely used term in research literature. Other frequently used synonymous terms are ‘social inclusion’, ‘social integration’, and ‘community involvement’. *Valuing People*, for example, uses ‘social inclusion’.
suggest that disabled people benefit from having privileged role models, social comparison theory (Festinger, 1954) suggests that heightened contact to non-accommodating ableist societies risks increased shame as a consequence of an internalisation of oppressive social structures (e.g. Suls & Wheeler, 2000).

In *Valuing People*, little acknowledgement was given to the reluctance of the people who make up ‘the community’ to accept and value individuals who might struggle to act in accordance with socially constructed norms. Neither were the provisions of collectivist solutions such as new employment opportunities or social activities for service users proposed (Burton & Kagan, 2006). Indeed, collectivist solutions were avoided entirely, and it has been argued that part of the reason that many institutions were ordered to close was that they did not adequately mimic the neoliberal ideal of the nuclear family model of care (Dalley, 1993).

Instead, the white paper appeared to demonstrate a political shift that exemplified individual choice concerning what an individual wants rather than needs as an aspirational paradigm, regardless of whether meaningful choice was something individual service users were capable of making or not. As has been argued previously, services that adhere to this ideology too closely can have a problematic tendency to emphasise the rights to freedom and choice over service users’ need to be protected. This can have the effect of exacerbating exclusion while exposing individuals to unsafe or unwanted situations that they chose without having the capacity to understand potential ramifications (Fyson & Cromby, 2012).

Intrinsically linked with consumerist agendas is the desire to accumulate wealth through wealth or entrepreneurialism and avoid spending deemed unnecessary. It is perhaps unsurprising then, that some service users have been found to receive reduced funding each year post move under the favoured model of community care (Hallam *et al.*, 2006).
Historically, care for individuals with intellectual disabilities was provided in long stay hospitals or institutions. Following events such as the Ely scandal (Howe, 1969), a 25-year plan was produced by the government to close these hospitals (Department of Health, 1971). A recommendation was made that all service users requiring 24 hour staffed care should reside in community settings rather than in long-stay institutions where, it was argued, they could better integrate with ‘the community’. The guiding ideology was that if institutions produce ‘institutionalised behaviour’, ‘normal communities’ would support ‘normal behaviour’.

Normalisation has remained the basis for UK government policy, including Transforming Care (Department of Health, 2012). In February 2015, the NHS responded to this by committing to close all long stay hospitals by 2018 (NHS England, 2015). The process of moving people from the institutions into community residences was known as deinstitutionalisation.

Deinstitutionalisation is assumed by policy to yield increased integration with wider communities.

Definitions of community integration are vague however. Szivos (1993) argues that it includes two major factors: relationships with others; and use of community resources. The latter factor helps normalise individuals through their being seen to do ‘normal things’ and through affording access to non-disabled others. Reinders (2002) argues that one has to be participating in others’ lives to be integrated:

‘[Community living] is neither a legal structure, nor is it an institutional space created by rights. All these things are necessary, but not sufficient conditions for inclusion in the community. Community is the experience of sharing one’s life with people.’ (Reinders, 2002, p. 2)

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3 ‘The community’ is placed in inverted commas due its problematic nature as a construct that is unwritten and insinuates that intellectually disabled individuals are placed outside of it and must work to become part of it.
Similarly, Schalock et al. (2002) argued that it is not enough to be living in the community; one must be a meaningful member within it to be integrated. As such, the extent to which presence in the community leads to a sense of integration is questionable. Service users living in the community who do not require 24 hour staffed support have been found to experience greater marginalisation (Bramstone, 2002) and fewer friendships (Clegg et al., 2008) than non-disabled peers.

In a UK based literature review by Emerson and Hatton (1996), the effects of deinstitutionalisation on community integration and social relationships were considered as part of a broader examination of quality of life. The authors concluded that use of community facilities increased but remained superficial and infrequent. Facilities accessed tended to be places that involved minimal contact with the general public. The number of social contacts increased but generally remained low, especially contact with people unrelated to services. These findings were in line with international literature reviews considering deinstitutionalisation that were critical of the lack of proper community integration post-move (e.g. Chowdhury & Benson, 2011; Walsh et al., 2010).

In light of equivocal evidence about the benefits of moving into the community, the current literature review aimed to update Emerson et al.’s review by critically evaluating more recent evidence concerning the impact on community integration of deinstitutionalisation. Using Szivos’ factors, this is taken to include both use of community facilities and social relationships. Given the significant impact of recent policies on the lives of individuals with intellectual disabilities, it was important to explore whether deinstitutionalisation was successful in meeting its stated aims.
2. Method

A systematic literature search of studies was conducted in *Applied Social Sciences Index and Abstracts*, *Cumulative Index to Nursing and Allied Health Literature*, *Medline*, *Psychinfo*, *Scopus* and *Web of Science*. These databases were chosen as they were deemed to encapsulate the full range of social care, medical, and psychological knowledge bases. The searches were conducted in August 2017 using the terms detailed in Table 1. Pilot searches had demonstrated that community integration was often studied as a domain of quality of life, so quality of life domains were included as search terms accordingly.

**Table 1: Search terms used in databases**

<table>
<thead>
<tr>
<th>First Search Term</th>
<th>Second Search Term (using the AND conjunction)</th>
<th>Third Search Term (using the AND conjunction)</th>
<th>Fourth Search Term (using the AND conjunction)</th>
</tr>
</thead>
<tbody>
<tr>
<td>disab* OR retard* OR handicap*</td>
<td>“challenging behav**” OR wellbeing OR “quality of life” OR “adaptive behav**” OR “life quality” OR inclusion OR exclusion OR excluded OR integrat* OR communicat* OR interact* OR enjoy* OR family OR relatives OR friend* OR relationship* OR “community presence” OR “community participation” OR choice OR choose OR rights</td>
<td>UK OR “United Kingdom” OR GB OR “Great Britain” OR NHS OR “National Health Service” OR Engl* OR Scot* OR “Northern Ireland” OR “Northern Irish” OR “Wales OR Welsh</td>
<td>Deinstitutionali* OR deinstitutionali* OR winterbourne OR “valuing people” OR “transforming care” OR “Building the right support” OR normali* OR reprovision OR move OR moving OR relocation</td>
</tr>
</tbody>
</table>

A total of 3246 unique articles were returned. After reviewing titles and abstracts, full text articles for 28 studies were retrieved. An additional 10 relevant papers were identified from other sources such as reference lists. Studies were reviewed against the inclusion criteria outlined in Table 2.
Table 2: Inclusion criteria and rationales

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research that took place in the United Kingdom.</td>
<td>The current review examined the direct impacts of British government policy on service users in the UK.</td>
</tr>
<tr>
<td>Research published in peer reviewed journals post 1994.</td>
<td>Emerson &amp; Hatton (1996) conducted a literature review examining research completed prior to this date.</td>
</tr>
<tr>
<td>Research that examined adult populations of individuals labelled with intellectual disabilities who resided in staffed residences in the community who had moved from hospital or institutional care as part of a deinstitutionalisation project.</td>
<td>The inclusion of studies examining other populations or moves between community residences would have impacted the generalisability of any findings.</td>
</tr>
<tr>
<td>Research that measured the community inclusion, community integration, or social relationships of service users either as a sole focus or as part of a wider examination of quality of life changes.</td>
<td>Primary searches demonstrated that few studies examined community integration exclusively, but a larger proportion examined it alongside other factors of life quality.</td>
</tr>
</tbody>
</table>

Thirteen papers met the inclusion criteria and were appraised using the Critical Appraisal Skills Programme Checklist for longitudinal studies (CASP, 2017). For the purposes of triangulation, eight of these papers were additionally reviewed by the author’s academic supervisor, with the author making decisions on final ratings following discussions concerning discrepancies. Two studies were deemed not to be of sufficient quality for inclusion, whilst an additional article published after the search period was included, resulting in a final sample of 12 papers (Figure 1). Appendices F and G present the Author’s and Supervisor’s CASP ratings respectively for the included studies.
Figure 1: Details of included and excluded studies.
3. Results

3.1. Overview of Reviewed Papers

Extracted data for the 12 included studies are summarised in Appendix H. Overall, the studies examined the experiences of 768 unique service users. Two studies shared a sample of 196 participants (Forrester Jones et al., 2002 and Forrester Jones et al., 2006) Individual studies ranged in size from four to 214 participants. Four studies used exclusively quantitative measures (Bhaumik et al., 2011; Dagnan et al., 1998; Perry et al., 2011), four used qualitative measures (Forester-Jones et al., 2002; Head et al., 2018; Hubert et al., 2010; McConkey et al., 2003), and three used mixed-methods designs (Dagnan et al., 1998; Donnelley et al., 1996; Forester-Jones et al., 2006).

The mean post-move follow-up period was 48 months (range ($\bar{x}$): 9 to 144 months). Most studies did not report average length of stay in institutions pre-move, but of the five studies that did, mean length of stay was 24 years (range ($\bar{x}$): 8 - 32 years).

3.2. Use of Community Facilities

Four of the included studies measured the frequency and quality of service users’ usage of community facilities pre and post deinstitutionalisation (Ager et al., 2001; Baker, 2007; Bhaumik et al., 2011; Dagnan et al., 1998). The findings of these studies are summarised in Table 3. In these studies, accessing community facilities was broadly defined as going to communal places unrelated to disability services such as supermarkets or pubs. All four studies indicated that access to non-segregated community facilities initially increased significantly post-move.
Table 3: Quantitative summaries of findings of studies relevant to the use of community Facilities

<table>
<thead>
<tr>
<th>Study</th>
<th>N</th>
<th>DVs</th>
<th>Findings</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ager et al. (2001)</td>
<td>58</td>
<td>Range of community facilities accessed</td>
<td>Increased 9 months post-move</td>
<td>Not reported</td>
</tr>
<tr>
<td>Baker (2007)</td>
<td>28</td>
<td>Range and frequency of community facilities accessed</td>
<td>Increased 18 months post-move</td>
<td>&lt;.01</td>
</tr>
<tr>
<td>Bhaumik et al. (2011)</td>
<td>51</td>
<td>Range of community facilities accessed</td>
<td>Increased 6 months post-move</td>
<td>&lt;.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Remained constant between 6 and 12 months post move</td>
<td>.76</td>
</tr>
<tr>
<td>Dagnan et al. (1998)</td>
<td>29</td>
<td>Range of community facilities accessed</td>
<td>Increased 30 months post move compared with baseline</td>
<td>&lt;.01</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Increased 41 months post move compared with baseline</td>
<td>&lt;.01</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Remained constant 53 months post move compared with baseline</td>
<td>Not reported</td>
</tr>
</tbody>
</table>

Baker (2007) utilised control groups of non-disabled adults and adults with intellectual disabilities living with their families. Although the deinstitutionalised sample experienced a significant increase in the range and frequency of community contacts, this was still far lower than was found for both control groups. It is possible that differing levels of ‘challenging behaviour’ and ability might account for some of the differences between the deinstitutionalised sample and those with intellectual disabilities living with their relatives. This would be in keeping with reviews demonstrating that severity of disabilities of a care receiver are proportionate with levels of stress and depression in familial carers (e.g. Cummins, 2001). Nevertheless, findings suggested that truly ‘normalised’ community integration had not occurred.

Baker (2007) focussed on samples who had been moved to accommodation on the same site as their pre-move hospital and tended to live amongst familiar peers and staff. As
such it is likely that the service users experienced this move very differently to individuals deinstitutionalised to completely alien services in different parts of the country.

Increases in use of community facilities do not necessarily indicate that individuals were spending more time interacting with others. It is possible that service users attended activities such as shopping or going to the pub but remained with staff or alone. Interaction with others during community use was only directly examined by one study: Dagnan et al. (1998) reported that the frequency of interactions with community members unrelated to services increased significantly post move. This study specifically looked at interactions with people who did not have intellectual disabilities. While it is clear that the intention of measuring this is to ensure that people labelled with intellectual disabilities are not segregated, that contact with people without intellectual disabilities is regarded as a positive outcome implies that non-intellectually impaired people are a more valuable population to integrate with than, for example, an expanded network of disabled peers, a critique which equally applies to much of the literature on normalisation and Government policy (e.g. Department of Health, 2001). Additionally, it would not be difficult for changes in interactions with non-disabled and non-staff others to be significant when compared to institutions where access to such people was severely limited.

Individual and external factors were found to influence the use of community facilities. Ager et al. (2001) examined the types of activities service users took part in post-move. Though no comparative pre-move figures were available, two thirds of participants were engaged in social activities such as going for a drink or meal post-move and a mutually inclusive two thirds were in education or employment. The authors noted that one participant did not engage in any activities post-move. This may have been appropriate for the individual’s cognitive and emotional capabilities however, and may indicate that community integration
was not something that necessarily benefited this individual. The authors also suggested that both age and size of post-move accommodation negatively affected the outcomes of deinstitutionalisation. Individuals who did not improve were disproportionately likely to be aged over 65. It is possible that this is simply because the older adults required a longer adjustment period than younger peers, or may indicate that the ability to make use of community facilities is negatively impacted by the decreased physical abilities associated with aging. Differences resulting from accommodation size are likely to be linked to number of staff available and number of peers requiring attention. Baker (2007) suggested that community planning had been another important factor in the success of deinstitutionalisation for their service users and highlighted that moving into the community without an appropriate plan would not be sufficient to increase community facility use.

Overall, the evidence appears to indicate that deinstitutionalisation into the community does lead to increases in access to and usage of community facilities amongst service users. However, there was a great deal of variation within and between studies. It appears that there are a number of under-researched factors likely to impact upon the use of community facilities such as age, ability and levels of support. As such, it appears difficult to conclude that the move to the community has unequivocally led to increases in community facility usage for all service users. Further, in reporting increased use of community facilities, studies failed to report what access to facilities might have been lost through moving from the hospitals: It is perhaps inevitable that use of community facilities increase when people are moved to live in such contexts, but it is unclear if use of such facilities inevitably increases a sense of integration for all.
3.3. Relationships with Others

3.3.1. Relationships with Friends and Family

Relationships with people who were unrelated to disability services were measured in nine studies (Ager et al., 2001; Bhaumik et al., 2011; Dagnan et al., 1996; Dagnan et al., 1998; Donnelley et al., 1996; Forrester-Jones et al., 2006; Hubert & Hollins, 2010; McConkey et al., 2003; Perry et al., 2011). Table 4 demonstrates summaries of quantitative results.

**Table 4:** Quantitative summaries of findings of studies relevant to relationships with friends and family (effect sizes are not specified as these were not reported in studies)

<table>
<thead>
<tr>
<th>Study</th>
<th>DVs</th>
<th>Findings</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ager et al. (2001)</td>
<td>Relationship quality and frequency</td>
<td>Increased 9 months post-move</td>
<td>&lt;.01</td>
</tr>
<tr>
<td>N = 76</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bhaumik et al. (2011)</td>
<td>Relationship quality and frequency</td>
<td>Increased 6 months post move compared with baseline</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>N = 51</td>
<td></td>
<td>Reduced 12 months post move compared with 6 months</td>
<td>&lt;.05</td>
</tr>
<tr>
<td>Dagnan et al. (1996)</td>
<td>Relationship contact frequency</td>
<td>Contact with friends and family reduced 3 months post move and 15 months post move</td>
<td>Not reported</td>
</tr>
<tr>
<td>N = 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dagnan et al. (1998)</td>
<td>Relationship quality and frequency</td>
<td>Increased 30 months post move compared with baseline</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>N = 29</td>
<td></td>
<td>Increased 41 months post move compared with baseline</td>
<td>&lt;.01</td>
</tr>
<tr>
<td>Donnelley et al. (1996)</td>
<td>Social functioning ability</td>
<td>No significant change 12 months or 24 months post move</td>
<td>Not reported</td>
</tr>
<tr>
<td>N = 214</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perry et al. (2011)</td>
<td>Contact with neighbours</td>
<td>No significant changes 3 months, 6 months or 12 months post-move</td>
<td>Not reported</td>
</tr>
<tr>
<td>N = 19</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Two studies (Bhaumik et al., 2011; Dagnan et al., 1998) demonstrated an initial increase in relationship scores on the Questionnaire on the Quality of Life (Dagnan et al., 1998), a quantitative measure of quality of life found to have good internal and interrater
reliability by the authors but one that has been criticised for focusing too narrowly on normalisation principles to define life quality (e.g. Cummins, 2005).

Dagnan et al. (1998) reported that these increases continued to rise throughout the period of measurement (up to 53 months) whereas Bhaumik et al. (2011) reported statistically significant deterioration between the six and 12 month measurement points. Nonetheless, the 12-month scores remained significantly higher compared to pre-move scores.

It is possible differences between the studies relate to differences with the samples, with the service users in Bhaumik et al. (2011) being reported to display behaviours that challenge and seeming to have relatively lower adaptive and functional skills relative to the people in Dagnan et al. (1998). Thus, those in the latter study might have been both more able and afforded more opportunity to develop relationships. Alternatively, differences might relate to staffing: In Dagnan et al.’s (1998) study, staff were NHS employed and so were likely to have been more highly paid and trained than the staff in Bhaumik et al. (2011). Thus staff retention and ability to support development of relationships might have been higher.

Perry et al. (2011) concluded that frequency of contact with family significantly increased post-move but that there was no significant change in relationships with friends. What was not emphasised however, was that the increase in contact with family was predominantly due to increases in telephone contact as visits to the family remained constant and family members visiting the service users’ homes reduced non-significantly.

Dagnan et al. (1996) demonstrated that service users experienced a reduction in contact with friends and family post move. Neither significance nor numerical data was reported but after twelve months contact had reduced to half what it had been pre-move.
Donnelley et al. (1996) reported that the frequency of service users who identified having no friends outside of services increased from 74% to 86% post move. The present author undertook a statistical analysis of this difference because the original author did not examine statistical significance. This was found to represent a significant increase in service users who had no friends outside of services ($X^2 = 16.61, p<.001$). Similarly, McConkey et al. (2003) stated that only nine of the 39 informants had one or more friends outside of their residence.

Ager et al. (2001) examined how often service users had contact with others. They found that during a seven day period examined around six to nine months post-move, only 31% of service users had seen a relative and 24% a friend.

