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Supported Accommodation Services for People with Intellectual Disabilities:

A review of models and instruments used to measure quality of life in various settings

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Supported Accommodation Services for People with Intellectual Disabilities: A review of models and instruments used to measure quality of life in various settings

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1.

Introduction

In 2005, the National Disability Authority (NDA) commissioned research on the outcomes and costs of supported accommodation for people with intellectual disabilities. The methodologies used to evaluate the quality and costs of residential service provision for people with intellectual disabilities were also reviewed.

The term 'supported accommodation' is used to describe services that include comprehensive residential supervision, training and other assistance in a small-group home (Lakin et al, in Stancliffe and Lakin, 2005). It is of note that in the UK and elsewhere 'supported living' is sometimes used to describe a situation where one or two persons might live in their own apartment or house with some support – in the UK, perhaps as local authority tenants. However, in this report, it is used as above.

The Australian Government – Department of Health and Ageing – uses the term 'supported community accommodation' to include community living settings or accommodation facilities in which clients are provided with support in some way by staff or volunteers. This category includes domestic-scale living facilities (such as group homes for people with disabilities, cluster apartments where a support worker lives on site, community residential apartments, congregate care arrangements, etc.) which may or may not have 24-hour supervision and care. It also includes larger-scale supported accommodation facilities providing 24 hour supervision and support services by rostered care workers (such as hostels for people with disabilities, serviced apartments in retirement villages and government-regulated Supported Residential Services/facilities (Victoria and South Australia only).

Distinctive features mark residential accommodation for people with intellectual disabilities in Ireland, where the voluntary sector has a leading role. Ireland stands in contrast to the United States, where provision of services in the least restrictive settings along with individualised supports is mandated by legislation and to the Nordic States or the UK, where wide-ranging deinstitutionalisation[1] policies have been implemented systematically at national level. Although similar advances are evident in other European countries, traditional large residential centres persist alongside attempts to offer a greater community presence to people with intellectual disabilities (European Intellectual Disability Research Network [IDRESNET], 2003). Differences are also apparent with respect to the providers of services. In the Nordic countries, providers are primarily in the public sector; in Ireland, in the voluntary sector; and in the UK, they are a combination of the two sectors.

In Ireland, developments underpinning policy and service provision for people with disabilities in the last two decades may be said to comprise the following elements: an information base for policy; mainstreaming of public service provision; equality legislation; disability specific legislation; and international perspectives related to these matters (Doyle, 2003). An important advance in gathering robust information took place with the National Census in 2006. This included a screening item to determine the presence of persons with disabilities in Irish households. In addition, a post-census National Disability Survey, using a population-based

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[1] Deinstitutionalisation is a social policy involving the replacement of large, state-run institutions by other forms of living arrangements for people with intellectual disabilities. "It must extend beyond the closure of institutions to individualised support to people with intellectual disabilities and societal change" (Bigby et al 2006, p567). Bigby et al (2006) highlight the danger of equating institutional closure with deinstitutionalisation and demonstrate how the closure process can hinder or further the aims of deinstitutionalisation.

representative sample of approximately 15,000 people with disabilities, was conducted in 2006. The Central Statistics Office directed this National Disability Survey in consultation with an expert group drawn from the disability and research sectors.

Goals and trends in residential supports for people with intellectual disabilities in Ireland today reflect international moves towards individualised supports and community inclusion. Reflecting these policies, providers over the past 20 years have recognised the importance of satisfactory living arrangements in the everyday lives of people with intellectual disabilities. Accordingly, they have developed smaller-scale and more ordinary residential supports, such as group homes in community houses. These trends are evident in changing patterns of residential accommodation for Irish adults with intellectual disabilities.

A total of 24,917 adults and children using statutory and voluntary services in Ireland were identified in the **2005 Report of the Irish Intellectual Disability Database Committee**, representing an overall prevalence rate of 6.36 per 1,000 of population (Barron and Mulvany, 2005). (This database reflects administrative returns and is not population-based.) Of these, 8,073 were in receipt of full-time residential services. For a second consecutive year, slightly more adults living outside family homes were living in group homes rather than in larger congregate residential centres (i.e. sites where large numbers o f persons are gathered in contrast to residences of domestic scale) or hospitals (Table 1.1). Those aged over 55 years were more likely to live in residential centres.

Table 1.1. Irish adults (20 years +), living with their families, in group homes or in residential centres (Barron and Mulvany, 2005)

	Family home	Group home	Residential centre
20-34	4553	861	689
35-54	2623	1836	1598
55 +	471	659	923
	7647	3356	3000

The body of evidence comparing outcomes for Irish adults in such settings is relatively modest. A study of n=125 Irish adults living in both group homes and congregate settings was undertaken in collaboration with colleagues in the UK. It indicated that people living in group homes had: greater levels of choice about everyday activities such as mealtimes, bedtimes and holidays; larger social networks; and more scheduled activities than people living in campus settings (Walsh, Linehan et al., 2000).

As the demand for personally satisfying living accommodation comparable with that available to other citizens continues to grow, what is the optimal strategy for shaping and sustaining good quality residential supports for people with intellectual disabilities in Ireland? How might desirable outcomes for this group be aligned with those of the general population in Ireland, the rest of Europe and internationally, in terms of sharing equal opportunities for full social participation? Allied questions for Government and policy makers have to do with linking costs of services to their quality, specifically in terms of outcomes for individuals using services.

The contemporary emphasis on quality and quality indicators reflects a transformed vision of what constitutes the life possibilities of persons with intellectual disabilities, as well as a new way of thinking about such individuals that focuses on: the rights and dignity of each person; the environmental variables that influence functioning; and the feasibility of change at the individual, organisational and systems levels.

Quality has emerged as a construct of great importance in health, social care, education and allied fields. Quality of life has widespread appeal and there is considerable consensus that this construct is multi-dimensional, that the domains hold true for all people, and that it comprises both subjective and objective components. Objective components have the merit of enabling comparisons between life outcomes for individuals and groups to be compared with those of their peers.

Quality indicators are used for at least three purposes: guiding quality improvement, monitoring social exclusion, and reducing inequalities and injustice. Their relevance is apparent in regard to: persons with intellectual disabilities who desire a life of quality; to providers who want to deliver a quality product that results in enhanced personal outcomes; and to policy makers and funders who desire valued outcomes for service recipients and data that can link these outcomes to social policy. Given these various purposes, there is a definite need to establish criteria by which one can select indicators that are pertinent for the particular purpose (e.g. appropriate indicators for a sustainable national quality system or indicators relevant for monitoring exclusion).

NDA's commissioned research attempted to address this issue and asked the following questions: what are the major outcomes for persons with intellectual disabilities? What are the strengths and weaknesses of the approaches used to date to evaluate outcomes for people with intellectual disabilities in supported accommodation, including quality of life? What are the contemporary approaches to the measurement of quality of life experiences of people with intellectual disabilities living in supported accommodation? This work by a consortium representing research, policy and practice communities in Ireland, the UK and the US was completed in October 2006.