Examining the paucity of reciprocal relationships, isolation was a theme that was discussed in four papers (Donnelley et al., 1996; Forrester-Jones et al., 2002; Hubert & Hollins, 2010; and McConkey et al., 2003). Ten per cent of participants in Forrester-Jones et al. (2002) described feeling lonely, whilst 40% and 30% of service users reported having no friends unrelated to ID services in Donnelley et al. (1996) and McConkey et al. (2003) respectively. The latter study demonstrated that both pre- and post-move, one of the greatest deficits service users experienced related to community living skills, and there was minimal change in these abilities post-move. It is possible that too little is done to support service users to develop community based competencies. It may also be that many service users are simply not capable of learning the complex and nuanced skills necessary to live in the community as it currently is and that the expectation that they can risks placing undue pressure on some people.
Donnelley et al. (1996) observed that there was a large variation in the quality of services, and argued that this impacted on the development of skills necessary for interacting with friends and others. They concluded that the places that had the best outcomes were the ones that were the ‘most normal’ whereas the ‘less normal’ environments tended to reduce skills. This conclusion was not backed up by empirical data and it is here argued that the assumption that ‘normalcy’ of an environment as the most important factor is not only problematic due to difficulties in defining what constitutes a ‘normal’ way of living, but risks neglecting other qualities of the homes; the skills and motivations of staff, the management, and the individual differences of the service users residing within. Indeed, the normalcy of which the article speaks is not clearly defined, and therefore left to the interpretation of the reader. This is typical of intellectual disability research but allows normalcy to be defined by the powerful majority.

Hubert and Hollins (2010) reported that there were also wider service provision factors that blocked community integration. One man would not wear clothes and so it was not appropriate to take him out. The authors noted that no attempts were made by professionals to understand or moderate this behaviour despite repeated requests by the home manager. As the authors argued, for community homes to be effective at integrating rather than isolating service users, it may be necessary to look more closely at what barriers exist and what can be done to support individuals to overcome them.

Social networks of deinstitutionalised service users were examined quantitatively by Forrester-Jones et al. (2006). Average network sizes were found to be between three and 51, with a median of 21.5 (SD = 9.4). Only approximately a third of contacts were found to be from community contexts that were unrelated to services, and of these, ten per cent were
stated to be friends rather than family members or people employed to have contact with others.

The study excluded 59 out of a possible 272 participants due to communication difficulties. It is conceivable that the excluded group would have had very different social networks and friendships due to their communication difficulties as such a pattern has been reported in previous research (e.g. an American study by Robertson, et al., 2001).

A further limitation of the finding was that pre-move comparison data was not available so it is not possible to make any conclusions about changes in social networks due to deinstitutionalisation.

Donnelley et al. (1996) did compare social network size pre- and post-move and reported no significant differences, with 40% of service users having no friends at either time point.

Head et al. (2018) interviewed service users about their experiences of moving into the community. Participants in their study reported benefitting from living closer to family and therefore having closer relationships with them. A small number of service users had found a connection to the community through neighbours or through attending church. In line with normalisation principles, some service users reported an increase in self-esteem through no longer seeing themselves as ‘patients’ and through the respect that they were given by others. As in other interview based studies however, service users who were unable to communicate or make sense of their experiences were inevitably excluded.

It appears that there is little clarity or consistency in the findings regarding relationships. Some findings demonstrated an increase in relationship scores on outcome measures, but there was little evidence that deinstitutionalisation resulted in tangible
increases in contact with family or friends, or members of the community. Comparing the findings of the two studies using social networks, it can possibly be argued that the trend appears to be that moving to the community yields better integration for service users with good communicative skills, but can yield little change in quality and frequency of relationships with friends and family for those without. The lack of consistency once again demonstrates the heterogeneity of the population. It is also perhaps worthy of note that community integration was specified as a goal based on normalisation principles rather than as a result of wishes or demands from people with intellectual disabilities or from research-based evidence.

Previous research has shown that members of the community can be less than enthused at the prospect of service users moving into their neighbourhood (Hudson-Allez & Barrett, 1996), and hate crime towards individuals with intellectual disabilities remains prevalent (e.g. Emerson & Roulstone, 2014). Alternatively, neighbours may require an amount of time to adjust to having service users living near them, and thus become more welcoming over time. This is supported by Hudson-Allez and Barrett (1996) who demonstrated that neighbours’ opinions became more positive the longer that service users lived near them.

While isolation appears to be an issue impacting service users in both the community or in institutions, these studies indicate that moving to the community has done little to achieve the aims of increasing feelings of integration and may have actually had the opposite effect for a number of people.

3.3.2. Relationships with Residential Staff and Residents

Whilst generally neglected in policy, relationships with co-residents and support staff can be very important for service users as they can become friends, confidants, or (especially in the case of staff) important attachment figures (Reinders, 2010).
Five included studies examined such relationships (Donnelley et al., 1996; Forrester-Jones et al., 2002; Forrester-Jones et al., 2006; Hubert & Hollins, 2010; McConkey et al., 2003). Service users interviewed by Forrester-Jones et al. (2006) reported that other residents or people with intellectual disabilities made up approximately a quarter of their social networks and staff accounted for a further 43%. Similarly, approximately half of the service users in McConkey et al. (2003) and 60% of service users interviewed by Donnelley et al. (1996) reported having one or more friends in their post-move home. Approximately a fifth of service users reported that the companionship of fellow residents and staff was one of the key positives of moving into the community in Forrester-Jones et al.’s (2002) interview-based study. Participants not only cited the importance of receiving assistance, but some emphasised the importance of being able to support staff. This makes sense when one considers Reinder’s (2002) definition of community integration, and that positive feelings come from having an impact on the lives of others.

Informants in the study by Head et al. (2018) reported that moving into the community had often meant a loss of important relationships with peers and staff members. The loss of contact with staff was especially important for these individuals, as it represented a loss of trusting relationships where they felt known and safe. To an extent, this was countered by the development of new relationships, though these continued to predominantly be with new staff members, family, or people in their homes. Interestingly, relationships with disabled others tended to be with the individuals that they lived with rather than other disabled people in the community.

The tendency of people with intellectual disabilities to want to please or acquiesce by saying what they think the other person wants to hear is well documented, especially in quality of life research (e.g. Rapley & Antaki, 1996). Addressing this, Hubert and Hollins (2010)
conducted ethnographic observations before and after deinstitutionalisation. The community homes were observed to be fraught with institutionalised practices that lacked basic human interaction between staff and service users. Though they witnessed improvements made as time went on, this was believed to change based on the ethos of individual service managers and there was great variation. They recorded that fewer interactions with staff were offered than had been in the hospital and that people continued to be frequently left unoccupied and alone. These were a group of service users who exhibited behaviours deemed highly challenging and results may not be representative of other service users. Nonetheless, the study demonstrated that the possibility remains for community residences to fail to support relationships within homes or even to promote humane approaches to care: That a move out of an institution does not necessarily mean leaving institutionalised practices behind.

Overall, it appears that interrelationships within homes are the most frequently occurring relationships for service users and can be considered by some to be important and beneficial. However, it is clear that appropriate consideration of compatibility between service users needs to be made, with the views of service users sought and respected as much as feasible for them when deciding who should live together. Service users living with people that they are unable to get along with can occur when the needs of services are put before the needs of individuals. There is a paucity of research examining the effects of deinstitutionalisation in terms of the loss of these relationships. Schuengel et al. (2010) did examine the effects of discontinuity for service users who had experienced attachment difficulties, trauma, or neglect. They found that these could inhibit attachment-based defences in individuals or lead to worsening attachment styles.
4. Discussion

The perceived benefits to people with intellectual disabilities of living in the community are based on a number of assumptions underlying Valuing People and similar governmental policies. Living in the community is assumed to afford a more ‘normal’ and therefore ‘better’ life, to allow for a greater sense of integration into the community, and to reduce feelings of segregation or isolation. The current critical literature review had aimed to examine the validity of this assumption. Key findings are summarised and contrasted with extant literature below, before considerations of the review’s limitations and implications.

In spite of some of the reviewed papers concluding that their results supported normalised deinstitutionalisation, the findings often did not fit with such conclusions (e.g. Dagnan et al., 1996; Donnelley et al., 1996). There was a great deal of variability in results, and a large number of personal differences that influenced the success or failure for individuals moving.

The overall trend appeared to be that community access increased, and service users attended a greater frequency and variety of community-based facilities post move. Many studies concluded that this was evidence of integration, with the insinuation that if one goes shopping or to the pub often enough, one will become a welcomed and valued member of the community. Using Reinder’s (2002) definition, for community integration to have occurred, moving to the community should have resulted in service users having reciprocal meaningful impacts with other members of their communities. There was no evidence that this had occurred for many service users.
Social networks continued to be small and mostly consisted of family members or people related to disability services. Very few service users had friends or acquaintances outside of these services. Family contact increased for some, but came at the cost of the loss of key relationships with staff and peers, especially when moving away from the area that individuals had spent their recent years living in. Both segregation and social isolation of service users in the community were highly prevalent.

Arguably the most damning finding is that, 22 years later, the present results mirror almost perfectly those of Emerson and Hatton (1996). As was found in their review, community use increased but did not appear to increase integration with members of ‘the community’. This indicates that despite the introduction of policies such as Valuing People and Transforming Care, no meaningful changes to the integration of deinstitutionalised service users have occurred over the past 14 years. And yet, perhaps rather than damning, this result is somewhat inevitable. When the problem is defined as a lack of normalcy and integration, the proposed solution continues to be make life more similar to what ‘normal’ people want, and support integration. In 2009, Valuing People Now (Department of Health, 2010) was published. This document recognised how little progress had been made towards the lack of community integration but pressed ahead regardless with social inclusion as a core strategy, ignoring how the prerequisites were difficult or impossible to achieve for most service users (Hall, 2010).

As Clegg et al., (2008) argued, when inclusion was not working, the solution has always been to do more of the same. The key issue is that people with intellectual disabilities are a heterogeneous group, separated by cognitive, adaptive, and communicative abilities (among others); personal desires; and any number of other individual factors and until that is recognised in policy, little progress will be made.
While community integration is not always possible for service users, meaningful and intimate social relationships do appear to be both possible and beneficial for far more service users. These relationships might neither be requisites of, nor benefited by integration into the community (Clegg & Standen, 1991).

Measures used to examine the things that matter to service users routinely demonstrate that close personal relationships are most important to them and community integration is least important (Cummins & Lau, 2003). Regardless of where service users reside, relationships with staff and family tend to be the most meaningful.

Throughout the reviewed literature, the importance of staff relationships were highlighted. Forrester-Jones et al. (2002) observed how the reciprocity of the relationships with staff were very important to some service users and Head et al. (2018) showed how upsetting the loss of pre-move relationships with staff members could be. When viewed from an attachment based perspective, this makes sense. The role of staff as secure bases has been highlighted in the British Psychological Society’s recent guidance as an important protective factor for the emotional wellbeing of service users (British Psychological Society, 2017). While clearly not a focus of the reviewed studies, this feels like an important consideration that has been neglected in both the studies and in wider policies.

Service users who are securely attached to staff members tend to be less irritable, lethargic, and demonstrate fewer stereotypic behaviours (De Schipper & Schuengel, 2010). Staff members who are attuned to and supportive of the needs of service users in their care are especially important for those who are less able to communicate. Properly attuned staff members can often identify changes in a service user’s mood from subtle changes in expression or behaviour, then can act accordingly to reassure them (Reinders, 2010). This is especially important in the community where acting in a way perceived as deviant or
inappropriate can lead to exclusion or being ostracised. Staff turnover can be high in care services however and this can lead severely impact the quality of care received (Buntinx, 2008). Individuals with attachment difficulties will struggle more with high turnover (especially when a trusted person leaves) and this may be a cause of problematic behavioural and relationship outcomes. Staff teams often decide that a service user ‘should not be told’ of a staff member leaving to avoid ‘causing behaviours’. Attempts to protect them that paradoxically lead to more anxiety and associated problems. This is exemplified by Hubert and Hollins (2010) observing that the lives of the studied service users ebbed and flowed with the coming and leaving of subsequent home managers and care staff.

4.1. Limitations of reviewed studies

The studies contained little information about the areas that were moved out of or into. Factors such as levels of deprivation or hate crime would be important for wider considerations about which areas are deinstitutionalised into. Forrester Jones et al. (2002) and others found that some participating service users experienced varying levels of harassment in the community and from neighbours. This is consistent with previous evidence which has demonstrated that people labelled with intellectual disabilities living in the community are made to endure far more discrimination and abuse than almost any other group (e.g Goodley & Runswic-Cole, 2011).

Alongside this, there was little information about the availability of community services. Additionally, as Transforming Care recommends that service users be moved closer to where they grew up, it would have been useful to have information regarding whether this happened and the distance that was moved. After-all, many service users in the studies had lived out of area for upwards of ten years and so moving back home may represent moving to an area that has become entirely unfamiliar.
There were no pre-move baseline data for some studies such as the social circles done by Forrester-Jones et al. (2006) or the seven-day diaries by Ager et al. (2001). As such, it is difficult to say whether these things had been different pre-move. However, as both demonstrated limitations in integration, it is perhaps irrelevant whether these things are better or worse if they are currently sub-optimal. Additionally, there were no rigorous comparison or control conditions that examined the results of moving to different community residence types or at different times.

While relationships with family were found to increase, none of the included studies examined if families continued to exclude service users from family events such as funerals or weddings despite living closer.

**4.2. Research implications**

Normalisation principles, as have been implemented, place the onus upon the disadvantaged group to meet the expectations of the majority. Instead of this, it might be time to examine what more can be done with individual communities to help them be more understanding and sensitive to the needs of service users who live near them. Researchers such as Walker and Scior (2013) have demonstrated that attitudes community members hold towards individuals with intellectual disabilities can be changed.

There is also a paucity of research examining what service users do in the community, and how much of a sense of integration they experience when engaged in the use of community facilities. Further research could study levels of integration as perceived by service users and others in a variety of environments including segregated and unsegregated community facilities.
4.3. Clinical implications

Services need to focus more on developing environments where service users feel safe and where attachment to key figures is prioritised. In addition to this, more needs to be done to address the turnover of staff and ensure that service users receive consistent care from people that they can develop trusting relationships with.

Policy documents such as *Valuing People* and *Transforming care* suggest that staff disempower service users by providing them support. However, as Bell and Clegg (2012) have argued, some individuals will experience increased access to local community facilities, and their own tenure on a rented property positively, while others prefer the containment, structures and safety of a setting where they are explicitly cared for and protected. Van Hooren (2002) argued that the best way for service users to achieve autonomy is to give them staff who can provide high quality support that fosters self-determination and self-development. Alongside this, services should be developed to value who the person is for who and how they are rather than prioritising skill development. This may mean moving away from normalisation or medical understandings of disability. Throughout *Valuing People*, it is implied that autonomy and independence should be aimed for as goals. This is not always a value that non-disabled people strive for however, as interdependence appears to be much more common in the form of relationships or marriage. Interdependence is not deemed by people making decisions for people with intellectual disabilities to be something said individuals should strive for or even be encouraged to experience.

If policy moves away from the normalisation model, it allows the argument that support for service users can look different to what is ‘normal’ and afford more creative solutions that incorporate both what the person deems important to them as per the current system, but also what those who know them best think is important for them. Specially
designed spaces can support service users to feel a sense of purpose and of belonging, while affording more meaningful social relationships (e.g. Hall, 2010).

More work needs to be done with communities to support them to be welcoming and understanding to service users. Rather than trying to present a romanticised version of what a small number of service users are capable of doing for the community, support needs to be provided to help community members to be welcoming and accepting of individuals as they are.

4.4. Conclusion

Policies such as Valuing People have stated unequivocally that deinstitutionalisation will improve the lives of service users, in part because of greater integration in the community. As has been demonstrated, the evidence base is not clear on this and does not warrant the blanket policy of how all service users should be cared for.

The dichotomy between institutions and community is a false one, because no approach will be successful when it attempts to imply that all service users are the same and that the desires and potential of a few are representative of them all. Some individuals will benefit from the freedom and relationships that they gain living in the community. Some may benefit more from the high levels of structure and containment of a hospital setting. If that or any other system is what an individual needs, then it should not be discounted because it doesn’t fit with policy. Ultimately, there is very unlikely to be a ‘one-size fits all’ solution given the heterogeneity of the population. Services need to be more centred around the person, their desires, and their capacity. Something that, somewhat ironically, appears to be lacking in modern ‘person-centred’ care.
5. References


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Section B: Research Report

The impacts of deinstitutionalisation on the quality of life of individuals with intellectual disabilities

Abstract

Background

Current UK policy regarding people with intellectual disabilities suggests that individuals who require staffed care services should be deinstitutionalised into the community. This is believed to yield greater quality of life for service users through a process of normalisation. Accordingly, the current study sought to examine how deinstitutionalisation impacted the quality of life of a cohort of 14 service users.

Method

A longitudinal mixed methods approach was adopted. Quality of life measures were conducted with staff members acting as proxy informants for the cohort. Measures were completed prior to service users moving out of long stay hospital accommodation and were repeated eight years later when they were living in private community services. At the second time point, conversations between researchers and staff members were transcribed and used as the basis for template analysis. Quantitative data was missing for some service users and so analyses were completed for between nine and 11 service users.

Results

Six themes were created: Social relationships; community use; choice; emotional wellbeing; adaptive behaviour; and challenging behaviour. Individual differences greatly impacted results, but most service users appeared to have experienced an increase in emotional wellbeing and were offered a greater range and frequency of access to community facilities. Most service users appeared to have developed important social relationships with staff, peers, and family but few had relationships with members of the community. Choice, adaptive behaviour, and challenging behaviour appeared unchanged by deinstitutionalisation for most service users.

Conclusions

Overall, the move from institutional to community based homes had varied greatly for the cohort of service users. Quality of life appeared very dependent on the ethos and quality of individual staff teams supporting individuals.
1. Introduction

1.1. Background

Deinstitutionalisation is the process of moving people with intellectual disabilities (ID) out of institutions and into community-based provisions. UK policy for people with ID has been organised around ideology supporting such processes for almost 50 years (Department of Health, 1971). These changes have been linked to growing concern from the 1960s and 70s about the effects of being institutionalised and as a critique of the current medical and political policies as made by antipsychiatry movements (Scull, 1984).

In part because of the public response to the levels of emotional and physical abuse of service users documented in the now infamous Winterbourne View hospital (BBC, 2011), a UK government report was commissioned in 2012 to examine how care services were run: Transforming Care (Department of Health, 2012). The main recommendations were that all long stay hospitals in the UK should be closed and that individuals should be cared for by family or in community residential settings. In February 2015, the NHS responded by committing to close all long-stay hospitals by 2018 (NHS England, 2015).

The current study aimed to examine how the quality of life had changed for a cohort of people with severe intellectual disabilities eight-years after moving from institutional care into community based services. The move was made in line with recent government policy (Department of Health, 2009) and was viewed by professionals as an opportunity to improve the quality of life for these service users.
1.2. Theoretical context

The notion that residing in community services will be better for service users than long-stay institutional care is underpinned by a ‘normalisation’ ideology (Nirje, 1982), a theoretical context that supports deinstitutionalisation by suggesting that if individuals are seen to behave and contribute in a similar fashion to other members of society, they will be perceived more positively. As such, practical and social supports are put in place to help service users to develop roles valued by communities (Jones, McWade & Toogood, 2016). Wolfensberger (1972) stated that an aim of normalisation was to be around more positive role models in the community.

The increased focus on service user self-determination through the freedom to make choices repositions individuals as consumers of care (Reinders, 2008). This supports current political ideologies rather than supporting the best interests of service users as it necessitates a decentralisation of resources in favour of privately managed services. In doing so, an increased focus is placed on services to prove their value through audits and paperwork, activities that take staff members away from the individuals that they support.

The normalisation agenda often neglects the impact of deficit with regards to the potential for individuals to act into the norms required for integration within an intolerant society (Cummins & Lau, 2003). Much of the literature considering normalisation and people with intellectual disabilities tends to invoke the voices of the more ‘able’ in ways that can mask the needs of people with more severe disabilities (Clegg & Bigby, 2017), providing a context for policy-makers to presume that what constitutes a ‘good-life’ for people with severe impairments will be similar to the neoliberal ideals for intellectually privileged people.

However, as has been argued previously, environments are rarely set up to afford the necessary changes that individuals are expected to make (Bell & Clegg, 2012). As the authors argue, too little consideration of service users’ abilities and limitations are given, and too few
concessions in the social environment are made. Integration with others, for example, requires some degree of communicative ability. Yet it is the person with intellectual disability who is expected to develop, possibly far beyond their personal limitations, to speak fluent English rather than members of the community being supported to understand other forms of communication and empathy. This is despite there being no evidence that Speech and Language interventions are able to develop speech in those with no verbal communication skills and only a small number of studies indicating that speech can be meaningfully improved (e.g. Terband et al., 2018).

Additionally, emphasis is placed on independence rather than interdependence, and too little importance is placed upon the experience of being loved or cared for by another (Bell & Clegg, 2012). Indeed, at other times such relationships with staff can be viewed negatively, as contrary to normalised principles of developing ‘independence’ and ‘maintaining boundaries’ (e.g. British Psychological Society, 2017). However, De Schipper and Schuengel (2010) showed that service users who demonstrated secure attachment behaviours towards paid carers were less irritable and more active.

Despite these criticisms, normalisation has many proponents in deinstitutionalisation based research: Examinations of service users’ quality of life pre- and post-move into the community have generally been measured according to normalisation based principles (e.g. Bhaumik, 2011; Donnelley, 1996). However, there has been little consensus with regards to what constructs should be considered relevant and how these should be measured, which is perhaps unsurprising given that this is a somewhat nebulous construct (Keith, 2007). Verdugo et al. (2012) argued that quality of life was based on eight basic rights: Personal development; self-determination; interpersonal values; social inclusion; rights; emotional wellbeing; physical wellbeing; and material wellbeing. Others have created similar lists with differing domains (see
Sines et al., 2012 for a review). Schalock et al. (2002) however, argued that the exact domains of quality of life are less important than the acceptance that there are multiple elements that will be differently weighted depending on what is important to individuals.

Behaviours deemed challenging (herein called challenging behaviours) are also often studied alongside quality of life in deinstitutionalisation studies as reduction in said behaviours is a stated aim of Transforming care (E.g. Bhaumik et al., 09). While not a domain of quality of life, challenging behaviours could be seen as either a potential barrier to domains such as community integration (Emerson & Hatton, 1996) or could be seen as a functional expression of unmet need that therefore acts as a communication of an individual’s personal experience of their quality of life (Emerson, 1995). Positive behaviour support methodologies tend to simplify challenging behaviour to triggers and consequences, but in doing so risk ignoring the emotional pain that a person might be experiencing (Skelly, 2016).

1.3. Previous studies examining the impacts of deinstitutionalisation

Numerous studies have found evidence of improvements in quality of life. Community access has been found to increase post move (e.g. Ager et al., 2001; Bhaumik et al; 2011; Dagnan et al., 1998). Adaptive behaviour has also been found to increase post-move (e.g. Hamelin et al., 2011). Choice making opportunities and abilities have been found to increase post-move in some studies (Sines et al., 2012), though a recent review found that moving did not guarantee increases in this area (Kozma et al., 2009). Another review by Emerson and Hatton (1996) demonstrated that service users experienced a wide range of improvements post move, though they found a large degree of variability between services and individuals.
Challenging behaviour tended not to be impacted by deinstitutionalisation. This was also found by Kozma and colleagues.

Negative aspects were also found however, with studies demonstrating that social networks appeared to be unaffected by moving into the community and social isolation and loneliness remained prevalent (e.g. Chung et al., 1995). Some services examined within studies remained institutional in nature, which has been argued could lead to increased dehumanisation (e.g. Hubert & Hollins, 2010).

1.4. Rationale and aims

That service users should be moved into the community has been a blanket government policy since 2011. While this is ostensibly done to improve lives, the evidence for the gains for the people being moved is equivocal. To ratify this claim, longer term evidence is required to explore whether such policies result in improved quality of life, and to consider if policy and service provision might be altered to benefit those who have been moved to community placements. This study examined changes in quality of life for 14 service users relocated from hospital settings in a UK city in 2009-2010. These service users were part of a cohort of 38, who were the last in the area to be deinstitutionalised out of multiple occupancy hospital-based accommodation.
2. Method

2.1. Design

A mixed-methods design was employed utilising qualitative and quantitative data for purposes of convergent triangulation (Fetters et al., 2013). The quantitative strand utilised a longitudinal within-subjects design. The IV was the period of measurement (2 Levels: T0= pre-move; T1 = 8 years post-move); the DVs were scores on various measures that aimed to assess different domains of quality of life. Qualitative data was gathered through interviews with staff familiar with a given service user at T1. Interviews focussed on perceived changes associated with the move. A ‘questerview’ design (Adamson et al., 2004) was employed, whereby transcriptions of the discussions surrounding completion of the quantitative measures were coded for perceived ‘positive’ and ‘negative’ changes. This allowed for contextual information about perceived differences for a given person to be considered within the study. Due to obtaining a small sample, the qualitative strand was foregrounded, with changes on the quantitative measures at an individual level used for purposes of triangulation.

2.1. Ethical Approval

Ethical approval for this study was granted through a University of Leicester research ethics panel (Appendix E).

2.2. Participants

The main informants for this study were staff members from three community-based services providing care for the service users. These services were funded by local authorities and included two charities and one private company. These services supported 22 of the original 38 people moved as part of the deinstitutionalisation project. However, one of the
services was not able to free up time for staff to meet with the Researcher during the course of the study. Three service users had been removed from that organisation’s care due to safeguarding issues. The Researcher met with the social workers that were rehousing these individuals as it felt important that information about these people’s experiences was included.

Accordingly, the experiences of a total of 14 service users were documented (37% of the original sample). Table 5 provides a breakdown of the included service user demographics.

At T1, service users’ physical, neurological, and physical difficulties were examined as these were potentially confounding. These are demonstrated in Table 6.

**Table 5: Characteristics of service users relocated into the community**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>12</td>
<td>86</td>
</tr>
<tr>
<td>Female</td>
<td>2</td>
<td>14</td>
</tr>
<tr>
<td><strong>Age (on date of move)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;45 years</td>
<td>2</td>
<td>14</td>
</tr>
<tr>
<td>45 – 54 years</td>
<td>7</td>
<td>50</td>
</tr>
<tr>
<td>≥ 55 years</td>
<td>5</td>
<td>36</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>14</td>
<td>100</td>
</tr>
<tr>
<td><strong>Residence post-move</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single occupancy</td>
<td>7</td>
<td>50</td>
</tr>
<tr>
<td>Single occupancy on same site as pre-move</td>
<td>2</td>
<td>14</td>
</tr>
<tr>
<td>2 person house</td>
<td>2</td>
<td>14</td>
</tr>
<tr>
<td>Multiple occupancy (3+) on same site as pre-move</td>
<td>3</td>
<td>22</td>
</tr>
</tbody>
</table>

**Table 6: Prolonged and degenerative difficulties experienced by service users**

<table>
<thead>
<tr>
<th>Condition</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pre-existing conditions maintained post-move</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Epilepsy</td>
<td>5</td>
<td>45%</td>
</tr>
<tr>
<td>Limited mobility requiring wheelchair use</td>
<td>2</td>
<td>18%</td>
</tr>
<tr>
<td><strong>Pre-existing conditions that have degenerated since move</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rheumatoid arthritis</td>
<td>1</td>
<td>9%</td>
</tr>
<tr>
<td>Dementia</td>
<td>1</td>
<td>9%</td>
</tr>
<tr>
<td>Limited mobility requiring wheelchair use</td>
<td>1</td>
<td>9%</td>
</tr>
<tr>
<td><strong>Post-move conditions</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loss of use of hand due to fall</td>
<td>1</td>
<td>9%</td>
</tr>
<tr>
<td>Limited mobility requiring wheelchair use</td>
<td>1</td>
<td>9%</td>
</tr>
<tr>
<td>Ill health condition being currently examined</td>
<td>1</td>
<td>9%</td>
</tr>
</tbody>
</table>
Participating staff were initially identified by home managers based on the inclusion hierarchy detailed in Table 7. Managers provided identified staff members with a participant information sheet (Appendix D) and interested staff members contacted the Researcher to arrange a time convenient for them to participate. A total of 12 informants participated, including 10 support workers and two social workers. The sample consisted of two men and ten women. All were ‘white British’. Table 4 indicates the frequency which informants met the different preference-levels for the inclusion criteria. The support workers had known the service users they were discussing for a mean of 13.46 years (SD = 10.14, range: six to 38). The social workers providing information about the three people under safeguarding had known the service users they were reporting on for a mean of 8 months (SD = 0, range: 8 months to 8 months).

**Table 7: Inclusion Hierarchy**

<table>
<thead>
<tr>
<th>Current key worker</th>
<th>Currently work with the individual</th>
<th>Minimum duration working with individual</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Most favoured</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>X</td>
<td>✓</td>
<td>Pre-move</td>
<td>5</td>
</tr>
<tr>
<td>✓</td>
<td>X</td>
<td>Pre-move</td>
<td>1</td>
</tr>
<tr>
<td>X</td>
<td>✓</td>
<td>2 years</td>
<td>5</td>
</tr>
<tr>
<td>X</td>
<td>✓</td>
<td>2 years</td>
<td>0</td>
</tr>
<tr>
<td>X</td>
<td>X</td>
<td>6 months</td>
<td>0</td>
</tr>
<tr>
<td><strong>Least favoured</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>X</td>
<td>X</td>
<td>6 months as external professional (e.g. social worker, physiotherapist etc.)</td>
<td>3</td>
</tr>
<tr>
<td><strong>Excluded</strong></td>
<td>X</td>
<td>&lt; 6 months</td>
<td></td>
</tr>
</tbody>
</table>
2.3. Materials

The quantitative measures are outlined in table 8 and psychometric properties are listed in Appendix I. There is a distinction in the measures between those that measure quality of life directly and those that measure skills. These are considered in parallel below as, privileging a social-model understanding of disability, ability could be understood as an interaction between person and context.

Social networks were examined with respect to the numerical frequency of different types of relationships. Individuals in a social network were ascribed a type of relationship based on relational role (family, staff, peer, member of the community), and perceived level of closeness, with informants making decisions about whether a given contact should be placed in a service user’s ‘inner’ or ‘outer’ circles based on a perception of how important this relationship was to the person (see Appendix J).
<table>
<thead>
<tr>
<th>Measure</th>
<th>Subscale / Factor</th>
<th>Aims to measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health of the Nations Outcome Scale - Learning Disability version (HoNOS-LD) (Roy et al., 2002)</td>
<td>Cognition and communication</td>
<td>Disturbances in cognitive and communicative function</td>
</tr>
<tr>
<td></td>
<td>Behaviour, mood, and relationships</td>
<td>Challenging behaviour directed at self or others; mood disturbances; relationship difficulties and breakdowns</td>
</tr>
<tr>
<td></td>
<td>Loss of adaptive functioning</td>
<td>Reduction in daily living skills</td>
</tr>
<tr>
<td></td>
<td>Internal dysregulation</td>
<td>Emotional, mood, or mental health based problems</td>
</tr>
<tr>
<td></td>
<td>Full scale</td>
<td></td>
</tr>
<tr>
<td>Mood, Interest and Pleasure Checklist (MIPQ) (Ross &amp; Oliver, 2003)</td>
<td>Mood</td>
<td>Positive emotions and mood</td>
</tr>
<tr>
<td></td>
<td>Interest and Pleasure</td>
<td>Positive interests and enjoyment</td>
</tr>
<tr>
<td>Adapted version of Resident Choice Scale (RCS) (Hatton et al., 2004)</td>
<td>Communication</td>
<td>Freedoms and abilities to make choices over daily life</td>
</tr>
<tr>
<td></td>
<td>Community use</td>
<td>Verbal communication skills</td>
</tr>
<tr>
<td></td>
<td>Communication</td>
<td>Community based skills</td>
</tr>
<tr>
<td></td>
<td>Home living</td>
<td>Home maintenance and management skills</td>
</tr>
<tr>
<td></td>
<td>Health and safety</td>
<td>Skills around personal safety in and outside of home</td>
</tr>
<tr>
<td></td>
<td>Leisure</td>
<td>Self-occupying and interactional skills</td>
</tr>
<tr>
<td></td>
<td>Self-care</td>
<td>Self-care skills</td>
</tr>
<tr>
<td></td>
<td>Self-direction</td>
<td>Independence and choice based skills</td>
</tr>
<tr>
<td></td>
<td>Social</td>
<td>Interpersonal skills</td>
</tr>
</tbody>
</table>

4 The Health of the Nations Outcome Scale - Learning Disability version (HoNOS-LD) (Roy et al., 2002) was divided into four factors as designed and validated by Skelly and D’Antonio (2008)
2.4. Procedure

All staff members participated at their work place. Interviews lasted a mean of 81.6 minutes (SD= 18.0 min, range= 59 to 115min). In keeping with the ‘questerview’ design, no formal interview schedule was developed, and recorded conversations revolved around completion of the materials described above. The Researcher asked questions from the measures and facilitated further discussion based upon responses (e.g. ‘how has this made things better for the person?’; ‘how has this led to a reduction in their skills?’). The social workers were not able to complete items on the quantitative measures due to lacking familiarity with the service users’ day-to-day lives, so instead responded to questions enquiring about their perceptions of changes for the individual(s) they worked with. Detailed notes were taken in addition audio-recordings. The audio was not usable for one informant and so these notes were used instead.

2.5. Analysis

Template analysis (King, 1998) was used to analyse the transcripts. An initial template of *a priori* themes was created as a starting point for reviewing transcripts and was devised based upon the seven domains of Quality of Life as outlined by Verdugo et al. (2012). This was applied to a single transcription and an initial full template was generated. This was then refined iteratively over subsequent transcriptions based on the themes’ relevance or lack thereof to the data. All transcriptions were then codified a second time against a final set of themes. With the focus being on evaluating the impact of living in the community, the Researcher examined the data in accordance with evidence of improvements, decline or maintenance. *A priori* themes are considered helpful and relevant starting points for analysis, especially from a realist stance (appendix A), as long as they are used tentatively and are open to refinement or removal as necessary (King, 1998).
Informants’ responses were then coded as referring to ‘positive’, ‘negative’ or ‘little/no’ change for each of the themes identified. Appendix K contains an outline of the analysis process.

Themes were created based on an ‘empathic interpretation’ (e.g. Willig, 2013) of transcription data. That is to say, interpretations were made with the implicit assumption that respondents were being genuine and truthful. Participants’ statements were not taken as necessarily reflecting the reality of a service users’ experience, but were taken to represent a valid representation of their perceptions of how things were for a given individual they supported. Quantitative data was used to support or refute these interpretations. Staff views that were supported by quantitative outcomes were considered to be more valid depictions of service users’ experiences than views that were contested by data.

Quantitative data was analysed using SPSS version 24 using parametric or non-parametric repeated-measures tests, dependent upon the properties of the data (normality assessments are detailed in Appendix L). One individual had dementia and this was potentially a large confound. Accordingly, data for the ABAS-II was not collected for that individual. All other analyses were completed with and without their inclusion and no differences in significance were found. As such, their data was included in all other analyses (see Appendix M for analyses with this service user excluded). In addition to the group-level comparisons, reliable change indexes (Jacobson & Truax, 1991) were utilised where possible to explore whether the change at an individual level was greater than could be expected based upon error associated with a scale’s reliability. Measurements were made using the Leeds Reliable Change Index Calculator (Agostinis et al., 2008).

Chi squared goodness of fit tests were utilised with the social networks data to examine differences between frequencies of the different relationship categories.
2.6. Data treatment

A Bonferroni correction was not applied to the data for multiple comparisons due to it having been elsewhere argued that such corrections are less applicable to studies with clearly defined, pre-determined DVs (Moran, 2003). As the cited article suggests, reducing the alpha level when more than 10 analyses are conducted risks being too conservative.

T0 data from one to two service users was missing on the ABAS-II, the MIPQ, the RCS, and the emotional wellbeing scale. At T1, no quantitative measures were completed for three service users due to informants not being familiar with these individuals’ day-to-day lives (see above). Accordingly, repeated-measures analyses were conducted with sample sizes ranging from nine to 11.

2.7. Quality Assurance

Elliott et al. (1999) outlined seven guidelines that should be followed to ensure that qualitative research demonstrates appropriate scientific rigour. These are detailed in Appendix N alongside a description of the ways in which the Researcher attempted to follow them.
3. Results

Six themes were created based on the qualitative data. These related to changes in: Social relationships; community use; choice; emotional wellbeing; adaptive behaviour; and challenging behaviour. Though these were partly based on previously defined domains of quality of life, they did not map perfectly onto these domains as they were rooted in the interview data.

This section begins with a presentation summary data and then discusses each theme as a sub section. All discussion and consideration of qualitative data is based on a full sample of 14 service users, including three for whom social workers acted as informants and therefore no quantitative data was available. These three were not examined separately as doing so was felt to be placing a judgement on their value. Accordingly, quantitative data may represent more positive findings than qualitative data, especially with regard to social networks.

Group level quantitative data for relevant measures are discussed in individual sub sections below. Reliable Change Index changes for each service user are tabulated in Appendix O. Overall, individual change scores indicated significantly more improvements than declines, \( \chi^2(1, N = 45.5) = 20.32, p < .001 \), however this comparison should be viewed cautiously due to interdependency between the skills and opportunities being measured.

Each of the qualitative themes are then discussed with consideration given to the relevant quantitative results for purposes of triangulation. Quotes are used to back up and elaborate upon theme content. Numbers following quotes refer to the identifying code assigned to each service user.