The report contains a summary of the main findings of the literature review including:

a) a review of deinstitutionalisation and post-institutionalisation[2] studies carried out in the 11-year period, 1995-2006;

b) an examination of the instruments used to measure outcomes;

c) the comparative costs and benefits associated with different approaches to providing supported accommodation for people with intellectual disabilities.

The report also presents the views of the authors on the evaluation of the outcomes of supported accommodation and possible quality indicators that could be used, based on their professional expertise as well as on the findings of the literature.

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[2] Deinstitutionalisation studies are studies mainly from the UK and the USA documenting the impact of the social policy, deinstitutionalisation, on the quality of life of people with intellectual disabilities. Post-deinstitutionalisation studies are generally cross-sectional design studies across a variety of supported accommodation settings examining the comparative costs and benefits associated with different approaches to providing supported accommodation for people with intellectual disabilities. These terms are further explained in the literature review.

2.

Summary of Main Findings of Literature Review

2.1. Outcomes

There is some evidence to suggest that smaller, less institutional settings are associated with greater choice and self-determination and greater participation in community-based activities (see Table 1.3). There is also some evidence to suggest that smaller, less institutional settings are associated with participation in wider or more active social networks and increased rates of physical exercise. There was no systematic evidence to suggest that larger or more institutional settings were associated with better outcomes for any quality of life domain.

While smaller, less institutional settings may offer a better quality of life in some domains, the post-deinstitutionalisation studies fail to provide a sufficient volume of evidence to draw clear conclusions between types of post-institutional accommodation and the development (or loss) of personal skills, material circumstances, employment, physical health, emotional and mental health, and personal life satisfaction.

There is a continuing debate in a number of countries (e.g. Ireland, UK, Australia and Poland) about the possible advantages associated with cluster housing or campus-type settings for people with intellectual disabilities. One of the main rationales underlying such models is that they are likely to facilitate the development of friendships and relationships among people with intellectual disabilities (Cummins and Lau, 2004a). The available evidence fails to substantiate this claim, indicating that such settings offer a poorer quality of life than more dispersed community-based provision (Emerson, 2004; Emerson et al., 2000; Emerson et al., 2000; McConkey et al., 2005; McConkey et al, 2007). Studies that have focused on quality of care (rather than quality of life) have also failed to report any systematic advantages associated with campus/cluster housing (Emerson, 2004; Emerson et al., 2000; Emerson et al., 2000; McConkey et al., 2005; Walsh, McConkey, and Sinclair, 2004).

The available evidence suggests that there is no systematic association between the type of post-institutional accommodation and participation in domestic activity. There is, however, considerable evidence to suggest that participation in domestic activity is strongly linked to both the personal skills of participants and staff activity (Felce and Emerson, 2004; Felce et al., 2003; Felce et al., 2000; Felce et al., 2002; Jones et al., 2001). It should be kept in mind, however, that deinstitutionalisation studies indicate significantly greater participation in domestic activities in smaller, less institutional settings (Emerson and Hatton, 1994; Felce, 2000; Hatton and Emerson, 1996).

In common with previous evidence (Emerson and Hatton, 1994; Felce, 2000; Hatton and Emerson, 1996), UK post-deinstitutionalisation studies have largely failed to identify any robust association within community-based residences between costs and outcomes (Emerson et al., 2005; Felce and Emerson, 2005; Felce et al., 2003; Felce et al., 2000; Myles et al., 2000).

2.2. Costs

The majority of evidence from the UK post-deinstitutionalisation studies indicates **higher costs** in smaller, less institutional settings and in specialised settings for people with particular needs (e.g. people with severe challenging behaviour and dual sensory impairment) (Hatton et al., 1995; Robertson et al., 2004). These findings are consistent with the UK deinstitutionalisation literature, which has consistently reported higher costs in community-based residences when compared to institutions (Emerson and Hatton, 1994; Felce, 2000; Hatton and Emerson, 1996). However, the relationship between costs and size is complex, with evidence suggesting that economies of scale primarily reflect the impact of fixed costs (e.g. night-time cover) in very small-scale services for people with severe disabilities (Emerson et al., 2005; Felce and Emerson, 2005). As such, economies of scale are less evident in larger services or in services for people with less severe intellectual disabilities.

In contrast, evidence from the US indicates lower costs in smaller settings (Rhoades and Altman, 2001). Again, this finding is consistent with the US deinstitutionalisation literature, which has consistently reported higher costs in institutional settings (Stancliffe et al., 2005).

The discrepancy between the findings from UK and US research is likely to reflect greater investment in institutional reform in the US and differences between the UK and US in wage rates between institutions and community-based residences (Stancliffe et al., 2005). The cost literature also indicates no difference in costs between supported living arrangements and either traditional services in the US (Howe et al., 1998) or small group homes in the UK (Emerson et al., 2001) and lower costs in semi-independent living arrangements when compared to group homes in Australia (Stancliffe and Keane, 2000).

In Ireland, findings from unpublished reports to date suggest the individualised costs of large residential centres are higher than of group homes.

In both the UK and the US, studies have largely failed to identify any robust association within community-based residences between costs and outcomes.

3.

Literature Review

3.1. Review Process

The results of a systematic review of research are summarised to allow valid inferences to be drawn concerning the direct outcomes and/or costs of supported accommodation services for adults with intellectual disabilities. Research papers that were published in English-language peer-reviewed academic journals between 1995 and 2005 are included in this systematic review.

Outcomes and Costs

Included in the review are papers from which it was possible to draw valid conclusions about either the outcomes of supported accommodation services or their costs. The term "outcomes" is used to mean all aspects of the life experiences of people with intellectual disabilities living in different forms of supported accommodation that could be directly linked to that person's quality of life.

Quality of Life

The following framework for conceptualising the domains of quality of life (Table 1.2) was used.

Table 1.2. Quality of Life: Core Domains

Independence	Civic Participation /Social Inclusion	Well-being
Personal skills (e.g. adaptive behaviour) Material well-being (e.g. income, possessions) Choice and self-determination Other	Social networks and friendships Community-based activities Employment Other	Emotional well-being /mental health (including challenging behaviour) Physical health Personal life satisfaction Other

Making Links

There are a number of problems associated with making valid inferences between the characteristics of supported accommodation and lifestyle outcomes for people with intellectual disabilities (Stancliffe, Emerson and Lakin, 2004). In particular, there is now overwhelming evidence that: (1) lifestyle outcomes in most domains are closely linked to the personal characteristics of people with intellectual disabilities, and in particular to their level of intellectual disability or adaptive behaviour (Emerson and Hatton, 1994; Felce, 2000; Felce and Emerson, 2001; Stancliffe et al., 2004); (2) the same personal characteristics also vary systematically across different types of supported accommodation with, typically, people with more severe intellectual disabilities often living in larger or more institutional provision or provision operated or funded by particular agencies (Stancliffe et al., 2004).