Interview data relating to the identified themes were further coded into subthemes reflecting ‘positive, ‘negative’ or ‘little-to-no’ change. Table 9 denotes the frequency with which an informant indicated a particular type of change for a given service user. Subthemes
were not mutually exclusive, meaning an informant might raise changes that were coded as both ‘negative’ and ‘positive’ for the same theme.

**Table 9: Themes that were created based on transcription data**

<table>
<thead>
<tr>
<th>Theme</th>
<th>Positive changes</th>
<th>Negative changes</th>
<th>Little-to-no change</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>Social relationships</td>
<td>12</td>
<td>86</td>
<td>6</td>
</tr>
<tr>
<td>Community use</td>
<td>10</td>
<td>71</td>
<td>4</td>
</tr>
<tr>
<td>Choice</td>
<td>10</td>
<td>71</td>
<td>3</td>
</tr>
<tr>
<td>Emotional wellbeing</td>
<td>8</td>
<td>57</td>
<td>5</td>
</tr>
<tr>
<td>Adaptive behaviour</td>
<td>6</td>
<td>43</td>
<td>5</td>
</tr>
<tr>
<td>Challenging behaviour</td>
<td>6</td>
<td>43</td>
<td>4</td>
</tr>
</tbody>
</table>

3.1. Social relationships

Social relationships was the most frequently cited area of improvement by informants, with 12 out of 14 informants indicating there had been positive changes in this domain, whereas six identified negative changes.

An underpowered comparison of the scores on the Social domain of the ABAS-II indicated that the social skills of service users had not changed significantly, however indicated a small improvement based on effect-size (see table 10). At an individual level, reliable change was only achieved for four service users as can be seen in Figure 2. No scores indicated reliably significant deterioration.
Table 10: Group level analysis for outcome measures related to Social relationships

<table>
<thead>
<tr>
<th></th>
<th>T0 n</th>
<th>Mean</th>
<th>SD</th>
<th>T1 Mean</th>
<th>SD</th>
<th>Paired samples t-test</th>
<th>t</th>
<th>p</th>
<th>dz</th>
<th>Power</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABAS-II: Social</td>
<td>10</td>
<td>17.88</td>
<td>17.27</td>
<td>23.13</td>
<td>17.16</td>
<td>1.02</td>
<td>.33</td>
<td>.30</td>
<td>.14</td>
<td></td>
</tr>
</tbody>
</table>

Figure 2: Reliable change index scores for ABAS-II: Social
(higher post-move scores indicate improvements, range of possible scores: 0-69)

Social circle data completed for 11 of the service users indicated that they had a mean of 19.45 members in their total networks (SD = 6.89, range: 12 to 35), with a mean of 8.36 being in their ‘outer circles’ (SD = 6.07, range: 2 to 22), and 11.09 in their ‘inner circles’ (SD = 2.55, range: 7 to 15). Pie charts indicating the relative proportion of different categories of people for each of these networks can be seen in Figures 3, 4 and 5 respectively and
descriptive statistics can be seen in Table 11. The remainder of the subsection will proceed by drawing out changes identified as important by informants, triangulated against data from the social network circles.

Figure 3: Breakdown of types of relationships in service users’ inner circle

Figure 4: Breakdown of types of relationships in service users’ outer circle
Figure 5: Breakdown of types of relationships in service users’ total social networks

Table 11: Descriptive statistics for social networks

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Inner circle</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family</td>
<td>2.18</td>
<td>1.78</td>
<td>0 – 6</td>
</tr>
<tr>
<td>Peers</td>
<td>1.09</td>
<td>0.70</td>
<td>0 – 2</td>
</tr>
<tr>
<td>Community members</td>
<td>0.27</td>
<td>0.65</td>
<td>0 – 2</td>
</tr>
<tr>
<td>Staff / professionals</td>
<td>7.55</td>
<td>2.21</td>
<td>4 – 11</td>
</tr>
<tr>
<td><strong>Outer circle</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family</td>
<td>0.45</td>
<td>1.21</td>
<td>0 – 4</td>
</tr>
<tr>
<td>Peers</td>
<td>0.73</td>
<td>1.27</td>
<td>0 – 5</td>
</tr>
<tr>
<td>Community members</td>
<td>2.27</td>
<td>2.49</td>
<td>0 – 8</td>
</tr>
<tr>
<td>Staff / professionals</td>
<td>4.91</td>
<td>3.73</td>
<td>0 – 13</td>
</tr>
<tr>
<td><strong>Full network</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family</td>
<td>2.64</td>
<td>1.73</td>
<td>0 – 10</td>
</tr>
<tr>
<td>Peers</td>
<td>1.82</td>
<td>1.02</td>
<td>0 – 4</td>
</tr>
<tr>
<td>Community members</td>
<td>2.55</td>
<td>2.05</td>
<td>0 – 6</td>
</tr>
<tr>
<td>Staff / professionals</td>
<td>12.45</td>
<td>3.28</td>
<td>5 – 19</td>
</tr>
</tbody>
</table>
3.1.1. *Family members*

Moving into the community was perceived to have resulted in increased contact with family members for seven people. Three service users saw one or more members of their family on at least a weekly basis.

‘Well, his mum and dad come frequently now, because they live quite close by. So, they come perhaps every day, every other day to see him.’ (11)

However, this wasn’t the case for all service users:

‘He’s no family contact. Basically, when [Service User] moved here, [Service Provider] wrote to his sister-in-law in Scotland, I believe there’s only her alive. And she never replied.’ (7)

‘She hasn’t got any family. We tried looking for family and nobody’s come forward.’ (2)

3.1.2. *Peers*

8 people (72%) maintained relationships with disabled others from previous accommodation or day-centres. Maintenance of these relationships tended to be reliant upon staff supporting contact. The community appeared to offer benefits through more boundaried contact with peers for one person:
'We take him by car up to some ladies that he used to live with. He used to live in the same bungalow as them. So, he does enjoy going to see them, but I don't think he’d enjoy going to live back with them. I think he enjoys his space here.' (11)

3.1.3. Community members

The social circles indicated that a relatively small proportion of contacts were with members of the service users’ communities, especially with regard to their ‘inner circles’.

One service user had developed relationships with members of a swimming group:

‘People there got to know him. To me, that’s community inclusion 110%. They knew him and me there. He doesn’t swim, he walks, but I think he really enjoys it. It’s the people talking to him and saying ‘hello’ that he really likes there. It’s the same people that go Monday, Wednesday, Friday.’ (8)

These relationships developed despite his ABAS-II Social scores being amongst the lowest of the cohort, and as the quote above illustrates, might have been aided by the consistent support of staff to accompany him to an activity regularly in which he was able to encounter the same people, who could become familiar with him over time. He was very much in the minority however, and accordingly had the highest number of community contacts in his network (8 people). While other service users had developed community relationships, these tended to be more superficial in nature and were not perceived as important by staff. Accordingly, community contacts made up only 2% of service users’ average ‘inner circles’.
'Every time they go shopping [Service User] will say ‘bye’, like that, then till operator will say ‘bye’, then [Service User] will go ‘bye-bye, bye-bye’.‘ (4)

‘He would talk to the neighbours as well. I wouldn’t say they were really important but if he saw them he would wave.’ (11)

For some service users who find relationships difficult, this may have been as close as they were able to get to making connections with others and may have represented meaningful relationships to them.

Service users tended to have few relationships with people unrelated to disability services: Nine (82%) had no community contacts in their inner circles and four (36%) had no community contacts in their networks at all. Excluding the people service users lived with, service users had a mean of four unpaid, non-family relationships in their lives (SD = 3.07, range: 1 to 10), with only a mean of one in their inner-circles (SD = 0.92, range: 0 to 3).

3.1.4. Staff and other professionals

Staff members and professionals such as GPs, dentists, and chiropodists constituted the largest type of relationship, accounting for 64% of the total networks. All service users had at least four staff members in their inner circles. The different ethos of community homes also appeared to have supported closer relationships between service users and staff members. Staff reported that smaller, more intimate staff teams and a shift in policy whereby staff would do more alongside service users (e.g. eating meals together) allowed for more connected relationships.
‘I would say most important [relationships for person] is staff. I’d say she’s possibly close to us all really.’ (2)

‘He’s like family, they all are. We spend so much time with them.’ (4)

Even the service users who were in the process of being moved were perceived by social workers to have some positive relationships with staff members.

“He did appear, to me, to have quite a good relationship with the staff that were on at that time because he was sort of leaning on their shoulder and laughing and joking with them.” (13)

Social relationships with one or more staff members were reported by all informants. However, one service user had been understood by services as becoming too obsessional with staff members and so had experienced close relationships being moved to other services. This was described as necessary for staff member safety as he had become aggressive towards them at times. Though staff members did not tell him that this was why others had been removed, he nonetheless experienced a loss of individuals that he became close to.

It is also possible the relative importance of relationships with staff might, for some, be related to the paucity of non-paid relationships however. Three service users were thought to have become more isolated due to the location of their home. Two of these had enjoyed being able to see others through the window, and one appeared to miss having other service users in their home.
‘I think at [institution], the bungalow that he was in, he could see activity going on. People going from one bungalow to another. Where he sat, he could look up the drive and see.

Whereas here, he was often looking out the window, [...] there’s not a lot of activity.’ (10)

In this regard, it could be argued that these service users were less part of a community than they had been pre-move. The difficulty in socialising for many individuals may have meant that this observation had been an important part of social contact for them.
3.2. Community use

Overall, the data indicated that service users experienced a greater range and frequency of community based activities. References to positive changes were made by 10 informants (71%), with four and zero reporting little change or worsening respectively.

There was a significant increase at the group level on the ABAS Community use and Leisure domains (Tables 12 and 13). Six people’s (55%) scores indicated reliable improvement on the Community domain (Figure 6), with seven people showing improvement on the Leisure scale (Figure 7). No person’s data indicated a reliable deterioration, though floor-effects may have prevented detection of any meaningful decline: Most scores suggested skills or opportunities remained low.

**Table 12: Group level analyses for ABAS-II subdomain: Community use**

<table>
<thead>
<tr>
<th></th>
<th>T0</th>
<th>T1</th>
<th>Wilcoxon signed rank</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Median</td>
<td>IQR</td>
</tr>
<tr>
<td>ABAS-II: Community Use</td>
<td>10</td>
<td>0.50</td>
<td>6.25</td>
</tr>
</tbody>
</table>

* p < .05

**Table 13: Group level analyses for ABAS-II subdomain: Leisure**

<table>
<thead>
<tr>
<th></th>
<th>T0</th>
<th>T1</th>
<th>Paired samples t-test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>ABAS-II: Leisure</td>
<td>10</td>
<td>12.60</td>
<td>11.22</td>
</tr>
</tbody>
</table>

** p < .01
Figure 6: Reliable change index scores for ABAS-II: Community use

(higher post-move scores indicate improvements, range of possible scores: 0 - 72)

Figure 7: Reliable change index scores for ABAS-II: Leisure

(higher post-move scores indicate improvements, range of possible scores: 0 - 69)
Increases in use of community-based facilities such as pubs, shops, and day centres were directly mentioned by 10 informants. Some individuals had regular trips for meals or activities such as bowling. All service users experienced one or more activity that they had not accessed pre-move. Only three people still accessed segregated services such as day-centres. This may represent a lack of desire to do so for some, or a lack of availability.

‘He used to go to the day centre ... when he first came here, for quite a few years, but it was his choice to stop going.’ (10)

One service user, whose scores reliably improved on both Community and Leisure ABAS domains, was encouraged to go horse riding post-move. This was built up slowly and relied on careful planning and implementation from staff.

‘I think he’s been going since last year now, it started with obviously just introducing him to the horse, and walking the horse round. ... our long term goal for him was to try and get him back on. And eventually we have got him back on.’ (9)

One of the most frequently coded statements concerning improved access to community facilities related to service users being provided with transport exclusively for them (n = 12) or shared between service users (n = 2).

‘He got a mobility car. The fleet one was only for him, whenever he wanted to. He knew it was his car. It was always parked there and [he’d say] ‘that’s my car’.’ (1)
This formed a stark contrast with the situation pre-move, where resources were more limited in terms of transport, staffing and less person-centred procedures:

‘Like if it was day trips or anything ... then they’d just pile everybody on the bus and we all went whether they wanted to go or not.’ (1)

‘He got out more. Because when we were at [Institution], we only had two staff, and when you had four wheelchairs, you couldn’t go anywhere. Here, we’re two staff with two wheelchairs.’ (11)

Four people had been on one or more holidays in the previous twelve months, with a fifth person declining such an opportunity.

Three informants described how, while not necessarily worse than in previous placements, service users did not always have the levels of community access that staff felt that they should have. For one, this was because staff had not been adequately following daily planners.

‘He was supposed to go to a day service and he wasn’t turning up to day service until after lunch.’ (13)
Two informants felt that staffing issues negatively impacted service users’ community use. One of these staff members had decided to work extra shifts to ensure that the person did not miss out.

‘With recent things where things are just getting swapped round and I felt as if he were losing out, so I’d actually come in and do an activity just purely so he’d actually get to do it.’ (5)

Another staff member reported that funding per service user had reduced to the detriment of the service they were able to provide:

‘My ideal would be if we could have two-to-one staff on all the time, so that we can take him out and do a lot more with him; where you can’t when you’re on your own….When he first came here, he did have two to one staff, at the beginning. But then, you know, it’s expensive, having extra staff on, so you’re limited.’ (11)
3.3. Choice

Service users’ increased opportunities to make choices were cited at least once by 10 informants, while inadequacies or reductions in opportunities were outlined by three. Underpowered group-level analyses revealed non-significant increases on ABAS-II: Self-direction and RCS: Choice, although the improvement on the ABAS-Self-direction scale had a medium effect size, suggesting a difference might have been detected had the sample been larger. Scores were predominantly clustered in the lowest third of possible scores however (Table 14).

Five people’s scores indicated a reliably significant improvement on this subscale, with one person’s data indicating a reliable deterioration (Figure 8). No data was available to calculate a RCI for the RCS Choice scale (Figure 9).

**Table 14: Group level analyses relevant to choice**

<table>
<thead>
<tr>
<th></th>
<th>T0</th>
<th>T1</th>
<th>Paired samples t-test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>ABAS-II: Self-direction</td>
<td>10</td>
<td>9.10</td>
<td>7.71</td>
</tr>
<tr>
<td>RCS: Choice</td>
<td>9</td>
<td>17.22</td>
<td>6.76</td>
</tr>
</tbody>
</table>

** p < .01

- Negative scores on t and dz columns denote detriments
Figure 8: Reliable change index scores for ABAS-II: Self-direction

(higher post-move scores indicate improvements, possible score range: 0 - 75)

Figure 9: Differences between T0 and T1 for scores for RCS: Choice

(higher post-move scores indicate improvements, possible range of scores: 0 – 25)
Eleven informants reported that service users experienced a wider variety of day-to-day choices in the community such as deciding when to bathe, go to bed, or what to wear. Staff typically offered choices of two sets of clothes to service users ($n = 7$). This seemed important for one person as it formed a stark contrast to how things had been for her.

‘It was ‘first up, best dressed’ in those days, whereas now it’s all individual, all her clothes and everything.’ (2)

However, this change related to a time in the service user’s life prior to immediately to the pre-move period. This woman’s scores on the RCS Choice were the lowest for the cohort, likely confounded by the difficulties staff would have offering choices due to her dementia.

Four informants described service users having had choices in the way that their homes were furnished. Five people had the choice to access the entirety of their homes, whereas pre-move areas such as kitchens had been inaccessible.

‘When he was at [Institution], he didn’t really have access to the kitchen where he has now.’ (10)

‘Like when he was in [institution], he couldn’t go in the kitchen or anything like that and food and drink are a very big thing for him.’ (1)

The qualitative improvements were supported by reliably significant improvements on the ABAS-Self-direction subscale for both these men.
Four informants reported that individuals had space and opportunity to be by themselves that were not possible in larger group environments.

‘Very much he likes being on his own so obviously it’s much better now he has his own space and it’s his choice whether he spends time with anybody.’ (1)

‘When he was in the hospital, living with other people, he liked his own space and he didn’t have it.’ (8)

While it could be argued that this was putting service users’ choice ahead of what might be best for them, such as going out, staff also reported that there was more opportunity for staff to be receptive to service users. Four informants reported service users had more choice over activities, with three adding they also had more freedom to not take part in things they did not want to

‘If we’re going out in the car, we’ll say to him, where do you want to go? I’ll say, you tell me where you want to go, and we’ll take you. Some days it’ll be just a drive …go to the park. Some days he’ll go to the coast and he’ll have a sort of walk along the sea front, have a drink.’ (7)

‘She doesn’t go out every single day. Some days she doesn’t want to go out. But we try to plan it for every day as if she’s going out.’ (2)

Staff did not always consider service users to be allowed to make choices they were capable of however: Three staff members identified service decisions that inhibited
individuals’ freedom. Two of these related to areas of the house that service users were not allowed to go in:

‘All of his kitchen cupboards are locked at all times. Including food cupboards. I don’t think that’s required any more.’ (14)

This represented a deprivation of liberty and the service user was in the process of being moved to a different service provider at the time of writing.
3.4. Emotional wellbeing

Overall, data indicated the moves had been positive for the cohort’s emotional wellbeing, however some gains may have been countered by the impacts of aging and related health conditions.

Underpowered comparisons of the scores on both the Mood and the Interest and pleasure domains of the MIPQ indicated that the emotional wellbeing of service users had not changed significantly, though both indicated medium improvements based on effect-size (see table 15).

However, adequate power was found in changes to scores on the emotional wellbeing scale, and significant improvements with a large effect size were observed (see table 16).

Individual scores on these measures are shown in Figures 10, 11, 12 and 13. As can be seen in Figure 13, scores were clustered around the very top. This indicates that staff considered service users to be very happy post-move, and six of the nine for whom data was available scored the highest possible post-move. However, the low range of possible scores (4 - 20) meant that ceiling effects were necessarily prevalent.

Table 15: Group level analyses relevant to emotional wellbeing

<table>
<thead>
<tr>
<th></th>
<th>T0</th>
<th>T1</th>
<th>Paired samples t-test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>MIPQ: Mood</td>
<td>10</td>
<td>31.70</td>
<td>7.96</td>
</tr>
<tr>
<td>MIPQ: Interest and pleasure</td>
<td>10</td>
<td>26.70</td>
<td>14.21</td>
</tr>
<tr>
<td>HoNOS-LD: Internal dysregulation</td>
<td>11</td>
<td>2.73</td>
<td>2.24</td>
</tr>
</tbody>
</table>

- Negative scores on t and dz columns denote detriments
**Table 16: Group level analyses for emotional wellbeing**

<table>
<thead>
<tr>
<th></th>
<th>T0</th>
<th>T1</th>
<th>Wilcoxon signed rank</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Median</td>
<td>IQR</td>
</tr>
<tr>
<td>Emotional wellbeing</td>
<td>9</td>
<td>15</td>
<td>5.00</td>
</tr>
</tbody>
</table>

* * p < .01

**Figure 10: Reliable change index scores for MIPQ: Mood**

(higher post-move scores indicate improvements, possible score range: 0 - 48)
**Figure 11:** Reliable change index scores for MIPQ: Interest and pleasure

*(higher post-move scores indicate improvements, possible score range: 0 - 52)*

**Figure 12:** Reliable change index scores for HoNOS: Internal dysregulation

*(lower post-move scores indicate improvements, possible score range: 0 - 16)*
Figure 13: Differences between T0 and T1 for scores on Emotional wellbeing

(higher post-move scores mean improvements, possible score range: 4 - 20)

Positive changes to service users’ emotional wellbeing post-move were described by eight staff members. Five of those made direct references to the service users being happier in their current home than they had been previously.

‘I think she’s happy. A lot happier.’ (2)

‘She tells you every day that she loves it.’ (3)

Alongside this, two staff members described a reduction in instances of low mood for the people that they supported.

‘He’ll go into a depressive phase, and that’s periodically. So, every three months he will dip into a depressive phase. Compared to when he lived in the hospital, that’s decreased dramatically,’
because when he was in the hospital that was probably for a month’s time. And now we’re talking for a week.’ (8)

This service user was rated as having made little change in his scores on the HoNOS-LD: internal dysregulation factor, indicating that staff considered him to still have these difficulties. Despite this, it was perceived that his emotional wellbeing was as ‘high as it could be’ and he had made a marked improvement in mood according to the MIPQ. However, internal dysregulation may not necessarily be indicative of mood changes per se as it is more focused on disturbances in sleep, stereotypy, and idiographic issues. As such, it is unlikely that these would be shifted by a change to environment alone, and would require direct medical or therapeutic intervention.

Negative changes were discussed by five informants. For three, this related to impacts of persistent illnesses or injuries that had occurred recently. One had been struggling to sleep recently and this had impacted their emotional wellbeing. For the last one, Service user 12, their emotional wellbeing was impacted negatively by the care that they had been receiving. Due to food not being cut up, they had developed pneumonia and were thus unable to engage in enjoyed activities.

Service user 5 had demonstrated reliable deteriorations on both subdomains of the MIPQ. This was not supported by the qualitative data beyond an indication that the service user was, at times, becoming distressed going into the community and so outings had reduced. This was being investigated at the time of writing.
3.5. Adaptive behaviour

Overall, it did not appear that service users’ adaptive behaviour changed post-move. Underpowered group level analyses (Table 17 and 18) only indicated significant improvements on ABAS-II: Health and safety, relating to understanding of safety rules and regulations, and ABAS-II: Home Living. It is possible these change related to increases in personal responsibility or greater freedoms within the home environments. This would appear to be the case as reliable improvements were made by the same service users as made improvements on the measures relevant to Choice.

Figures 14 to 20 illustrate changes on the quantitative measures at the individual level. Five service users scored zero both pre- and post-move on the ABAS-II: Functional academics subtest. This measured skills such as reading, writing or seeking knowledge.

### Table 17: Group level analyses for outcome measures related to Adaptive behaviour

<table>
<thead>
<tr>
<th></th>
<th>T0</th>
<th>T1</th>
<th>Paired samples t-test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>ABAS-II: Communication</td>
<td>10</td>
<td>24.90</td>
<td>23.76</td>
</tr>
<tr>
<td>ABAS-II: Health and safety</td>
<td>10</td>
<td>12.10</td>
<td>9.99</td>
</tr>
<tr>
<td>ABAS-II: Home living</td>
<td>10</td>
<td>15.40</td>
<td>13.43</td>
</tr>
<tr>
<td>HoNOS-LD: Loss of adaptive functioning</td>
<td>10</td>
<td>7.45</td>
<td>3.86</td>
</tr>
<tr>
<td>HoNOS-LD: Cognition and communication</td>
<td>10</td>
<td>5.36</td>
<td>2.46</td>
</tr>
</tbody>
</table>

**p < .01

<table>
<thead>
<tr>
<th></th>
<th>T0</th>
<th>T1</th>
<th>Wilcoxon signed rank</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Median</td>
<td>IQR</td>
</tr>
<tr>
<td>ABAS-II: Functional Academics</td>
<td>10</td>
<td>0.00</td>
<td>6.75</td>
</tr>
<tr>
<td>ABAS-II: Self-Care</td>
<td>10</td>
<td>47.5</td>
<td>42.50</td>
</tr>
</tbody>
</table>

Z statistics and dz effect sizes denoted with a minus symbol indicate detrimental effects.
**Figure 14:** Reliable change index scores for ABAS-II: Communication

(higher post-move scores indicate improvements, possible range of scores: 0 - 75)

**Figure 15:** Reliable change index scores for ABAS-II: Health and safety

(higher post-move scores indicate improvements, possible range of scores: 0 - 60)
Figure 16: Reliable change index scores for ABAS-II: Home living

(higher post-move scores indicate improvements, possible range: 0 - 69)

Figure 17: Reliable change index scores for HoNOS-LD: Loss of adaptive functioning

(lower post-move scores indicate improvements, possible range of scores: 0 - 20)
Figure 18: Reliable change index scores for HoNOS-LD: Cognition and communication
(lower post-move scores indicate improvements, possible range of scores: 0 - 20)

Figure 19: Reliable change index scores for ABAS-II: Functional academics
(higher post-move scores indicate improvements, possible range of scores: 0 - 81)
Positive changes seen in service users’ skills and behaviours were directly spoken about by six informants. Most of the adaptive behaviours that had been developed post-move related to cleaning or household tasks.

‘He came on leaps and bounds. Like, he washed his hands after he’d been to the toilet, which he didn’t used to do before, he brought his washing down from his bedroom, down to the laundry room.’ (10)

There was also evidence that staff were offering scaffolding to support service users to develop their skills by offering more support rather than more independence. Five spoke about getting service users to help out in tasks for a couple of seconds at a time and another shared tasks with the service user that they supported.
‘We try and get him involved with the cleaning. Obviously, we support him, we help. It’s like half and half. Like cleaning the windows or cleaning his bathroom and toilet, things like that.’

(9)

Five members of staff also spoke about reductions in adaptive behaviours, where skills were seen to have reduced or eroded since leaving institutional care. One staff member spoke about how the service user they cared for had started favouring pointing or dragging staff members around rather than speaking. Newer staff members found him difficult to understand and the staff member perceived him at becoming frustrated about this. The perceived result was that he was beginning to use these same gestures with staff who were able to understand him.

‘He is actually decreased with that lately, because I think, you know when he’s had like different staff at times, it’s like we’re the... Because his communication is quite a big issue with him, he is harder to understand when you first work with him. And I think a lot of that staff actually says point or show me, so then he’s actually, unless you’re encouraging him to speak.’ (5)

Overall, it appeared that the service users had only minimal changes in their adaptive skills, despite moving into environments designed with independence and skill development in mind. This lack of difference in abilities may account, in part, for why it was not frequently discussed by staff members. The HoNOS-LD: Loss of adaptive functioning factor had a medium effect size, indicating that service users may have been experiencing losses of functioning. It is possible that this is related to the impacts of aging rather than moving into the community however.
3.6. Challenging behaviour

Overall, the data indicated that moving into the community did not have a profound impact on the frequency or severity of service users displaying behaviours others find challenging. Six informants described that there were some slight reductions in challenging behaviours, whereas four described ways that such behaviours had not improved.

While no measures specifically examined challenging behaviour, The HoNOS-LD included items that related to aggressive and potentially harmful behaviour directed towards self or others. Table 19 outlines the group level changes for relevant measures. Figure 21 demonstrates that four of the service users made improvements in behaviour, mood and relationships. It also demonstrates that the individuals with the largest problems in these areas (service users 2, 6 and 9) made the least change post move. Additionally, of the six service users for whom positives were discussed, only one made a reliable improvement on the HoNOS: Behaviour, mood, and relationships factor, whereas four actually made reliable declines.

Figure 22 demonstrates that very little change was made in the total HoNOS-LD scores, indicating that staff may not have been effective in reducing problems in these areas.

<table>
<thead>
<tr>
<th>Table 19: Group level analyses relevant to challenging behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>T0</strong></td>
</tr>
<tr>
<td>n</td>
</tr>
<tr>
<td>HoNOS-LD: Behaviour, mood and relationships</td>
</tr>
<tr>
<td>HoNOS-LD: Total</td>
</tr>
</tbody>
</table>
Figure 21: Reliable change index scores for HoNOS-LD: Behaviour, mood, and, relationships
(lower post-move scores indicate improvements, possible range of scores: 0 - 20)

Figure 22: Reliable change index scores for HoNOS-LD: Total
(lower post-move scores indicate improvements, possible range of scores: 0 - 88)
Positive reductions in challenging behaviour were discussed by six informants, all referencing how individuals had become calmer and more content.

‘We don’t have no behaviours now. He was, when he first came, he could be verbally aggressive, and he did throw items at people, but we don’t have none of that now. No swearing, no aggressiveness to staff.’ (7)

One staff member, who supported a service user whose transition to the community had meant remaining in the same location, suggested that reductions in behaviour were due to the differences in ethos.

‘They were tipping furniture over left, right, and centre to start with, but then obviously that’s while they were living in NHS. But that’s what it was like in NHS. Obviously, it’s took him a long time to come away from that. To say I’ve only seen in my six and a half seven years working with him, I’ve only seen it six or seven times, tipping a table or chair up. It’s nothing.’ (4)

Another staff member suggested improvements were a result of increased freedoms.

‘Because he’s in his own environment, he’s in what he’d call an ideal setting. In his own home, he’s got nobody telling him what to do and when to do it, what to eat or what to wear.’ (7)

One staff member suggested that while the service user that they supported showed fewer ‘challenging behaviours’, demands placed upon them to engage in activities could result in problems:
‘It probably decreased, but then it’s like, you know, when you’re actually trying to push the boundaries a bit more, trying to get him to do other bits, it probably highlights up a bit then.’

(5)

Overall, increases in behaviours deemed challenging were described by four staff members.

‘He has actually started attacking in the car.’ (5)

‘She does hit herself a lot more than she used to. And she punches.’ (2)

One of the service users open to safeguarding was perceived to be engaging in less challenging behaviour due to the physical impacts of poor quality of care.

‘He used to have challenging behaviour, but he was that poorly that you could tell he didn’t have the strength in him to challenge anybody.’ (13)
4. Discussion

The current study aimed to examine how the quality of life of a cohort of people with ‘severe’ intellectual disabilities had changed eight years after moving out of institutional care and into community services. This was assessed by comparing changes on various quantitative scales as well as through a template analysis of informants’ perceptions of positive and negative changes for each individual.

Results suggested that the move seemed to have had more positive than negative effects for the majority of the sample. However these improvements were not observed for everyone and there was a large amount of variation in how the move impacted different people. To suggest that any area of service users’ lives had become better or worse post-move would be somewhat reductionist and would risk ignoring the heterogeneity of the service users included in the study and of people labelled with ID generally. Reinders (2010) made a similar argument: The objective assessment of quality in care services necessarily ignores the individuality of those being cared for.

This section begins by summarising key findings in relation to extant literature, before considering limitations that impact on what can be concluded from the research. Clinical implications and ideas for future research are then discussed.

Current UK policy around care of service users prioritises choice and autonomy as being key determinants of quality of life (e.g. Transforming care). The studied cohort did not appear to have a greater freedom of choice over their lives once moved into the community, and even smaller day to day decisions such as what to eat did not appear to change for many. While this is contrary to the intentions of normalisation principles, it is consistent with previous research. Dagnan et al. (1998) demonstrated that service users’ choices increased...
initially but then returned to pre-move levels after 41 months as regular routines became implemented and staff became familiar with service users. A similar effect may have happened with the current cohort, although evidence about possible post-move increases was not available. Stancliffe and Abery (1997) found that choice making did increase significantly post-move, though reported that choice-making remained low and superficial.

In a review by Kozma et al. (2009), it was argued that moving into smaller homes did not guarantee increases in autonomy or choice making, but rather, increases were a product of staff facilitating choice making. The main area where the current cohort were perceived by informants to be afforded greater opportunities for choice making related to being able to go out in the community more. This appeared to be because service users had greater access to transport and more appropriate staffing levels, and so represented an increase in availability of choices rather than an increase in service users necessarily making those choices.

The service users also had a greater freedom to go in areas of their home that had been locked off in previous placements, especially kitchen cupboards. As such, the increased choice could perhaps be better understood as a reduction in restrictions. This may have been because of changes to legal frameworks, specifically the introduction of Deprivation of Liberty Safeguards (Department of Health, 2005), rather than because of the move to the community however.

Individual differences were prevalent within the cohort, and these appeared to affect service users’ choice making abilities. Cognitive abilities impacted the amount and level of decisions that service users were offered to make for themselves, with many given binary choices so as to avoid distress. For the service user with dementia, choice making was intermittent and reliant on staff assessing her mental wellbeing each day. It was therefore up to them whether the service users’ choices were honoured or not. Likewise, service users who had experienced reduced mobility or injuries were not always offered choices over aspects of
their lives where their preferred choices had become unfeasible or dangerous. Kozma et al. (2009) likewise found that levels of disability and adaptive behaviour were better predictors of autonomy than availability of resources. The role of staff can be a precarious one then, balanced on a knife edge trying to support autonomy while offering high quality care (Van Hooren et al., 2002). As the authors argue, perhaps rather than through freedom of choice, autonomy should be promoted through focusing on fostering self-development and understanding.

It appeared that the adaptive behaviour of the service users tended not to change in many areas post move. This may be somewhat contrary to some existing research. Hamelin et al. (2011) conducted a review of the impacts of deinstitutionalisation on adaptive behaviour and found significant increases post-move. It is possible that the difference highlights a lack of sensitivity or validity on the part of the current researcher’s measures. This may also be a product of the aging cohort that was used, possibly representing institutionalised mind-sets that take longer to change, or a reduction in physical ability that negates some benefits of being in the community.

However, an important consideration may be that many of the service users in the current cohort scored zero on the ABAS-II: Functional Academics subscale both pre- and post-move. The skills measured by this include reading, writing and comprehension of data. Many of these skills require high levels of communicative ability and fine motor skills and are not the sort of skills that are generally taught to service users, possibly because of the obvious limitations of the population. However, it could be argued that from a normalisation perspective, such skills are requisites of numerous everyday functions and therefore may be key community based skills. Thus, it may not be enough to move individuals into the community and expect these skills to develop without additional training. Quality of life is about opportunity, but equally it is about imagining these opportunities and being well
enough and motivated to engage in them. This can be especially problematic for individuals with autism, for whom sameness can be desired and therefore range of and opportunities for activities are self-limited.

Normalisation works on the idea that service users will lead more ‘normal’ lives if they are around better role models in the community. However, the cohort in the current study were not widely integrated and so did not have more access to these role models. The lack of necessary skills also precluded this further as communicative and functional skills appeared not to change.

As was argued in the introduction, the focus on choice inherent in modern policy is not necessarily in the interest of service users (Reinders, 2008). In the current study, a number of informants described that service users tended to favour being alone in the house. This could arguably be indicative of insecure-avoidant attachments, and so what is understood as contentment or preference could be an expression of inner distress. Alternatively, it could represent autistic or anxious tendencies, where avoidance is used to protect oneself from too many demands or unpredictable others. In such instances, it may be better for the person to be given extra support rather than accepting their outward choice and leaving them alone (Schuengel et al., 2013).

According to both quantitative and qualitative data, the prevalence of behaviours deemed challenging appeared not to change post-move. This was similar to previous findings that have argued that such behaviours may not be affected by deinstitutionalisation (Emerson & Hatton, 1996; Kim et al., 2001).

If one considers the definition of challenging behaviour posited by Emerson (1995), these behaviours are expressions of need or emotion. Service users’ functional communicative
abilities were very limited and tended not to change. As such, it may be that their ability to express or understand their feelings had not improved and so it is perhaps inevitable that challenging behaviours remained frequent. Especially if, as Hundert et al. (2003) demonstrated, such behaviours are more frequently responded to than other behaviours.

In the current study, one service user had begun exhibiting physical aggression towards drivers when going out. This may have been the only way to communicate an anxiety or choice that was available to him. This could be especially true as it was noted that he was using speech less and less because new staff members were struggling to understand him.

Relationships between service users and their key staff appeared to cut across all areas of quality of life. Staff members supported interactions and modified environments. The concept of affordances could be used to demonstrate this (Bell & Clegg, 2012). Staff demonstrated how they had been able to use their skills to afford greater opportunities to service users and thus allow them to exceed some limitations. One staff member discussed supporting a service user to attend a swimming club. This appeared to have allowed the service user to develop meaningful interactions. It is likely that the service user and staff member were viewed by others as a dyad that came together. The staff member had used their skills to contain and support the service user to utilise the environment in a way that they seemed to enjoy. Likewise, other staff members described modifying environments or simplifying choices so that service users could get more out of them. In doing so, social situations and environments were modified to make them accessible and potentially meaningful for service users. In this way, the interdependence of service users is highlighted alongside the development of their independence.

From a relational perspective, there appeared to also be evidence of some support staff going beyond what was expected of them. One staff member attended extra shifts to
ensure that the individual that they supported would not lose out on preferred activities. Three staff members had worked with the same service users for more than 20 years and developed close bonds. Others maintained relationships after no longer being employed to work with them. This possibly demonstrates a commitment that goes beyond a working relationship. While authors such as Reinders (2010) have discussed the importance of relationships with staff, this is often neglected in policy.

Staff members can also be important attachment figures for service users. Schenguel and Janssen (2006) argued that the experience for a service user of being liked by someone can be an important buffer against the stigma and bullying that one might experience in the community. As well as this, staff members take on a role of container and are required to hold the emotions of some service users in the way a caregiver would for a small child, which could be important in understanding and managing challenging behaviours (Skelly, 2016). However, the quality of care that an individual receives appears to be disproportionately dependent on the quality of individual staff members and the support that those staff receive (Hubert & Hollins, 2010), and this may account for some of the variation seen in the current cohort, between both time points and individual service users.

4.1. Strengths and Limitations

A key strength of this study was the length of time between time points zero and one. This allowed service users time to settle into the community fully and allowed time for services to develop identities and preferred methods. However the lack of follow up in between these time points was also a limitation as the duration did not pick up how quality of life changed over the period. This also made it harder to attribute any changes to the move itself as there would have been various confounding variable that have been shown to impact quality of life such as difficulties associated with increasing age (e.g. Ager et al., 2001).
Keyworkers and social workers were recruited to participate on behalf of service users. It is accepted that there are a number of methodological issues with the use of proxies in intellectual disabilities (Verdugo et al., 2005). While proxies can only give an approximation of an individual's voice, the alternative for people who lack the cognitive or communicative ability to speak for themselves is that their voice is ignored entirely. This certainly appears to be prevalent in most qualitative research including people with intellectual disabilities (e.g. Forester-Jones et al., 2002). To not include less able people in research risks giving a distorted view of what research says about the needs and individualities of people with intellectual disabilities (McDonald & Kidney, 2012). Additionally, proxy respondents’ ratings of quality of life have been reported to match ratings made by service users able to do so (e.g. Schmidt et al., 2010).