As a result, it is crucial to attempt to separate the impact of personal characteristics from the impact of supported accommodation on quality of life outcomes. Three main approaches have been used to address this issue in the research literature:

- Some studies have employed longitudinal designs (i.e. following the same people as they move from one form of provision to another). This approach is particularly common in studies that have attempted to evaluate the impact of deinstitutionalisation,
- Other studies have attempted to select (match) participants living in different forms of supported accommodation on the basis of their similarity on key personal characteristics (e.g. level of intellectual disability),
- Finally, some studies have used statistical procedures (usually some form of multivariate analyses) to take account of (control for) any differences in the personal characteristics of participants across settings.

While none of these approaches is perfect (Stancliffe et al., 2004), they do increase the confidence with which links can be drawn between the type or characteristics of people's living situations and their quality of life. Included within the review are papers that employed one of these three approaches to disentangle the effects of personal characteristics from the impact of supported accommodation on quality of life outcomes. Therefore, uncontrolled studies that simply reported differences in quality of life across or within settings while making no attempt to determine whether such differences could be due to differences in the personal characteristics of the people served are excluded.

An additional problem in making valid links between living situations and quality of life lies in the tenuous relationship between indicators of quality of care and quality of life (Emerson and Hatton, 1994; Felce, 2000; Stancliffe et al., 2004). The research to date has largely failed to identify indicators of care practices that are robustly and reliably linked to quality of life outcomes for people with intellectual disabilities. As such, drawing links between living situations and quality of life requires the direct measurement of indicators of lifestyle or life experience outcomes for people with intellectual disabilities. Excluded from the review, therefore, are any papers that only reported on the quality of care practices in or satisfaction with outcomes by other stakeholders (e.g. family carers) within supported accommodation services for people with intellectual disabilities.

Time Frame

The time frame 1995-2005 was selected because: (1) systematic reviews covering earlier periods are already available for the UK and Ireland (Emerson and Hatton, 1994; Felce, 2000; Hatton and Emerson, 1996), Australasia (Young et al., Suttie, 1998) and the US (Kim, Larson and Lakin, 2001); (2) research from earlier periods predominantly focused on the impact of deinstitutionalisation on a narrow range of outcome indicators (Emerson, 1985; Stancliffe et al., 2004). As such, evidence from earlier periods is of more limited relevance to current policy in Ireland. However, the results of previous reviews are incorporated in this discussion of the results of the present systematic review.

Sources of Evidence

Included within the review is evidence drawn from research published in English-language peer-reviewed academic journals. This reflects both a concern to base the review on high-quality evidence (peer review being the standard approach to quality assurance within the scientific community) and pragmatic considerations in that to undertake a systematic review of the "grey" literature was simply not feasible within either the time frame or the resources available.

While a comprehensive review of this literature is not practicable, we recognise that certain "grey" literature publications are of significant value. A number of studies that have sought to evaluate quality and/or costs across significant geographical areas, for example, have developed approaches to measurement that are often more comprehensive and efficient than many traditional research studies (Bonham et al., 2004; Bradley and Kimmich, 2003; Emerson et al., 2005; Gardner and Carran, 2005; Human Services Research Institute and National Association of State Directors of Developmental Disabilities Services, 2003). In order to gain the benefit of the information gathered through these resources, we have, wherever possible, incorporated data from key "grey" literature sources in our discussion of the results of our present systematic review.

Potentially relevant studies were identified through a combination of procedures including:

- bibliographic searches of web-based engines PsychInfo, Medline, Academic Search Premier and SSCI;
- "snowballing" through hand searches of papers cited in publications already identified;
- email correspondence with active researchers in this field in the UK, Ireland, US, Canada and Australia to identify additional papers that met our criteria.

Summarising the Evidence

The methodology and results of all studies that met our criteria are summarised in tabular form for studies of deinstitutionalisation

(Appendices 1 and 2) and post-deinstitutionalisation studies (Appendices 3 and 4). By deinstitutionalisation studies, we refer to studies whose primary aim has been to evaluate the impact of the process of deinstitutionalisation on the quality of life of people with intellectual disabilities. By post-deinstitutionalisation studies, we refer to studies whose aim is either to compare quality of life outcomes across different types of community-based residences or to identify factors associated with variation in quality of life outcomes within community-based residences.

We have made this distinction for two main reasons. First, the deinstitutionalisation literature is primarily drawn from studies undertaken in the UK and US, whose primary aim was to evaluate the impact of a particular social policy, that of deinstitutionalisation. In both these jurisdictions, institutional provision comprised large state-operated facilities that were widely acknowledged to be in crisis (Blatt and Kaplan, 1966; Kugel and Wolfensberger, 1969; Martin, 1984). That is, the deinstitutionalisation literature addresses the impact of a particular social policy (the closure and replacement of failing large state-operated facilities) in two particular jurisdictions at a particular point in time. Although no similar universal change was implemented in Ireland as the result of mandate or radical policy change, there has nonetheless been a gradual transfer to smaller-scale supported accommodation for people with intellectual disabilities, and many are currently documented as requiring this form of residential support (Barron and Mulvany, 2005).

However, the post-deinstitutionalisation literature, while also mainly drawing on studies undertaken in the UK and US, has addressed a quite distinct question: in the absence of large state-operated institutions, what are the comparative costs and benefits associated with different approaches to providing supported accommodation for people with intellectual disabilities? This question has clear relevance to the current situation in Ireland and elsewhere.

The second reason for the distinction is that deinstitutionalisation literature typically undertakes a comparative evaluation of institutional and community-based settings within the context of the (primarily involuntary) relocation of people from more to less institutional settings. The post-deinstitutionalisation literature typically undertakes a comparative evaluation of different forms of community-based settings in the absence of relocation of people from one setting to another.

Methodological aspects of the studies are summarised in Appendices 1 and 3 in relation to sampling, design, type of supported accommodation and the extent to which the study showed characteristics of participative or emancipatory research (Ramcharan, Grant and Flynn, 2004). The results of the studies are summarised in Appendices 2 and 4 in relation to the domains of quality of life listed in Table 2. Those results are shown that are reported in the studies as being statistically significant with an alpha value of at least 0.053.

Given the heterogeneity of designs and measures, it is not possible to undertake any meta-analysis of the pooled results of these studies. Instead, we have employed a narrative approach to summarising the key points that arise from this evidence-base in relation to: (1) what is known about the quality and costs of different approaches to providing supported accommodation for people with intellectual disabilities; (2) the identification of major omissions in the evidence-base.

The Evidence-base

We identified a total of 86 papers, reporting the results of 67 studies, that allowed conclusions to be drawn regarding the association between the type or characteristics of living circumstances and quality of life outcomes for people with intellectual disabilities.