A related limitation involved the use of ‘empathic’ analysis of data (e.g. Willig, 2013), where informants reports of changes were taken at face value. Such interpretations risk neglecting that informants might have presented a person’s quality of life inaccurately, either because of poorer understanding of an individual or because they may have been motivated to present a positive or negative impression of changes for a given person. A strength of this study was the utilisation of quantitative scales to triangulate qualitative data against. Although responses on such measures would also have been subject to the same potential for bias as the interview data (at baseline as well as follow-up), this might have been minimised somewhat through ensuring that the Researcher and informants were blind to baseline scores.

A key limitation of the current study was the lack of quantitative data for the three service users for whom things had not gone well, which would likely have resulted in group-level quantitative comparisons presenting a more positive outcome. Further, no follow-up data was obtained for 24 of the 38 original cohort members. The services included were ones who expressed interest in the study and it is possible that services not supporting access might
have had more concerns about the quality of care being provided. Alongside this, the low sample size could have been problematic, although this is reduced somewhat by the use of a ‘questerview’ design to allow for deeper analysis of the completed measures.

4.2. Further Research

To address the limitations of the current study, further research could focus on examining changes in service users at more time points, ideally annually or every two years. Within this, an examination of what had occurred for that person over the period would be useful. To eliminate inter-rater issues, multiple copies of outcome measures could be completed by different professionals who support service users. This data could also be triangulated with family members and service users themselves as appropriate.

An important predictor of service users’ quality of life appears to be staff relationships with service users and so factors such as expressed emotion, relational style, psychological mindedness and their own attachment type could be operationalised and examined for the key caregivers in each service user’s life.

4.3. Implications and Conclusion

Choice and autonomy are proposed by normalisation principles as naturally occurring in ‘correct’ environments. This implies the underlying presumption that service users have not been heavily conditioned throughout their lives to behave in a way that is in the interest of others, and that they possess the necessary executive, memory and reasoning abilities to make choices. These presumptions are arguably fundamentally flawed because of the nature of intellectual disability itself.
While problematic, choice and autonomy are deemed important determinants of quality of life. The current evidence appeared to suggest that moving to the community was not necessarily sufficient to increase service users’ freedom or abilities to choose. As such, it may be that more support needs to be offered to service users to afford more opportunities. Training systems such as Active support (Mansell & Beadle-Brown, 2012) have been shown to be effective in increasing the skills and abilities of people with intellectual disabilities in the community, and these may be beneficial in supporting individuals to develop autonomy (Felce et al., 2000). This is a system designed to support the development of skill subroutines by breaking tasks into manageable steps that are completed with progressively little staff support over time as service users become more adept at completing them.

Relatedly, staff appeared to be vital in supporting service users to be able to make the most of social and ecological environments, and some of the differences in service users’ use of facilities appeared to be centred around staff members’ attitudes. As Bell and Clegg (2012) have argued previously, organisations should ensure that procedures are put in place to take some of this onus away from individual staff members. Environments need to be chosen and adapted to maximise their value to individual service users.

Overall, the move from institutional to community based homes had varied greatly for the cohort of service users. Quality of life appeared very dependent on the ethos and quality of individual staff teams supporting individuals. As such, the evidence did not appear to support the normalisation based UK policy that moving to the community would be beneficial for all service users.

The service users also experienced a great deal of change over the eight year period, including declining health and sustained injuries. This highlights the importance of services that are managed in a way that is sensitive to service users’ needs, not just at the outset, but throughout the provision of care as these needs change.
5. References


BBC (2011). Undercover Care: The abuse exposed. BBC Panorama first shown on Tuesday 31 May 2011.


Section C: Critical Appraisal

1. Introduction

The following section provides a reflective account of the research process that was undertaken. Reflections are based, in part, upon a reflective journal that was completed throughout design and analysis. The appraisal summarises the research process and outlines key decision points. Following this, reflections upon personal development are considered.

2. The research journey

2.1. Choosing a research topic

The research topic chosen was an area of interest that I had from my pre-training experiences. I had been employed in a variety of intellectual disability services in healthcare assistant or assistant psychologist roles. These services did not always appear adequately person centred or supportive to me. Many of the older members of staff had supported service users in institutional and then community contexts and bemoaned many of the changes that deinstitutionalisation had brought. Generally, these complaints were based on how much harder things were for those staff members themselves rather than the relative merits for service users. Nonetheless, this did make me interested in alternative forms of support for service users. This was especially pertinent as I joined the staff of a community care home in Bristol shortly after the exposure of Winterbourne View and so issues of practice and suitability of services were often discussed.
I was reminded of this when potential supervisors gave presentations of their research interests when it was time to decide on a research project. The offered study was the second half of a longitudinal examination of the move from institutional to community care. As well as being interesting and relevant to my past experiences, this felt like an important research area.

2.2. Choosing a methodology

The research design was based, to a large degree, on the available number of participants. While the original plan had been to do a purely quantitative follow up to the original study, it had been unlikely that a sufficiently large sample could be found to have adequate power and thus three possible methodologies were proposed. If 15 or more participants could be found, a quantitative methodology would be used. If five or fewer participated, a case report methodology would be utilised. Ultimately, there was a sample of 14 and so a mixed method design was adopted. The qualitative strand was prioritised, with the quantitative strand used to triangulate data to provide a check that the staff members acting as proxies properly encapsulated service users’ opinions.

The ethics process was challenging for the current study as the tangential involvement of service users via proxies appeared to exist in an ethical grey area. There was a great deal of discussion between the author and research leads for both NHS and university-based research teams. Ultimately, it was decided that as service users were not recruited directly through the NHS, NHS ethics were not applicable. This came with a number of qualifications however, including the necessary anonymization of data from myself and the exclusion of any service users who wished to have their direct views included.

The quantitative measures were predetermined by the original study upon which the current one was based. For the qualitative part, the possibility of holding separate interviews
with staff or family members was considered. However, audio recordings were taken while staff members completed outcome measures, and the author asked further questions to facilitate this. The transcriptions of this audio demonstrated that the conversations yielded answers to the questions that would have been asked at interview. Additionally, the specific questions on the measures prompted staff members to think of examples of abilities and behaviours that they may not have considered in a semi-structured interview. Accordingly, the recordings of these conversations were used as the interview data to be analysed.

I was initially unsure about the validity of using these conversations qualitatively. If the purpose of quantitative data was to triangulate the things that staff members said, but the things that staff said were based on the questions for quantitative outcome measures, then it formed more a check of staff perspectives than of service users’ experiences. However, emerging research such as that carried out by Adamson et al. (2004) had demonstrated that transcriptions of the completion of outcome measures can be analysed qualitatively to give meaningful context to data.

My initial preference had been for a purely quantitative study due to personal familiarity. I am naturally more confident with numerical data and enjoy the relative sense of certainty that this can provide. However, I think that qualitative methodologies better fitted with the research question and allowed for a fuller examination of service users’ inner worlds. As has been argued by Schalock et al. (2002), some of the most important domains of quality of life are idiographic. The use of a mixed methods design also gave me the opportunity to engage in qualitative analysis and to develop skills in a technique that I was less confident with. Immersion in the transcribed data also allowed me to feel like I had developed a deeper insight into the service users and their experiences.

This technique allowed me to spend time getting to understand the perspectives of staff members and, contrary to some of my previous experiences, the members all seemed
very passionate about the support that they gave to the individuals they worked with. Many staff had developed relationships with services over twenty or thirty years and, for some, it was clear that they loved them as family. However, based on what is known about attachment styles, it is likely that these staff members’ previous attachment relationships or personal traumas influenced their decisions to become care staff initially, and impact upon the security of the attachment relationships they develop with service users.

2.3. Choosing an epistemological position

I adopted a realist epistemology as it was most suitable for template analysis and it best supported empathic interpretations of staff members’ perspectives. I struggled with adopting this stance as I naturally orient towards more social constructionist and constructivist perspectives. This meant trying to change the way that I understand the world and likely coloured some of the ways that I interacted with staff members during interviews. However, this also encouraged me to broaden my perspective and allow for a better consideration of differing viewpoints.

2.4. Collecting data

Collecting data meant the involvement of private service providers. I was initially concerned that such services would not want to be involved in an assessment of the quality of lives of the people that they supported in case findings were not positive. In reality, the three services that I worked with were very accommodating and were excited to have the chance to demonstrate the positive changes that they had brought to individuals’ lives. It is unclear if this would have been the case for services that believed themselves to be doing less well, or if I had approached individual homes rather than area managers.
It was a privilege being allowed into service users’ homes. Though they were not involved in the study directly, some knew that they were the focus and came and spoke to me about their lives or the things they did and did not like. It was unfortunate that I had no way of involving these perspectives in the study directly.

I adopted an empathic interpretation of what staff members said. This meant that while I didn’t necessarily assume what they said accurately portrayed how things were for service users, I did assume that what they said was honest and portrayed their belief of how things were for service users. As stated above, this is not natural for me, and I generally consider the content and form of communications as indicative of the current discourses; that people will say the things that they think they are expected to say in line with service and government policies. I minimised my own biases as much as possible but it was sometimes with a conscious effort that I asked questions in a particular way to support an empathic interpretation and I do not believe I was always successful.

Even with this held in mind, I was also approaching the assessment as a trainee clinical psychologist and I considered that this would also have coloured the way that I understood the lives of service users. I felt that I would have benefitted from working alongside other multidisciplinary team members, such as occupational therapists, who would have asked very different questions, especially around skills and deficits.

Staff members’ enthusiasm for positive change may have been a potential source of bias. Their desire to see service users in terms of what they had been able to achieve may have made it more difficult for them to consider negative aspects of service users or their lives, and may have limited their ability to accept service users for who they were, limitations and all.
2.5. Analysis

During the qualitative analysis, I kept the reflective journal beside me and made the following notes as I went.

Based on my reading of different models of care and best practices, there were a number of occasions where I felt at that my beliefs were at odds with the staff members being interviewed. This was often in relation to when they pushed a service user to achieve a certain task. Where they saw this as evidence of person centred-ness, I found it difficult to see how the service user was benefitting from the achievement. One particular example was a staff member describing how they had managed to support a service user to use a cash machine. The staff member would put the card in and then would point to which buttons to press to get money out. This was for an individual who had no understanding of what they were doing, how much money they were getting, or what money is used for. It appeared highly unlikely that the individual would develop the skills or knowledge to independently manage their finances and so the task seemed, to me at least, to have been putting a lot of stress on them for very little personal gain. I am not advocating that skills should not be developed of course, but I feel that more thought could have been put into considering what skills would actually be meaningful for the person and working on those. This and other examples felt indicative of service users being trained to complete tasks that looked good on paper or as advertisements for services.

Likewise, it appeared that staff were well versed in evidencing person centred values and activities. Staff appeared to demonstrate a degree of guilt when describing decisions that they had made for a service user because the individual was unable to do so for themselves. They were usually very quick to justify why the staff chose for service users or demonstrate a tokenistic way that the service user had been involved (e.g. being present when the decision was made). While it is obviously possible that this was because I was asking about choices and
they were pre-empting my expectations, it also felt like a more ingrained defensiveness. Again, while developing the ability to choose is important where possible, it feels as though an inability to choose is seen as being somehow devaluing.

The way that staff spoke about service users felt problematic at times. It was clear that many of the members of staff I spoke to were dedicated to their service users to the point of devotion and it was clear they had a very relaxed rapport. However, there is a fine line between playful and disrespectful, and at times it felt like the way staff spoke about service users fell into the latter category.

From listening to recordings and reading transcripts, it was also apparent how often I fell into more therapeutic questioning rather than interviewer style questioning. The differences are, perhaps, fairly subtle but there was something I noticed in the ways that I would phrase questions or responses that at times led conversations more towards abstract notions such as staff members inferring how they thought service users experienced things that were perhaps less useful for research. As well as this, I noticed that I frequently asked closed questions. This is something that I am guilty of in clinical practice as well and may be a side effect of predominantly working with individuals with difficulties in communication.

While analysing and subsequently writing up findings, I was very aware that I would be reporting back to services and individual staff members about global findings. As such, I found myself experiencing a desire to report findings positively so as to not be ungrateful to the people who had helped. This positivity bias was overcome by discussions with my academic supervisor and a collaborated interpretation of the results. In my literature review, I was very critical of others reporting exclusively positively and so to have experienced similar pressures offered me a more empathic understanding of these authors. At the same time however, this
positive viewpoint can be clinically useful as it allows one to come alongside services to promote greater learning.

3. Reflections on professional and personal development

The evolving nature of the research has allowed me the opportunity to develop my research skills in a number of ways that I would not have done so if the research had remained as it was originally planned. I was afforded the chance to engage in a qualitative analysis of data that made my understanding of the subject that much deeper. This greater understanding of the subject matter is something that I will be able to carry forward in any roles that in which I work with service users or members of vulnerable populations, and any staff that support them.

Conducting the research also allowed me the perspective to see the research evolve. Prior to this, I had never worked on a single project for such an amount of time. Most projects that I have been a part of have been comparatively short term, or else my involvement only constituted a small part of the total project. In completing the current research, I was able to be involved from beginning to end, and both witness and enact changes that completely altered the potential directions of the project.

Perhaps the biggest insight was in the difference between individual service users. Even over a fairly small sample, the personalities and abilities of individuals were vastly different. Accordingly, both the research project and literature review demonstrated how different the care needs of individuals are and how little consistency there were in research findings. This is contrasted somewhat by relevant government policy, which speaks with a
certainty and authority that this a right and wrong way for services to be designed, and a right and wrong way to be person-centred which is the same for all persons.

There was an implicit sense of discomfort in writing in a way that challenged the qualities of community residential care, especially while writing the literature review. I struggled to understand this initially. One evening, I was in a pub with an old friend and he asked me what my research was on. When I explained, he jokingly stated “I hope you’re not going to say that institutions were better”. This summed up a number of the conflicted feelings that I had been experiencing. Firstly, he demonstrated that the term “institutions” had such deep emotional connotations attached to it that a person who knew almost nothing about the area had a strong opinion. Secondly, it highlighted dominance and pervasiveness of the narrative that institutional and community based care are the only two possibilities in a dichotic dyad. This, I think, was a sense that I had on some level as well. It manifested as a fear that in questioning the quality of community care as it exists now, I was somehow advocating that things should return to the way they were.

4. Absent and extended ideas

Below, I have outlined two thoughts that were relevant to both the literature review and empirical piece, but were not relevant enough to either for inclusion.

4.1. Acculturation

Though there I didn’t have the space in either of the main articles, I would like to have considered ideas of acculturation (Berry, 1997). Acculturation is a theory linked to refugee
populations, and indicates that there are four possible outcomes of an individual’s immigration dependent on the strength of their cultural identity and that of the society that they are joining: integration; assimilation; segregation; marginalisation.

This theory has only rarely been applied to populations of people labelled with intellectual disabilities (e.g. Minnes et al., 2002). However, it makes sense to me that acculturation could be used more thoroughly to explore how service users experience the move into community residential care, specifically in relation to community integration. The move would here be understood as somewhat analogous to immigration, as both the expectations and procedures change. As Minnes et al. (2002) argue, the success or otherwise of community integration could therefore be viewed as dependent on two questions: Is it considered valuable to recognise and support the unique characteristics of people with intellectual disability? And is it considered valuable for people with intellectual disabilities to maintain relationships with other groups?

I would argue that current government policy, and especially normalisation focuses very heavily on the latter question, while ignoring the former entirely. Institutions conversely, appeared to focus entirely on the latter at the expense of the former. For true integration to be achieved therefore, it appears that equal focus needs to be placed on finding a way to combine both perspectives.

4.2. Sexual and Romantic Relationships

During the completion of the literature review, it was noted that none of the studies made any references to participants having or wanting romantic or sexual relationships. It is possible that no studies examined prevalence of such relationships because it was anticipated that no changes would have occurred post-move. That none of the studies examined these relationships is perhaps somewhat telling of the standard discourses surrounding people with
disabilities and the tendency to infantilise or asexualise them (see Milligan & Neufeldt, 2001 for a review). Likewise, in my own research, no staff members made any reference to service users’ sexuality or having had a romantic relationship, and this may represent a similar viewpoint.

5. Alternative or Future Research

The research study formed, at least in part, the second half of a longitudinal study. As such, I had little control over the instruments and measures that were used. While these measures were appropriate and suitable, on reflection I think I would have used a different method if I were to design the study from the beginning.

I would predominantly focus on social inclusion, and specifically the social networks. Previous studies have examined social networks of deinstitutionalised populations of people labelled with intellectual disabilities (e.g. Robertson et al., 2001). However, no studies appear to have used this method in a longitudinal way before and after a move and so I would aim to do this. One of the major drawbacks of this method was the somewhat arbitrary nature of inner and outer circles and so I would define clear guidance on what constituted a relationship in inner or outer circles. I would ideally also have this completed by multiple people who knew the service user well. Where possible I would include the service user themselves, though a service user’s inability to consent to this or communicate these ideas would not mean that others were excluded from participating on their behalf. If possible I would use the same respondents at T0 and T1, though this would not always be feasible depending on the intervening time period.
Alongside this, I would complete a measure of quality of life such as the Questionnaire of Quality of Life (Dagnan et al., 1998). While this measure has been criticised for being narrowly focused on normalisation-based principles (Cummins, 2005), this would be appropriate as it is what current government policy on care for individuals with intellectual disabilities focuses on (e.g. Department of Health, 2012) thus measures the success of services at achieving what they ostensibly set out to do (whether this is right or wrong). I would use this section to compare with the results from the social networks. My hypothesis based on the anecdotal evidence I received while conducting the current study would be that service users who had the same staff members supporting them pre and post move would score higher on quantitative measures of quality of life. As well as this, I would examine whether moving closer to, and having increased contact with, family would yield higher scores. This latter examination would be an examination of the core tenet that underpins current governmental policy (e.g. Department of Health, 2012).
6. References


Section D: Mandatory Appendices
Appendix A: Trainee's statement of epistemological position

A stance of critical realism was approached for the completion of the research. Critical realism pairs realist ontology with more constructivist epistemology and posits that the world exists independently of perceptions and constructions but that it cannot be observed or measured without the imposition of one’s own perspective and construction (Maxwell & Mittapalli, 2010). In doing so, this marries the classically opposing quantitative postpositivist empiricist and qualitative constructivist positions (Johnson & Gray, 2010).

Maxwell and Mittapalli (2010) argued that critical realism can be very effective in mixed methods research designs as the position facilitates a common language between qualitative and quantitative methodologies and can therefore minimise the limitations of each. Accordingly, this stance was taken throughout the collection and analysis of both quantitative and qualitative data.


### Appendix B: Chronology of research process

<table>
<thead>
<tr>
<th>Event</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research Proposal submitted for peer review</td>
<td>May 2016</td>
</tr>
<tr>
<td>Lay proposal submitted to Service User Reference Group</td>
<td>April 2016</td>
</tr>
<tr>
<td>University Research and Development ethical approval granted</td>
<td>March 2017</td>
</tr>
<tr>
<td>Participant recruitment and data collection</td>
<td>March 2017 – February 2018</td>
</tr>
<tr>
<td>Transcription and analysis of qualitative data</td>
<td>December 2017 – March 2018</td>
</tr>
<tr>
<td>Data analysis of quantitative data</td>
<td>March 2018</td>
</tr>
<tr>
<td>Write-up of thesis manuscript</td>
<td>March 2018 – April 2018</td>
</tr>
<tr>
<td>Thesis submitted</td>
<td>April 2018</td>
</tr>
<tr>
<td>Research Viva</td>
<td>July 2018</td>
</tr>
<tr>
<td>Preparation of manuscript for publication</td>
<td>July 2018 – September 2018</td>
</tr>
</tbody>
</table>
Appendix C: Guidelines to authors for journal targeted for literature review

British Journal of Clinical Psychology

The British Journal of Clinical Psychology publishes original contributions to scientific knowledge in clinical psychology. This includes descriptive comparisons, as well as studies of the assessment, aetiology and treatment of people with a wide range of psychological problems in all age groups and settings. The level of analysis of studies ranges from biological influences on individual behaviour through to studies of psychological interventions and treatments on individuals, dyads, families and groups, to investigations of the relationships between explicitly social and psychological levels of analysis.

All papers published in The British Journal of Clinical Psychology are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

The following types of paper are invited:

• Papers reporting original empirical investigations
• Theoretical papers, provided that these are sufficiently related to the empirical data
• Review articles which need not be exhaustive but which should give an interpretation of the state of the research in a given field and, where appropriate, identify its clinical implications
• Brief reports and comments

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

The word limit for papers submitted for consideration to BJCP is 5000 words and any papers that are over this word limit will be returned to the authors. The word limit does not include the abstract, reference list, figures, or tables. Appendices however are included in the word limit. The Editors retain discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length. In such a case, the authors should contact the Editors before submission of the paper.

3. Submission and reviewing

All manuscripts must be submitted via Editorial Manager. The Journal operates a policy of anonymous (double blind) peer review. We also operate a triage process in which submissions that are out of scope or otherwise inappropriate will be rejected by the editors without external peer review to avoid unnecessary delays. Before submitting, please read the terms and conditions of submission and the declaration of competing interests. You may also like to use the Submission Checklist to help you prepare your paper.

4. Manuscript requirements

• Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
• Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author’s contact details. You may like to use [this](#) template. When entering the author names into Editorial Manager, the corresponding author will be asked to provide a CRediT contributor role to classify the role that each author played in creating the manuscript. Please see the [Project CRediT](#) website for a list of roles.

• The main document must be anonymous. Please do not mention the authors’ names or affiliations (including in the Method section) and refer to any previous work in the third person.

• Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.

• Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.

• All papers must include a structured abstract of up to 250 words under the headings: Objectives, Methods, Results, Conclusions. Articles which report original scientific research should also include a heading ‘Design’ before ‘Methods’. The ‘Methods’ section for systematic reviews and theoretical papers should include, as a minimum, a description of the methods the author(s) used to access the literature they drew upon. That is, the abstract should summarize the databases that were consulted and the search terms that were used.

• All Articles must include Practitioner Points – these are 2–4 bullet points to detail the positive clinical implications of the work, with a further 2–4 bullet points outlining cautions or limitations of the study. They should be placed below the abstract, with the heading ‘Practitioner Points’.

• For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide DOI numbers where possible for journal articles.

• SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.

• In normal circumstances, effect size should be incorporated.

• Authors are requested to avoid the use of sexist language.

• Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the [APA Publication Manual](#) published by the American Psychological Association.

If you need more information about submitting your manuscript for publication, please email Melanie Seddon, Managing Editor ([bjc@wiley.com](mailto:bjc@wiley.com)) or phone +44 (0) 1243 770 108.

5. Brief reports and comments

These allow publication of research studies and theoretical, critical or review comments with an essential contribution to make. They should be limited to 2000 words, including references. The abstract should not exceed 120 words and should be structured under these headings: Objective, Method, Results, Conclusions. There should be no more than one table or figure,
which should only be included if it conveys information more efficiently than the text. Title, author name and address are not included in the word limit.

6. Supporting Information

BJC is happy to accept articles with supporting information supplied for online only publication. This may include appendices, supplementary figures, sound files, videoclips etc. These will be posted on Wiley Online Library with the article. The print version will have a note indicating that extra material is available online. Please indicate clearly on submission which material is for online only publication. Please note that extra online only material is published as supplied by the author in the same file format and is not copyedited or typeset. Further information about this service can be found at http://authorservices.wiley.com/bauthor/suppmat.asp

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If the OnlineOpen option is not selected the corresponding author will be presented with the copyright transfer agreement (CTA) to sign. The terms and conditions of the CTA can be previewed in the samples associated with the Copyright FAQs.

For authors choosing OnlineOpen
If the OnlineOpen option is selected the corresponding author will have a choice of the following Creative Commons License Open Access Agreements (OAA):

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To preview the terms and conditions of these open access agreements please visit the Copyright FAQs and you may also like to visit the Wiley Open Access Copyright and Licence page.

If you select the OnlineOpen option and your research is funded by The Wellcome Trust and members of the Research Councils UK (RCUK) or the Austrian Science Fund (FWF) you will be given the opportunity to publish your article under a CC-BY license supporting you in complying with your Funder requirements. For more information on this policy and the Journal’s compliant self-archiving policy please visit our Funder Policy page.

8. Colour illustrations

Colour illustrations can be accepted for publication online. These would be reproduced in greyscale in the print version. If authors would like these figures to be reproduced in colour in print at their expense they should request this by completing a Colour Work Agreement form upon acceptance of the paper. A copy of the Colour Work Agreement form can be downloaded here.

9. Pre-submission English-language editing

Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. A list of independent suppliers of editing services can be found at http://authorservices.wiley.com/bauthor/english_language.asp. All services are paid for and
arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

10. Author Services

Author Services enables authors to track their article – once it has been accepted – through the production process to publication online and in print. Authors can check the status of their articles online and choose to receive automated e-mails at key stages of production. The author will receive an e-mail with a unique link that enables them to register and have their article automatically added to the system. Please ensure that a complete e-mail address is provided when submitting the manuscript. Visit http://authorservices.wiley.com/bauthor/ for more details on online production tracking and for a wealth of resources including FAQs and tips on article preparation, submission and more.

11. The Later Stages

The corresponding author will receive an email alert containing a link to a web site. A working e-mail address must therefore be provided for the corresponding author. The proof can be downloaded as a PDF (portable document format) file from this site. Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from the following web site: http://www.adobe.com/products/acrobat/readstep2.html. This will enable the file to be opened, read on screen and annotated direct in the PDF. Corrections can also be supplied by hard copy if preferred. Further instructions will be sent with the proof. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately.

12. Early View

British Journal of Clinical Psychology is covered by the Early View service on Wiley Online Library. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Articles are therefore available as soon as they are ready, rather than having to wait for the next scheduled print issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors’ final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have volume, issue or page numbers, so they cannot be cited in the traditional way. They are cited using their Digital Object Identifier (DOI) with no volume and issue or pagination information. E.g., Jones, A.B. (2010). Human rights Issues. Human Rights Journal. Advance online publication. doi:10.1111/j.1467-9299.2010.00300.x
Further information about the process of peer review and production can be found in this document: What happens to my paper? Appeals are handled according to the procedure recommended by COPE.
INTRODUCTION
I am investigating how quality of life has altered for individuals with learning disabilities who have moved from hospital to community settings. In your location, I am interested particularly in how____________ has changed. I would like to ask for your help in doing this as you have been recommended as one of the people who knows them best. Your participation is entirely voluntary.

WHO IS CONDUCTING THE RESEARCH?
My name is Rob Jones and I am a trainee clinical psychologist studying at The University of Leicester. I am conducting a research project as part of the academic requirements of the programme. My project is supervised by Dr Kevin Baker (Clinical Psychologist) and Dr Gareth Morgan (Clinical Lecturer).

WHAT WILL HAPPEN?
If you would be willing to talk to me about this person, please return the enclosed expression of interest form with details about how you would like me to contact you. I will then contact you to arrange a time and location that will be convenient for you. Possible times and locations will have been discussed with your manager but your input is welcomed in this. We will complete four questionnaires together about the person that you care for. These will look at the person’s ability to make choices, adaptive behaviours, social networks, and mood and interests. These should not take more than two hours and it is not necessary for them to all be completed at the same time. These same questionnaires were completed before the person moved to their current home and so I will compare the scores to see how much the person has changed. With your permission, I will make an audio recording of our discussion to garner more detail from the information that I receive. This will be transcribed by a professional transcription service who understand confidentiality of data and information governance. Although verbatim quotes might be used in a subsequent publication to illustrate findings, care will be taken to ensure that you or those you work with (colleagues and service users) would not be identifiable from any quotes. If you do not wish to be audio recorded whilst completing forms, or wish audio recording to stop at any time, please say so.

With your consent, I may also propose a follow up meeting within six months if additional information would be beneficial. This will be separate and entirely voluntary. Additional consent will be requested if and when this occurs.

CONFIDENTIALITY FOR THE SERVICE USER AND SERVICE
Your engagement in the study is completely voluntary and can also be stopped at any time should you wish it. A manager in your service has identified you as a good person to approach for participation. As such, it is likely that they will know that you have participated. Despite this, confidentiality will be ensured as far as possible with regard to the content of your participation and neither yourself or the service you work for will be identifiable in any way.

Some limits to confidentiality do apply. If any safeguarding concerns become apparent because of the outcomes of questionnaires or discussions, I will be obligated to follow standard safeguarding procedures. Additionally, if the results demonstrate that a person being cared for has reduced in their abilities or wellbeing, I may have to discuss this with healthcare or social care funders to see if additional input can be provided.

It has been agreed that data regarding the person in your care can be used for the purposes of the study, but if you feel that the use of their data could in any way harm them, your consent and theirs can be withdrawn during the completion of questionnaires or any time afterwards up until December 2017 when analysis will be being finalised.
All data will be entered onto a computer and then paper copies will be destroyed. Electronic data will reside securely at the University of Leicester. All personally identifiable data for the individual that you care for will be held securely on NHS servers until it is needed. At this time, it will be anonymised and combined with the data of other service users involved in the study.

CONFIDENTIALITY FOR YOU AS A STAFF MEMBER
Nothing that you discuss will be identifiable as coming from you in any publications coming from the research. No specific details will be shared with your organisation and with the exception of the limits to confidentiality mentioned above, no identifiable information will be shared with any other agencies. It is possible that others within your organisation may know you have participated given that your managers will have recommended you and you might be interviewed on site. A pseudonym (false name) will be used instead of your real name and all names you mention, including service users and colleagues, will also be altered in any publications.

BENEFITS AND RISKS
Your participation in this study will help to gain a better understanding of what is good about residential care in the community and what still needs improving. In this respect you may be helping to shape the future of residential care for service users and staff. The information gathered for the service user you support might indicate if they would benefit from any further input from NHS services. It is also your chance to be listened to as a staff member as to how you feel that the service user is doing.

WHO CAN I CONTACT ABOUT THE STUDY?
For further information about the study, or any questions about the information provided here, you can contact the researcher or supervisors using the details below:

Rob Jones (Principal investigator Trainee Clinical Psychologist)

Gareth Morgan (Clinical Psychologist)

Kevin Baker (Clinical Psychologist)
CONSENT FORM

Title of Project: How does deinstitutionalisation affect the quality of life of service users with intellectual disabilities? An eight year follow up of adults who moved out of long stay hospital accommodation in Nottinghamshire.

Name of Researcher: Rob Jones

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<th>I confirm that I have read the participant information sheet dated 17.10.2016 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.</th>
<th>Please Initial each box</th>
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<td>I consent to participate in the above study</td>
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<td>I understand that all information about me, the service user, others, and the service will be anonymized</td>
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<td>I understand that confidentiality will be adhered to with the possible exceptions described in the participant information sheet where it appears that the service user or others are at risk.</td>
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<td>I understand that I have the right to pause or end my involvement with the study at any time</td>
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<td>I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my rights being affected.</td>
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<td>I understand that if I become upset or distressed in any way by participating in the study and wish to talk to somebody about this, I can contact the researcher or Dr Kevin Baker (contact details are on the Participant Information Sheet).</td>
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I understand that all data will be held securely on servers at the University of Leicester.

I understand that transcription may be completed by external transcribing services who will be trained in information governance and confidentiality.

Optional Additions

I understand that if I wish to, I can be emailed a copy of the final report (please write your email address here______________________________________).

I consent to possibly being emailed about an offer of taking part in an additional interview in up to six months’ time. I understand that consenting at this stage does not require me to accept this offer (please write your email here______________________________________).

I understand that my email address will not be used for any purpose other than those listed above.

I understand that my email address will be held securely and separately from any data taken in this study. The file containing my email address will be deleted when no longer necessary and no later than the 1st of June 2018.

____________________  ____________________  ____________________
Name of Participant    Date                 Signature

____________________  ____________________  ____________________
Name of Person         Date                 Signature

taking consent
I am here to talk to someone about how you are.

Is this ok?

[Thumbs up]

[Thumbs down]
I am happy for Rob Jones to talk to ____________ about how I am now and how I have changed

I understand that I can change my mind at any time and say to staff that I don’t want to be talked about any more

I understand that I can later say that I don’t want my information used any more

__________ ____________ ____________
Name

Date

Signature

__________ ____________ ____________
Name of Person taking consent

Date

Signature
Appendix E: Correspondence with Ethics Committee

16/03/2017

Ethics Reference: 10796-rj170-neuroscience,psychologyandbehaviour

TO:
Name of Researcher Applicant: Robert Jones
Department: Psychology
Research Project Title: Deinstitutionalisation and quality of life in an intellectual disabilities sample: Eight-year follow up of adults who moved out of long-stay hospital accommodation into the community.

Dear Robert Jones,

RE: Ethics review of Research Study application

The University Ethics Sub-Committee for Psychology has reviewed and discussed the above application.

1. Ethical opinion

The Sub-Committee grants ethical approval to the above research project on the basis described in the application form and supporting documentation, subject to the conditions specified below.

2. Summary of ethics review discussion

The Committee noted the following issues:
Reasonable steps have been taken to ensure consent when possible when sharing information about individuals with intellectual disabilities, by having an independent evaluation of their ability to provide informed consent. Other ethical issues are appropriately addressed.

3. General conditions of the ethical approval

The ethics approval is subject to the following general conditions being met prior to the start of the project:

As the Principal Investigator, you are expected to deliver the research project in accordance with the University’s policies and procedures, which includes the University’s Research Code of Conduct and the University’s Research Ethics Policy.

If relevant, management permission or approval (gate keeper role) must be obtained from host organisation prior to the start of the study at the site concerned.

139
4. Reporting requirements after ethical approval

You are expected to notify the Sub-Committee about:
- Significant amendments to the project
- Serious breaches of the protocol
- Annual progress reports
- Notifying the end of the study

5. Use of application information

Details from your ethics application will be stored on the University Ethics Online System. With your permission, the Sub-Committee may wish to use parts of the application in an anonymised format for training or sharing best practice. Please let me know if you do not want the application details to be used in this manner.

Best wishes for the success of this research project.

Yours sincerely,

Prof. Panos Vostanis
Chair
Section E: Literature Review Appendices
Appendix F: Quality Appraisal based on Critical Appraisal Skills Programme (2017) completed by trainee

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<td>Were multiple sites investigated?</td>
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<td>Was everybody included who should have been?</td>
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<td>Can the results be applied to the local population?</td>
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**Table:**
- **Can the results be applied to the local population?**
  - **Was a cohort study appropriate?**
    - Yes: 1
    - No: 0
  - **Are the participants typical of the population?**
    - Yes: 1
    - No: 0
  - **Were the settings moved out of and into similar to those of the population?**
    - Yes: 1
    - No: 0
### Appendix G: Quality Appraisal based on Critical Appraisal Skills Programme (2017) completed by Academic supervisor for purposes of triangulation

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<td>Is the population studied focused?</td>
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<td>Are the outcomes considered focused?</td>
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<td>Is it clear whether the study tried to detect a beneficial or harmful effect?</td>
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<td>Was the cohort recruited in an acceptable way?</td>
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<td>Was the cohort representative of the population?</td>
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<td>Were multiple sites investigated?</td>
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<td>Was everybody included who should have been?</td>
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<td>Was the exposure accurately measured to minimise bias?</td>
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<td>Were service users responses measured first hand?</td>
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<td>Confounding variables</td>
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<td>Have they taken account of the confounding variables in the design and/or analysis?</td>
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<td>Was the follow up of subjects complete enough?</td>
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<td>Was there enough time between T0 and T1 for effects to be seen and stabilise?</td>
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<td>Were people who were not included at T1 examined and controlled for?</td>
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<td>Do you believe the results?</td>
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<td>Are effect sizes reported?</td>
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<td>Does the conclusion fit the results?</td>
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<td>Can the results be applied to the local population?</td>
<td>Was a cohort study appropriate?</td>
<td>Do the results fit with other available evidence?</td>
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<td>Forester-Jones et al. (2002)</td>
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<td>McConkey et al. (2003)</td>
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### Appendix H: Summary of included data