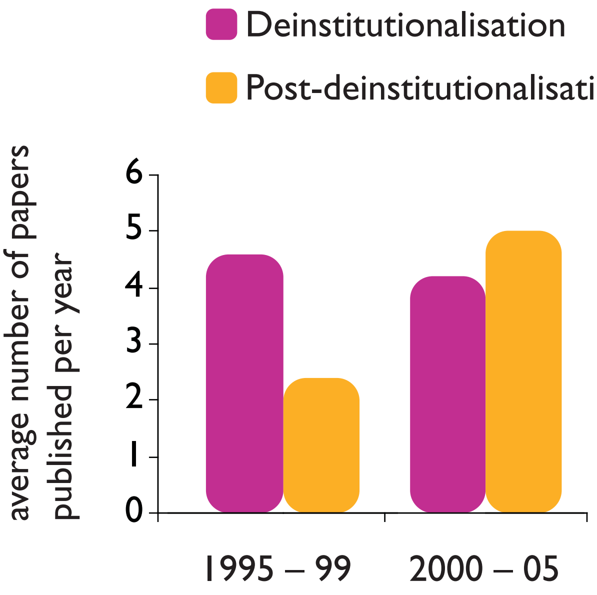
Deinstitutionalisation was the focus in 49 papers, which reported the results of 37 studies, while post-deinstitutionalisation was the focus of the other 37 papers, reporting the results of 30 studies. Some basic characteristics of these papers/studies are summarised below.

Basic Characteristics and Methodological Aspects of the Studies

Year of Publication

As it is not always possible to determine when studies are actually undertaken, Figure 1 summarises the years in which individual papers from deinstitutionalisation and post-deinstitutionalisation studies were published.

Figure 1. Year of publication

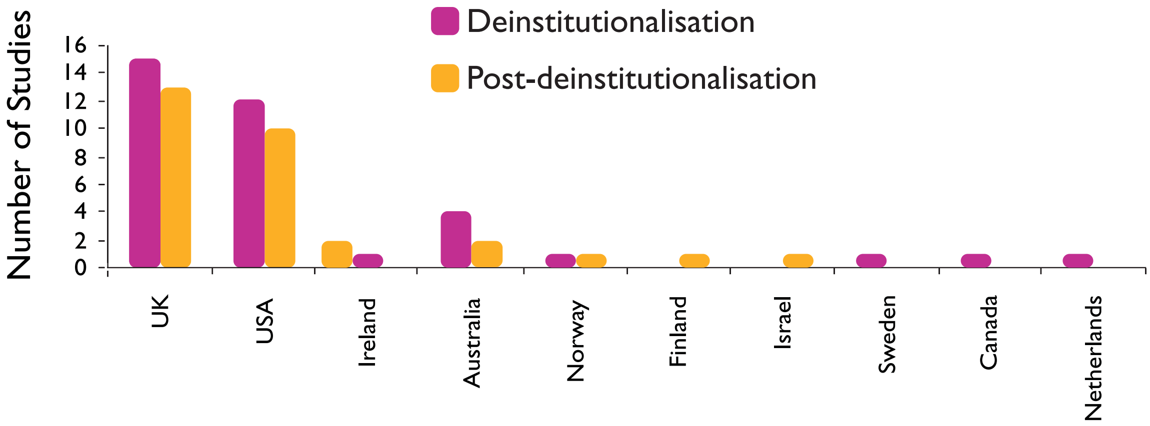


As can be seen, there was a slight reduction in the average number of scientific papers published on deinstitutionalisation over the period of the review. This was accompanied by a marked increase in the average number of post-deinstitutionalisation papers published.

Country Where Study Undertaken

Figure 2 summarises the country in which deinstitutionalisation and post-deinstitutionalisation studies were undertaken.

Figure 2. Studies by country

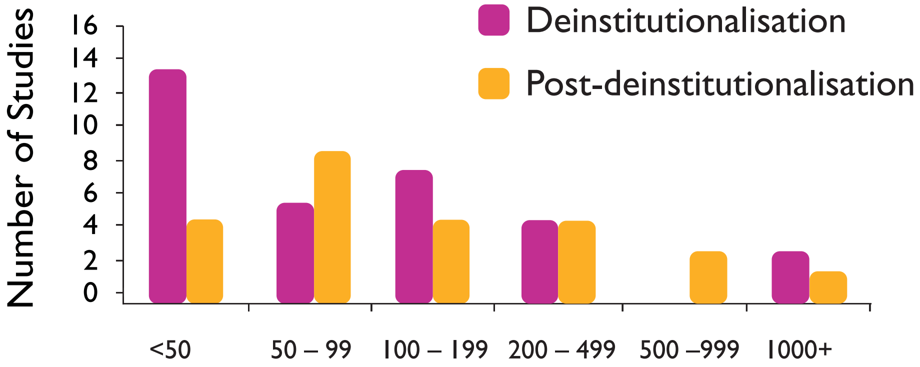


As can be seen, the vast majority of post-deinstitutionalisation studies have been undertaken in the UK and US. Together, these countries account for 75% of all deinstitutionalisation studies and more than 75% of all post-deinstitutionalisation studies. The small number of studies undertaken outside these two jurisdictions has implications for the confidence with which the literature findings can be generalised across national boundaries.

Sample Size

Figure 3 summarises the sample sizes involved in deinstitutionalisation and post-deinstitutionalisation studies.

Figure 3. Studies by sample size

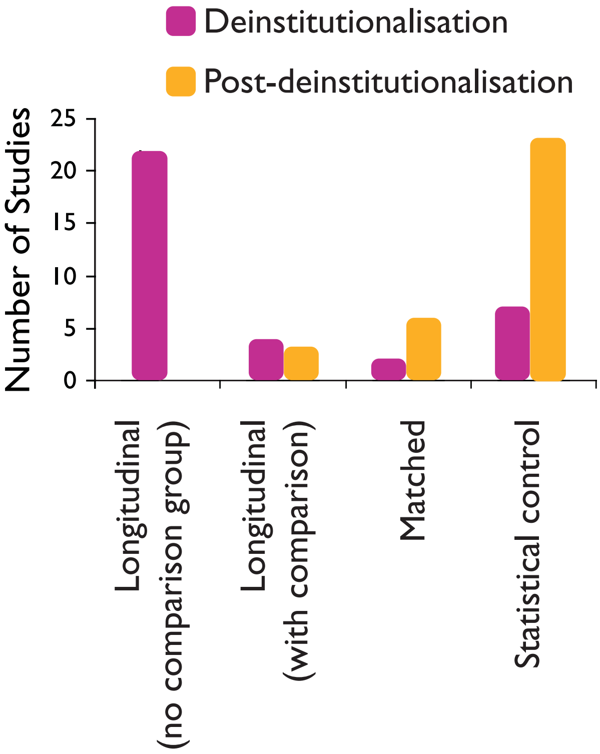


Half of the post-deinstitutionalisation studies and over half of the deinstitutionalisation studies have employed very small (n<50), or quite small (n<100), sample sizes. These studies are significantly "underpowered" in that the small size of the sample markedly reduces the probability that real and potentially socially significant differences in quality of life between or within community-based residences will be identified through statistical procedures to be statistically significance (the criteria for reporting used in our review). One way around this problem would be for studies to report effect sizes for comparisons as well as whether comparisons attain a level of statistical significance. Unfortunately, we are only aware of one study that has adopted this approach (Emerson, 2004). As a result, care needs to be taken when considering the results of "underpowered" studies as the failure to find a significant difference may reflect either the lack of statistical power of the study and/or the lack of such a difference in reality.

Design

Figure 4 summarises the designs used in deinstitutionalisation and post-deinstitutionalisation studies.

Figure 4. Studies by methodological design



As can be seen, post-deinstitutionalisation studies have primarily relied on statistical procedures to attempt to control for between or within sample differences in quality of life that may be attributable to the personal characteristics of participants rather than the impact of the accommodation setting. Deinstitutionalisation studies have tended to rely on rather weak uncontrolled pre-post designs.

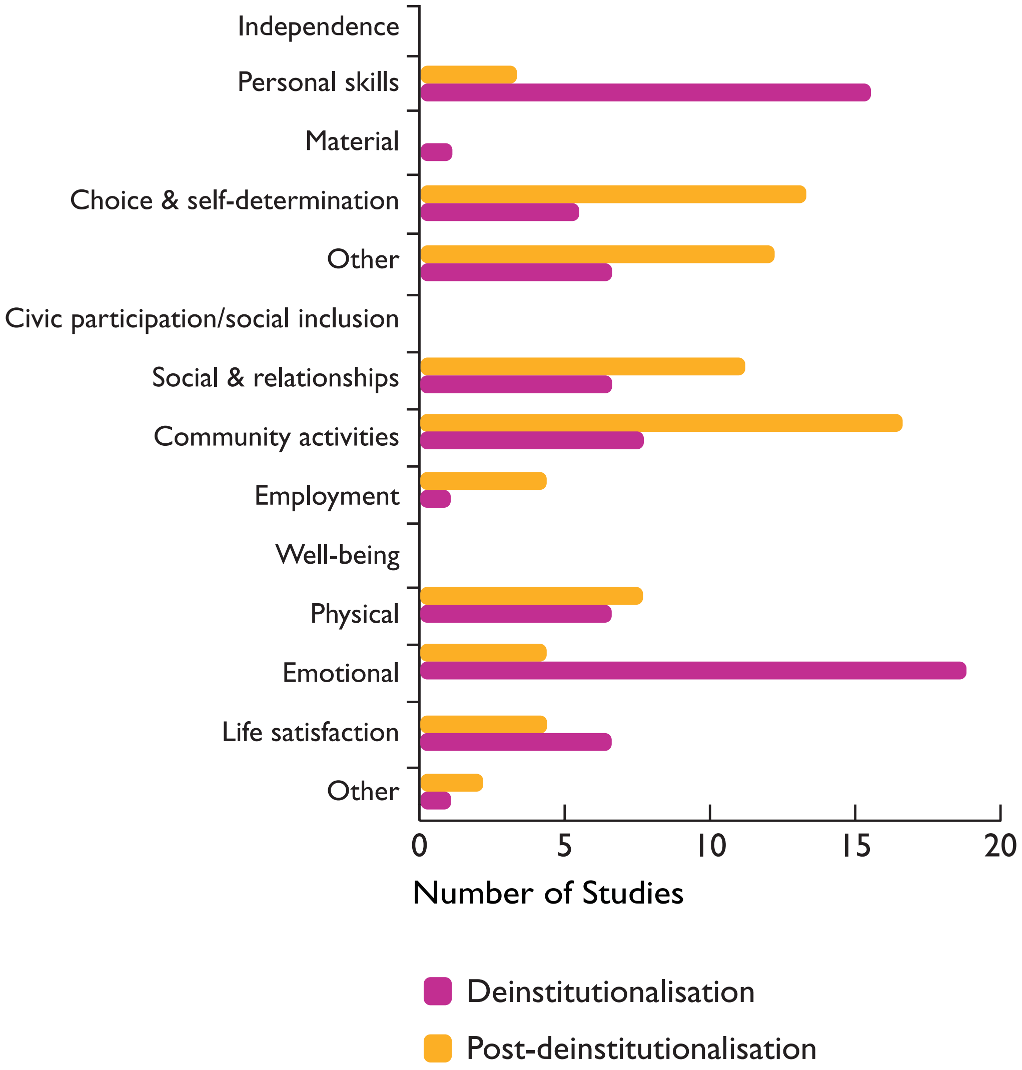
Participatory and Emancipatory Approaches

Two post-deinstitutionalisation studies (and no deinstitutionalisation studies) showed some evidence of adopting a participatory approach to research. In each case, the participation of people with intellectual disabilities was restricted to having some degree of input over the selection of measures employed (Emerson, 2004; Emerson and McVilly, 2004; Gardner and Carran, 2005). No instances of emancipatory research were identified.

Quality of Life Domains Investigated

Figure 5 summarises the quality of life (QOL), domains investigated in deinstitutionalisation and post-deinstitutionalisation studies.

Figure 5. QOL domains investigated



As can be seen, both post-deinstitutionalisation and deinstitutionalisation studies have tended to focus on outcomes that fall within the quality of life domains proposed. However, they have addressed a rather restricted range of indicators. Deinstitutionalisation studies have primarily addressed changes in emotional and mental health (in particular challenging behaviour); changes in personal skills; and (to a lesser extent) changes in choice and self-determination; participation in community-based activities, social networks and relationships; and physical health. Post-deinstitutionalisation studies have primarily addressed participation in community-based activities; choice and self-determination; social networks and relationships; physical health; and other indicators of independence (primarily, engagement in domestic activities). Few studies have examined the impact of living situations on material well-being and employment.

Measures of Choice and Self-determination in the Literature Reviewed

The variety with which outcome domains are investigated is matched by the variety of specific measures used. In most domains, there is little or no consistency across studies regarding the use of specific measures. The following 12 measures of choice and self-determination have been employed in the literature reported on here:

1) Resident Choice Assessment Scale (Kearney, Bergan and McKnight, 1998; Kearney, Durand and Mindell, 1995; Young and Ashman, 2004);
2) Resident Choice Scale (Emerson et al., 2001; Emerson et al., 2000; Hatton et al., 2004; Robertson et al., 2001);
3) Choice Questionnaire (Perry and Felce, 2005; Stancliffe, 1997);
4) Life Experiences Checklist (Ager et al., 2001; McConkey, Walsh-Gallagher and Sinclair, 2005);

5) Index of Adult Autonomy (Felce et al., 1999); the Choice Scale (Heller, Miller and Hsieh, 2002);
6) Consumer Choice Scale (Stancliffe and Abery, 1997);
7) Arc's Self-Determination Scale (Wehmeyer and Bolding, 2001);
8) Opportunities for Choice Making Scale (Conroy, 1996);
9) Self-Determination Scale (Saloviita and Åberg, 2000);
10) Minnesota Opportunities and Experiences of Self-Determination Scale (Stancliffe, Abery and Smith, 2000);
11) Quality of Life Questionnaire (Stancliffe and Keane, 2000);
12) Single item rating scales (Tossebro, 1995).

There are two areas, however, in which there is a modest degree of consistency in the use of specific measures. Personal skills have been most commonly measured through use of the **AAMR Adaptive Behavior Scale** (Nihira, Leland and Lambert, 1993) and participation in community-based activities has most commonly been measured through use of the **Index of Community Involvement** (Raynes, Sumpton and Flynn, 1987; Raynes et al., 1994).