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<thead>
<tr>
<th>Authors / date</th>
<th>Sample and design</th>
<th>Duration</th>
<th>Measures</th>
<th>Findings</th>
<th>Q'</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ager et al. (2001)</td>
<td>Qualitative design</td>
<td>T0: 6 months pre-move</td>
<td>7 day diaries</td>
<td>In the seven day period: 61% were in education or employment Less than ½ had any contact with the community 1/4 went to a friend’s house Almost 1/3 saw a relative 1/3 did not take part in any social activities Almost 2/3 did not take part in any organised activities outside of the home 1 person did not take part in any activities There was an overall significant increase in LEC scores for relationships $(p &lt; .01)$, indicating that a greater range of relationships were experienced. There was a significant increase in combined use of community facilities $(p &lt; .01)$ 8 participants did not improve. 10 saw a reduction in scores. 61% of the latter groups were aged 65 or over</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td>Longitudinal quantitative design</td>
<td>T1: 6 – 9 months post move</td>
<td>Life Experiences Checklist (LEC)</td>
<td>Average age at time of relocation = 53 years (range = 21 – 92 years) Average length of stay in hospital = 29 years (range = 1 – 66 years)</td>
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<td></td>
<td></td>
<td>N = 58</td>
<td>Index of Community Involvement (ICI)</td>
<td>N = 58</td>
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<tr>
<td>Baker et al. (2007)</td>
<td>Longitudinal quantitative design</td>
<td>T0: 6 months pre-move</td>
<td>Guernsey Community and Leisure Assessment (GCPLA)</td>
<td>There was a significant increase in range and frequency of community contacts for the deinstitutionalised group post-move $(p &lt; .01)$. Community use remained low compared to non-disabled populations</td>
<td>Moderate</td>
</tr>
<tr>
<td></td>
<td>Repeated measures subset of larger sample</td>
<td>T1: 18 months post move</td>
<td></td>
<td>Participants (n=28) who were measured pre and post-move from a hospital to five 6-bedded staffed group houses and a comparison group of participants with ID who already lived in the community at T0 (n=32).</td>
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**Q:** 1/4
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<th>Duration</th>
<th>Measures</th>
<th>Findings</th>
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</thead>
<tbody>
<tr>
<td>Bhaumik et al., (2011)</td>
<td>Longitudinal repeated measures quantitative design N = 51</td>
<td>T0: prior to move</td>
<td>Questionnaire on Quality of Life (QoL)</td>
<td>Significant increases were seen in the measured areas of Relationships, and Community access between T0 and T1 (both p &lt; .001). This meant service users were accessing more community facilities and experiencing a greater frequency of relationships. Between T1 and T2, Community access remained constant and Relationships reduced significantly, though remained significantly higher than at T0 (p &lt; .05).</td>
</tr>
<tr>
<td>Dagnan et al., (1996)</td>
<td>Longitudinal mixed methods design N = 4</td>
<td>T0: at time of move</td>
<td>Diary records of activity</td>
<td>Diary records indicated an increase in times engaged in activity at T1 and a further reduction at T2. The mean amount of contact at T2 was approximately half of that at T0 and two participants had zero contact at T1 or T2.</td>
</tr>
<tr>
<td>Dagnan et al., (1998)</td>
<td>Longitudinal repeated measures quantitative design N = 29</td>
<td>T0: 5 months pre-move</td>
<td>Questionnaire on Quality of Life – short form (QoL)</td>
<td>Relationships increased significantly between T0 and T1 (p &lt; .001) and between T1 and T2 (p &lt; .01) and between T2 and T3 (p &lt; .05) Community access increased significantly between T0 and T1 (p &lt; .01) and between T1 and T2 (p &lt; .01) but not between T2 and T3.</td>
</tr>
<tr>
<td>Authors / date</td>
<td>Sample and design</td>
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<td>Measures</td>
<td>Findings</td>
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<tr>
<td>Donnelly et al. (1996)</td>
<td>Longitudinal mixed methods design N = 214</td>
<td>T0: prior to move</td>
<td>Residents' interviews Social Functioning Questionnaire (SFQ)</td>
<td>Social functioning did not significantly change between T0 and T1.</td>
</tr>
<tr>
<td></td>
<td>Move from a hospital to: Nursing homes; private run residential homes; voluntary sector residential homes; hostels; or independent living T1: 12 months post move T2: 24 months post move</td>
<td></td>
<td></td>
<td>Social networks did not change post-move. 74% in hospital and 86% in the community reported having no friends outside of their home and 40% at all time points reported having no friends anywhere. A slight increase was noted in participants’ access to social clubs and going shopping but whether this was significant was not reported.</td>
</tr>
<tr>
<td>Forester-Jones et al., (2002)</td>
<td>Qualitative structured interview design N = 196</td>
<td>T1: 12 years post-move</td>
<td>Interview</td>
<td>Positive aspects of community living most frequently cited: living environment (35%) Social milieu (16%) Independence (6%) Negative aspects most frequently cited: No problems (21%) Social milieu (15%) Loneliness, worry, or boredom (10%)</td>
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<tr>
<td></td>
<td>Move from long stay hospitals to residential nursing homes, hostels, staffed group homes, or supported accommodation</td>
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<tr>
<td>Forester-Jones et al., (2006)</td>
<td>Mixed methods design N = 213 (this sample was drawn from the same population as in Forester-Jones et al., 2002)</td>
<td>T1: 12 years post-move</td>
<td>Social Network Guide (SNG)</td>
<td>Median social network size was 21.5 with a range of 3 – 51 Family members comprised 14% of networks Social acquaintances and friends comprised 11% Approximately a third of network members were acquired from community contexts The remaining members were related to intellectual disabilities services or were peers</td>
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<tr>
<td></td>
<td>Move from long stay hospitals to residential nursing homes, hostels, staffed group homes, or supported accommodation 117 males (mean age = 51 years) 96 females (mean age = 56 years)</td>
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<table>
<thead>
<tr>
<th>Authors / date</th>
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<th>Duration</th>
<th>Measures</th>
<th>Findings</th>
<th>Q*</th>
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<tbody>
<tr>
<td>Head et al., (2018)</td>
<td>Qualitative interview design</td>
<td>T1: 4 months to 2 years post-move</td>
<td>Interview with participants and internalised other interview with key workers answering as though they were service users</td>
<td>Service users expressed sadness at loss of relationships with previous staff and peers post-move</td>
<td>High</td>
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<td></td>
<td>N = 9 took part in interviews</td>
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<td>Length of stay in hospital range</td>
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<td>= 4 – 40 years</td>
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<tr>
<td>Hubert et al., (2010)</td>
<td>Longitudinal ethnographic observational design</td>
<td>T0: pre-move covering a 33 month period</td>
<td>Ethnographic observation</td>
<td>High levels of social exclusion were observed post-move and in some cases, participants had fewer community based activities than they had experienced pre-move.</td>
<td>High</td>
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<tr>
<td></td>
<td>N = 20 male adults who exhibited long-term challenging behaviours, generally related to autism spectrum and mental health problems</td>
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<td>All had been institutionalised since childhood</td>
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<tr>
<td>McConkey et al., (2003)</td>
<td>Qualitative interview design</td>
<td>T0: various times pre move</td>
<td>Resident interview</td>
<td>Over half (21) of the informants reported having friends but only 9 reported having friends outside of their residence. 12 said they had no friends at all</td>
<td>Moderate</td>
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<td>N = 39 took part in interviews</td>
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<td>Moved from a long stay institution to residential accommodation</td>
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<td>37 males and 31 females</td>
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<td>Median age = 37 at discharge (range = 19 – 62 years)</td>
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| Perry *et al.*, (2011) | Longitudinal two way repeated quantitative measures and independent measures design  
N = 19. n = 2 moved before T1, n = 12 more moved before T2. n = 5 remained in hospital until 6 months before T2 and acted as a control group  
13 males and 6 females  
Mean age = 47 years (range = 36 – 67 years)  
Adults with severe challenging behaviours  
Moving from a hospital to six 5-place housing schemes | T0: 3 months prior to move  
T1: 3 months post-move  
T2: 6 months post move | Residential Services Setting Questionnaire | Non-significant increase in contact with neighbours in the community  
There was a significant increase in family contact between T0 and T2 (*p* < .05)  
There was no significant increase in community integration or in range or frequency of community activity | Moderate |

1. **Elapsed time between data collection pre-move and post-move**
2. **Quality according to appraisal.** Studies were rated as low, moderate, or high. These ratings are qualitative and are based on a critical appraisal of the research as demonstrated in Appendix F.
Section F: Research Report Appendices
**Appendix I: Measures used with evidence of validity and reliability**

**Health of the Nations – Intellectual Disability version (HoNOS-LD) (Roy et al., 2002)**

The HoNOS-LD is an 18-item questionnaire designed for individuals with intellectual disabilities and mental health problems. Each item measures the severity of a presenting problem on a five-point scale. It is a staff rated scale that is widely used and was designed to be completed by nursing staff that work directly with the individual. Items on the scale can be grouped into four factors: Communicative-cognitive competence; behaviour disturbance incorporating relationship breakdown; loss of adaptive behaviour incorporating acute physical illness; and internal dysregulation (Skelly & D’Antonio, 2008). The full HoNOS-LD and all factors were analysed.

Evidence has demonstrated that the HoNOS-LD can be used to measure change across time, has good interrater reliability ($r = .70$), and has fair convergence validity with a similar measure (the Aberrant Behaviour Checklist - ABC) ($r = .66$) (Roy et al., 2002).

**Mood, Interest and Pleasure Checklist (MIPQ) (Ross & Oliver, 2003)**

The MIPQ is a 25 item questionnaire that is completed by staff. Items are scored on a five point Likert scale based on the prevalence of behaviours indicative of emotional states over the previous two weeks. Three outputs are produced: A ‘mood’ score; an ‘interest and pleasure’ score; and a ‘total’ score.

Preliminary evidence demonstrates that the MIPQ has good interrater ($r = .76$), test-retest ($r = .87$) and internal reliability ($r = .67$), as well as evidence of convergent validity with the Lethargy, Social Withdrawal subscale of the ABC ($r = -.59$) (Ross & Oliver, 2003).
An adapted version of the Resident Choice Scale (RCS) (Hatton et al., 2004)

A bespoke choice scale was developed for use in the current study based on the RCS. This was done at T0 prior to the researcher’s involvement. Whereas the full RCS utilises 26 items, the adapted scale utilises six that were deemed by the authors to be exemplary of the remainders (Baker & Collins, 2009).

Rather than directly measuring the degree of choice that an individual is afforded, the RCS scale considers a person’s ability to make choices.

Because the full RCS was not used, no relevant reliability or validity studies exist. However, the full RCS has been shown to have medium inter-rater reliability (Spearman’s rho = .89) and a total internal reliability of $\alpha = .95$ (Hatton et al. 2004).


The ABAS-II is typically administered as an informant-based assessment of a person’s abilities to complete tasks relevant to the following areas of adaptive functioning: Communication; community usage; functional academics; home living; health and safety; leisure, self-care; self-direction; socialisation; and work. As the ABAS-II was used at T0, it was also utilised at T1 despite the release of an updated version (ABAS-III). This is relevant because some skills measured by the ABAS-II are now functionally defunct (such as the use of phone books or payphones).

While not designed as an outcome measure, evidence has demonstrated that the ABAS-II can be used as such due to its sensitivity to changes in adaptive functioning (Hamelin et al., 2011). This also links with the normalisation model, which underpins much of the current deinstitutionalisation policy: access to a more ‘normal’ life will produce more ‘normal’
behaviours. Accordingly, adaptive behaviour will be improved if one is placed in a setting that affords such behaviour.

The ABAS-II has been demonstrated to have very good internal consistency (range: $\alpha = .98$ to $\alpha = .99$), test-retest reliability ($r = .90$), moderate construct validity (range: $r = .4$ to $r = .7$), and moderate concurrent validity with a number of other measures (for a review, see Rust & Wallace, 2004).

The ABAS-II was used as opposed to the ABAS-III because the former had been utilised at T0 and thus was thought to offer a better comparison.

**Emotional wellbeing**

The emotional wellbeing of service users was studied using a bespoke measure. This contained four questions that staff members were asked. Answers were scored from 1 (not at all) to 5 (very much). Questions included: Do you think _ is happy here?; Do you think _ needs are being met?; How much would you say _ enjoys life?; How much do you like _? Analyses were conducted on aggregates of scores for the four questions. This measure was created at T0, prior to the author’s involvement.

**Social networks**

Social networks were mapped using a ‘wheel of life’, similar to previous research examining social networks (e.g. Robertson et al., 2001) whereby the service user’s name was placed in the centre of two concentric circles. The names of all the people that they knew were then placed at points on the form, with proximity to the service user indicating the importance of the relationship to the service user, as perceived by the member of staff being interviewed.
Family Questionnaires

In total, 12 service users had regular and close contact with family members. Questionnaires were sent to all of these family members but only one was returned in time for inclusion. As such, the questionnaires were not included within the results.
Appendix J: Example of a social network diagram

- Staff
- Mum
- Close friend
- Neighbour
- Keyworker
- Friend
- Dad
- Service user name
Appendix K: Template analysis process

Following guidelines by King (1998), analyses were conducted in the following stages.

Create initial template

The initial template used was based on the eight basic rights of quality of life as outlined by Verdugo et al. (2012):

1. Personal Development  
   a. Skills  
   b. Behaviour  
2. Self Determination  
   a. Choice  
   b. Activity  
3. Interpersonal Relations  
   a. Family  
   b. Staff  
   c. Others  
4. Social Inclusion  
   a. Segregated  
   b. Unsegregated  
5. Rights  
6. Emotional Wellbeing  
7. Physical Wellbeing  
   a. Aging  
   b. Changes because of home  
8. Material Wellbeing

This template was applied to two transcriptions using nVivo software package.

Revise template

Based on the two transcriptions, the template was amended. This was then applied to all the transcriptions. Inadequacies and overlap with templates and codes were examined.
Modify template

Modifications were made to the codes and themes based on findings of all the transcriptions. Codes were cut out and placed into plastic wallets. These were then examined and rearranged using a white board to write up temporary themes.

Interpretation

Once themes had been created, these were then refined using a top-down approach to ensure relevance to the research topic. Six final themes were created, each with subthemes of positive changes, negative changes, little-to-no change, and offered explanations. Transcriptions were then subjected to these codes a final time. Coding from this run through was used as the final data for the research. Interpretation was applied to the final set of codes and themes.
Present

Data was then presented as themes rather than as individual case studies and exemplar quotes were used to support findings.
### Appendix L: Normality assessments

<table>
<thead>
<tr>
<th>Measure</th>
<th>Shapiro-Wilk</th>
<th>df</th>
<th>Sig.</th>
</tr>
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<td>0.503</td>
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<td>0.101</td>
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Total Emotional pre-move
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<th>Sig</th>
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<td>scaAbCUPos</td>
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<td>0.004</td>
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<td>0.001</td>
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</table>
Appendix M: Measures completed without inclusion of service user 4

Due to concerns regarding the confounding impact of Service user 4’s dementia symptoms having become more pronounced since move, measures were repeated without this service user’s inclusion. This did not significantly impact any group level changes and so analyses included in the final report were presented with this service user’s data included. Below is an SPSS printout of t tests conducted with this service user’s data excluded.

ABAS-II scores are not included as T0 data was missing for this service user.

<table>
<thead>
<tr>
<th>Paired Differences</th>
<th>Mean</th>
<th>SD</th>
<th>Std. Error Mean</th>
<th>Lower</th>
<th>Upper</th>
<th>t</th>
<th>df</th>
<th>Sig. (2-tailed)</th>
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<tbody>
<tr>
<td>HoNOS Total pre-move - HoNOS Total post-move</td>
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<td>4.80</td>
<td>1.52</td>
<td>-2.64</td>
<td>4.24</td>
<td>0.53</td>
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<td>HoNOS C &amp; C pre-move - HoNOS C &amp; C post-move</td>
<td>0.00</td>
<td>1.83</td>
<td>0.58</td>
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<td>1.31</td>
<td>0.00</td>
<td>9.00</td>
<td>1.00</td>
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<tr>
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<td>3.60</td>
<td>1.14</td>
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<td>4.07</td>
<td>1.32</td>
<td>9.00</td>
<td>0.22</td>
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<td>honosAPre - honosAPost</td>
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<tr>
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</tr>
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<td>4.78</td>
<td>1.69</td>
<td>-4.00</td>
<td>4.00</td>
<td>0.00</td>
<td>7.00</td>
<td>1.00</td>
</tr>
<tr>
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<td>-1.90</td>
<td>-4.11</td>
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</tbody>
</table>
Appendix N: Quality assurance

Elliott et al. (1999) outlined seven guidelines that should be followed to ensure that qualitative research demonstrates appropriate scientific rigour. These are detailed below along with a description of ways that the researcher attempted to follow them.

Owning One’s own Perspective

The Researcher attempted to engage with staff members in an unbiased and naïve way. However, they had been employed in various community residential care homes for individuals labelled with intellectual disabilities. As they had considered many of these homes to be service centred rather than person centred and often dehumanising, it is possible that this will have influenced the researcher’s interpretations of what staff members reported. Despite the study being based on a critical realist epistemology, the trainee’s natural stance is more constructionist and this may also have impacted the way that statements were understood and interpreted. In an effort to minimise potential biases, close discussions were held with the researcher’s academic supervisor about generated themes and codes.

Situating the Sample

Staff members participating in the study were a mixture of ten support workers and two social workers. The sample consisted of two males and ten females, all of whom were Caucasian and British. Staff members were invited to participate based on the length and intimacy of relationships with service users and so it is likely that responses offered were biased in favour of the service users. Alongside this, with the exception of the two social workers, all staff members were employed by the service providers who cared for service
users and so may have felt implicit expectations to emphasise positive changes resulting from moving into the community while minimising negatives.

**Grounding in Examples**

Throughout the results section, quotes were used to demonstrate phrases or statements that the researcher interpreted as being indicative of particular themes. In this way, readers are able to reflect on whether they agree or not with the quote’s inclusion within the theme.

**Providing Credibility Checks**

All themes were triangulated with relevant quantitative outcome measure scores to ensure credibility.

**Coherence**

All themes were categorised into a hierarchy of themes and sub themes to allow easy navigation and comprehension.

**Accomplishing General Research Tasks**

As the study attempted to produce generalizable findings, service users were not excluded if they were unable to communicate, had developed physical or mental health conditions, or had recently become deceased. As all service users had previously lived in institutional accommodation, it cannot be assumed that the pertinent themes created from
interviews could be generalised to service users who have moved into homes in the community after living at home with parents, or individuals with intellectual disabilities who do not live in 24 hour staffed residential care.

Resonating with Readers

All attempts were made to ensure that information was presented clearly and concisely so as to engage readers and clarify or expand upon existing knowledge.

Epistemological position

The Researcher’s adopted epistemological stance was one of realism. This is detailed in Appendix A. Madill et al. (2000) argued that for such a stance, quality should be ensured in terms of objectivity and reliability. Objectivity relates to the absence of bias. To minimise bias, themes were generated and named using participants’ own words where possible rather than the researcher’s interpretation of them. Any interpretations done afterwards were therefore grounded within this. A reflective journal was kept throughout the interpretation process. Previous research has demonstrated how this can allow for the exploration of critical self-reflection to minimise unconscious biases (e.g. Ortlipp, 2008).
Appendix O: Reliable improvements and deteriorations for service users across outcome measures

<table>
<thead>
<tr>
<th>Service user</th>
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<th>Reliable deteriorations</th>
<th>Non-reliable change</th>
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