A particular characteristic of this literature is the tendency of researchers to employ relatively detailed and complex measures to investigate discrete aspects of quality of life (e.g. choice). While such an approach clearly has value, it does not allow for within-study conclusions to be drawn about the association between different forms of supported accommodation and the overall quality of life of participants or about the interrelations between different dimensions of quality of life.

A number of more comprehensive approaches to evaluating quality of life have been developed and used within a small number of peer-reviewed research studies and the "grey" literature.

- The two most commonly used approaches within the peer-reviewed research literature are: a) **Life Experiences Checklist** (Ager, 1990); b) the **Quality of Life Questionnaire** (Schalock and Keith, 1993).
- The most commonly used approaches within the "grey" literature are:
    - **National Core Indicators** (Human Services Research Institute and National Association of State Directors of Developmental Disabilities Services, 2003), selected items from which have been incorporated into comprehensive quality of life measurement systems in England (Emerson et al., 2005) and Australia (E-QUAL and Donovan Research, 2000);
    - **Personal Outcome Measures** (Gardner and Carran, 2005).

The results of the literature are now summarised, first in terms of outcomes, then in terms of costs and finally in terms of the instruments used.

3.2 Outcomes

The outcomes reported on include civic participation/social inclusion and well-being and are first outlined in Table 1.3.

Table 1.3. Supported Accommodation and Quality of Life Core Dimensions

	Deinstitutionalisation Studies	Post-deinstitutionalisation Studies
Independence		
Personal skills	Relatively consistent evidence of limited improvements in personal skills immediately following deinstitutionalisation.	Few studies. Some evidence of increased skills in smaller, less institutional settings.
Material well-being	Little evidence.	No evidence.
Choice and self-determination	Consistent evidence of greater choice and self-determination in community-based settings.	Consistent evidence that greater choice and self-determination is available in smaller, less institutional settings.
Other	Some evidence of increased participation in domestic activities following deinstitutionalisation.	Little evidence of association between the nature of setting and engagement in domestic activity. Strong evidence that engagement is related to personal skills of participants and staff activity.

Table 1.3. Supported Accommodation and Quality of Life Core Dimensions (continued)

	Deinstitutionalisation Studies	Post-deinstitutionalisation Studies
Civic participation/Social Inclusion		
Social networks and friendships	Consistent evidence of greater participation in social networks/relationships in community-based settings.	Evidence inconsistent, but suggests that larger and/or more active social networks are available in smaller, less institutional settings.
Community-based activities	Consistent evidence of greater participation in community-based activities in community-based settings.	Consistent evidence that greater participation in community-based activities occurs in smaller, less institutional settings.
Employment	Little evidence.	Little evidence, but suggests no relationship between type of setting and employment.

Table 1.3. Supported Accommodation and Quality of Life Core Dimensions (continued)

	Deinstitutionalisation Studies	Post-deinstitutionalisation Studies
Well-being		
Emotional well-being /mental health	Considerable evidence of no systematic association between deinstitutionalisation and emotional well-being, mental health or challenging behaviour.	Little evidence. No consistent pattern.
Physical health	Little evidence. Conflicting reports of possible association between deinstitutionalisation and increased mortality.	Little evidence. Some suggestion of increased rates of physical exercise in smaller, less institutional settings.
Personal life satisfaction	Consistent evidence of greater satisfaction in community-based settings.	Little evidence, but suggests no relationship between setting and personal life satisfaction.
Other	N/A	Little evidence. No consistent pattern.

Independence

Personal Skills

Studies evaluating the impact of deinstitutionalisation have most commonly reported that deinstitutionalisation is associated with a statistically significant increase in personal skills or adaptive behaviour (Beadle-Brown and Forrester-Jones, 2003; Conroy, Spreat and Yuskauskas, 2003; Cullen et al., 1995; Dudley, Conroy and Calhoun, 1999; Golding, Emerson and Thornton, 2005; Lerman, Apgar and Jordan, 2005; Maisto and Hughes, 1995; Young, 2003; Young and Ashman, 2004; Young et al., 2001). It should be noted, however, that these changes are: often of a limited nature (Cullen et al., 1995; Golding et al., 2005); are most apparent soon after the move to a community-based setting (Beadle-Brown and Forrester-Jones, 2003); and are far from inevitable consequences of deinstitutionalisation (Bowen and Gerry, 1995; Brook and Bowler, 1995; Donelly et al., 1996; Nottestad, Stromgren and Linaker, 2000; Stancliffe et al., 2002; Young et al., 2000).

These results are consistent with the existing deinstitutionalisation literature in indicating that a move from a more to a less institutional setting is associated with a reported increase in personal skills in the short-term, but that there is relatively little evidence of the continued development of personal skills following deinstitutionalisation (Emerson and Hatton, 1994; Felce, 2000; Kim et al., 2001; Young et al., 1998).

The majority of post-deinstitutionalisation studies have employed cross-sectional designs in which personal skills (adaptive behaviour) are used to either match participants across settings or as a control variable in statistical analyses. The need for such control strategies is illustrated by the strong relationship between personal skills/adaptive behaviour and key quality of life outcomes such as:

choice and self determination (Felce et al., 2000; Felce et al., 1999; Perry and Felce, 2005; Robertson et al., 2001; Stancliffe, 1997; Stancliffe et al., 2000); engagement in domestic activities (Felce and Emerson, 2004; Felce et al., 2003; Felce et al., 1999; Perry and Felce, 2005); social networks and relationships (Emerson and McVilly, 2004; Robertson et al., 2001); participation in community-based activities (Felce and Emerson, 2001; Felce et al., 2000; Felce et al., 1999; Perry and Felce, 2005); employment (Emerson et al., 2005; Heller et al., 1998); physical health (Emerson et al., 2005); and emotional and mental health (Emerson et al., 2005).

As a result, few post-deinstitutionalisation studies have evaluated the impact of living circumstances on the development of personal skills. Those that have addressed this issue have reported greater skill gain over time: in smaller settings (Heller and Miller, 1998); on the move from nursing homes to community-based residences (Heller et al., 1998; Heller et al., 2002); and in community-based residences when compared to ICF/MR facilities (Conroy, 1996), though there is some dispute with regard to the statistical procedures used in the last study (Crinella, McCleary and Swanson, 1998; Heifetz, 1998). These results are consistent with the deinstitutionalisation literature.

Material Circumstances

No post-deinstitutionalisation studies have addressed the potential impact of the living environment on material well-being, apart from those few studies that have examined the association between residential setting and employment (see below). Deinstitutionalisation studies have (somewhat unsurprisingly) reported that community-based residences are more homelike and pleasant than institutional provision (Donnelly et al., 1997). These results are consistent with those of the pre-1995 deinstitutionalisation literature (Emerson and Hatton, 1994; Felce, 2000; Kim et al., 2001; Young et al., 1998).

Choice and Self-determination

All the deinstitutionalisation studies that have addressed this outcome have reported that deinstitutionalisation is associated with an increase in choice and self-determination (Ager et al., 2001; Dudley et al., 1999; Howard and Spencer, 1997; Stancliffe and Abery, 1997; Wehmeyer and Bolding, 2001; Young, 2003; Young and Ashman, 2004; Young et al., 2000, 2001). These results are consistent with those of the pre-1995 deinstitutionalisation literature (Emerson and Hatton, 1994; Felce, 2000; Kim et al., 2001; Young et al., 1998).

The vast majority of the post-deinstitutionalisation studies have also reported significant differences within or across settings in levels of choice and self-determination. When controlling for the effects of participant characteristics, increased choice and self-determination has been reported in:

- community-based residences when compared to campus/cluster housing (Emerson et al., 2000; Emerson et al., 2000; Robertson et al., 2001), "traditional" services (Felce et al., 2000; Felce et al., 2001) and ICF/MR facilities (Conroy, 1996; Stancliffe et al., 2000);
- supported (Emerson et al., 2001) and semi-independent living (Stancliffe, 2005; Stancliffe and Keane, 2000) arrangements when compared to group homes;
- smaller settings (Perry and Felce, 2005; Robertson et al., 2001; Saloviita and Åberg, 2000; Stancliffe, 1997; Stancliffe et al., 2000; Tossebro, 1995a, 1995b);
- more homelike settings (Robertson et al., 2001).

The one study that did not report a significant difference between living environment and self-determination was an evaluation of different forms of small community-based residences for people with severe challenging behaviour (Robertson et al., 2004). These associations have been reported for people with severe challenging behaviour (Felce et al., 2000, 2001) and people with severe and complex disabilities (Emerson et al., 2000). They have also been reported in studies undertaken in the UK, US, Australia, Norway and Finland.

Participation in Domestic Activities

Seven deinstitutionalisation studies have investigated the impact of deinstitutionalisation on participation in domestic activities. Of these: four have reported significant increases on deinstitutionalisation (Dagnan, Ruddick and Jones, 1998; Jahoda and Cattermole, 1995; Mansell, McGill and Emerson, 2004; Young et al., 2000); and three have reported no change (Baker, in press; Felce, Lowe and Blackman, 1995; Golding et al., 2005). None has reported a significant decrease in participation on deinstitutionalisation. These results are consistent with those of the pre-1995 deinstitutionalisation literature (Emerson and Hatton, 1994; Felce, 2000; Kim et al., 2001; Young et al., 1998).

A number of post-deinstitutionalisation studies have investigated the association between living environment and participation in domestic activity, either through direct observation of participant behaviour or informant report. These studies have typically reported strong associations between participation in domestic activity and participant skills/adaptive behaviour and staff behaviour (Felce et al., 2003; Felce et al., 2000; Felce, Lowe and Jones, 2002). Once these factors have been taken into account, there appears to be no robust association between living environment and participation in domestic activity. The few studies that have found an association have reported higher rates of participation in semi-independent living arrangements when compared with group homes (Stancliffe and Keane, 2000), in community-based residences when compared with campus/cluster housing (Emerson et al., 2000), in more physically integrated housing (Perry and Felce, 2005) and in larger settings (Felce et al., 2002).

Civic participation/Social Inclusion

Social Networks and Relationships

Six deinstitutionalisation studies examined the impact of deinstitutionalisation on social networks and relationships. Five of these reported that deinstitutionalisation is associated with significant increases in networks and relationships (Ager et al., 2001; Conroy et al., 2003; Dagnan et al., 1998; Hundert et al., 2002; Spreat and Conroy, 2002). The remaining study reported no change (Donelly et al., 1996). These results are consistent with those of the pre-1995 deinstitutionalisation literature (Emerson and Hatton, 1994; Felce, 2000; Kim et al., 2001; Young et al., 1998).

Approximately 50% of the post-deinstitutionalisation studies that have investigated the association between living environment and social networks and relationships have reported statistically significant differences within or across settings. Specifically, participants have been reported to have more extensive social networks and/or to have more frequent contact with people in their social networks in:

- community-based residences when compared with campus/cluster housing (Emerson et al., 2000a; Emerson et al., 2000b), nursing homes (Emerson and McVilly, 2004) and ICF/MR facilities (Spreat, Conroy and Fullerton, 2005);
- smaller settings (Emerson et al., 2001);
- supported living arrangements when compared to group homes (Emerson et al., 2001) and "traditional" services (Howe, Horner and Newton, 1998);
- settings in which residents hold tenancies (Emerson and McVilly, 2004) or have a keyworker (Felce et al., 2002).

Participants expressed greater satisfaction with their social networks and relationships in semi-independent living arrangements than in group homes (Stancliffe and Keane, 2000) and in intentional communities[4], such as Camphill Communities or L'Arche communities, than in community-based residences (Gregory et al., 2001).

It is notable, however, that a similar number of studies failed to report any association between living environment and social networks and relationships when comparing community-based residences with campus/cluster housing (Emerson, 2004; Hatton, Emerson, Robertson, Henderson and Cooper, 1995), ICF/MR facilities (Stancliffe et al., 2000) and nursing homes (Heller et al., 2002).

Community-based Activities

Six deinstitutionalisation studies investigated the impact of deinstitutionalisation on participation in community-based activities. All reported a significant increase on deinstitutionalisation (Ager et al., 2001; Baker, in press; Brook and Bowler, 1995; Conroy et al., 2003; Dagnan et al., 1998; Hundert et al., 2002). These results are consistent with those of the pre-1995 deinstitutionalisation literature (Emerson and Hatton, 1994; Felce, 2000; Kim et al., 2001; Young et al., 1998).

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[4] In Ireland, intentional communities have been established by the Camphill and L'Arche communities. Intentional communities include communes, housing co-operatives, eco-villages, co-housing, residential land trusts, etc. There is a range of legal and ownership possibilities including private ownership, lease holding or share holding and the properties may have freehold, strata or community life. This is according to an invitation for expressions of interest from the Department of Ageing, Disability and Home Care in New South Wales. This document defines an intentional community as a planned residential community designed to promote a much higher degree of social interaction than other communities. The members of an intentional community typically hold a common social, cultural, political or spiritual vision. They also share responsibility and resources (www.dadhc.nsw.gov.au). According to the Joseph Rowntree Foundation in the UK, intentional communities are those where people with a disability and non-disabled people live together outside professionalised care arrangements or family obligation. (www.jrf.org.uk/knowledge/findings/socialcare/SC7.asp)

The vast majority of the post-deinstitutionalisation studies that have investigated participation in community-based activities have reported significant differences within or across settings. When controlling for the effects of participant characteristics, increased participation in community-based activities has been reported in:

- community-based residences when compared to campus/cluster housing (Emerson, 2004; Emerson et al., 2000; Hatton et al., 1995), nursing homes (Heller et al., 1998; Heller and Miller, 1998; Heller et al., 2002), ICF/MR facilities (Conroy, 1996; Spreat et al., 2005);
- supported living (Emerson et al., 2001; Howe et al., 1998) and semi-independent living arrangements (Stancliffe and Keane, 2000) when compared to group homes;
- non-congregate services for people with challenging behaviour when compared to congregate services (Robertson et al., 2004);
- both smaller (Felce et al., 2000, 2001; Heller and Miller, 1999) and larger (Perry and Felce, 2005) settings;
- less institutional (Felce et al., 2002) and more homelike settings (Egli et al., 2002).

These associations have been reported in studies undertaken in the UK, US and Australia. They are also consistent with the existing literature on deinstitutionalisation in indicating that a move from a more institutional setting to a less institutional one is associated with a reported increased participation in community-based activities (Emerson and Hatton, 1994; Felce, 2000; Kim et al., 2001; Young et al., 1998).

Employment

Few post-deinstitutionalisation studies have investigated the association between living environment and employment. None has reported any statistically significant association between these two factors (Conroy, 1996; Emerson, 1985; Emerson et al., 2000; Heller et al., 1998). One deinstitutionalisation study investigating this outcome reported an increase in rates of employment following deinstitutionalisation (Conroy et al., 2003).

Well-being

Physical Health

Few studies have investigated the impact of deinstitutionalisation on physical health. However, those that have addressed this issue, have reported that deinstitutionalisation is associated with: improved oral health (Gabre et al., 2001); no change in oral health (Gabre, Martinsson and Gahnberg, 2002); poorer diet and unintended weight gain and loss (Bryan, Allan and Russell, 2000). Significantly greater attention has been paid to the impact of deinstitutionalisation on mortality, with some studies from California reporting that deinstitutionalisation is associated with increased mortality (Shavelle and Strauss, 1999; Strauss and Kastner, 1996; Strauss, Shavelle and Baumeister, 1998). These results have not been replicated elsewhere (Conroy and Adler, 1998; Lerman, Apgar and Jordan, 2003; O'Brien and Zaharia, 1998).

A small number of post-deinstitutionalisation studies have investigated the association between living environment and various aspects of physical health including overall health, mobility, diet, exercise, obesity and underweight, accidents and injuries. The only consistent findings are:

- people in community-based residences are more likely to participate in physical exercise than participants in campus/cluster housing (Emerson, 2004; Emerson et al., 2000; Robertson et al., 2000);

- there are no differences between settings in rates of obesity (Emerson, 2004; Emerson et al., 2001; Emerson et al., 2000).

Other findings that have not yet been replicated include:

- There is a greater prevalence of underweight in campus/cluster housing than in community-based residences (Emerson, 2004);
- There is an increase in general health and mobility on moving from nursing homes to community-based residences (Heller et al., 1998);
- There are increased injuries from co-tenants in congregate settings for people with severe challenging behaviour (Robertson et al., 2004).

Emotional and Mental Health

Numerous studies have investigated the impact of deinstitutionalisation on various aspects of emotional and mental health, most commonly on reported frequency or severity of challenging behaviours. The majority of studies have reported that overall deinstitutionalisation is not associated with any significant change in emotional well-being or mental health (Bramston and Cummins, 1998; Donelly et al., 1996; Dudley et al., 1999; Golding et al., 2005; Hundert et al., 2002; Mansell et al., 2004; Nøttestad and Linaker, 2001; Nottestad et al., 2000; Nøttestad and Linaker, 1999; Stancliffe et al., 2002; Young, 2003; Young and Ashman, 2004; Young et al., 2000, 2001).

An identical number of other studies have reported that deinstitutionalisation is associated with increased emotional well-being (Brook and Bowler, 1995; Conroy et al., 2003; Cullen et al., 1995; Golding et al., 2005; Young et al., 2000) or decreased emotional well-being (Bowen and Gerry, 1995; Macleod, 2002; Nøttestad and

Linaker, 2002; Nottestad et al., 2000; Nøttestad and Linaker, 1999). These results are consistent with those of the pre-1995 deinstitutionalisation literature (Emerson and Hatton, 1994; Felce, 2000; Kim et al., 2001; Young et al., 1998).

Few post-deinstitutionalisation studies have investigated the association between living environment and various aspects of emotional and mental health. Those that have addressed this issue have reported:

- no difference in rates of challenging behaviour between community-based residences and ICF/MR facilities (Conroy, 1996);
- less stereotyping and aggression in more homelike settings (Thompson et al., 1996);
- increased rates of challenging behaviour over time in congregate settings for people with severe challenging behaviour (Robertson et al., 2004).

Personal Life Satisfaction

Seven studies have investigated the impact of deinstitutionalisation on personal life satisfaction or other aspects of satisfaction. All have reported an increase in satisfaction on deinstitutionalisation (Cullen et al., 1995; Donelly et al., 1996; Donnelly et al., 1997; Dudley et al., 1997; McConkey et al., 2003; Young, 2003; Yu and Jupp, 1996). These results are consistent with those of the pre-1995 deinstitutionalisation literature (Emerson and Hatton, 1994; Felce, 2000; Kim et al., 2001; Young et al., 1998).

Few post-deinstitutionalisation studies have investigated the association between living environment and personal life satisfaction. Those that have addressed this issue have reported no association between overall life satisfaction between participants living in community-based residences and intentional communities (Gregory et al., 2001) or between participants living in semi-independent settings and group homes (Stancliffe and Keane, 2000).

Risk of Crime or Abuse

A small number of post-deinstitutionalisation studies have investigated the association between living environment and various aspects of perceived or actual risk of crime or abuse (Emerson et al., 2001; Emerson et al., 2000; Stancliffe and Keane, 2000). Those that have addressed this issue have found that staff report:

- less risk of crime, verbal abuse and exploitation by the public for participants living in intentional communities (Emerson et al., 2000);
- increased risk of vandalism to the person's home for people living in supported living arrangements (Emerson et al., 2001);
- increased risk of abuse from co-residents in larger group homes (Emerson et al., 2001).

Other Results

A small number of studies have reported the results of measures that provide a global estimate of quality of life (rather than reporting quality of life domains). These have found:

- deinstitutionalisation is associated with increased quality of life (Ager et al., 2001; Cullen et al., 1995; Dagnan et al., 1998; Golding et al., 2005; Howard and Spencer, 1997; Janssen et al., 1999; Young and Ashman, 2004; Young et al., 2000, 2001; Yu and Jupp, 1996);
- increased quality in small- to medium-sized organisations (Gardner and Carran, 2005);
- increased quality in more independent settings for people with less severe intellectual disabilities (Gardner and Carran, 2005);

- an inverted-U shaped relationship between quality and the independence of settings for people with more severe intellectual disabilities (Gardner and Carran, 2005);
- increased quality in community-based residences when compared to campus/cluster housing (McConkey et al., 2005);
- increased satisfaction with living arrangements in which staff management practices are more highly organised (Gregory et al., 2001);
- an "aggressive-defensive" cultural style is associated with lower quality in community-based residences (Gillet and Stenfert-Kroese, 2003).

3.3. Costs

Relatively few studies have investigated the relationships between the costs of different forms of supported accommodation for people with intellectual disabilities. Those that have addressed this issue have primarily been post-deinstitutionalisation studies. They have reported:

- a robust and consistent relationship between the personal characteristics of participants (primarily level of intellectual disability or adaptive behaviour) and the costs of services;
- increased costs associated with deinstitutionalisation (Beecham, Knapp, McGilloway and Donnelly, 1997);
- no difference in costs between supported living arrangements and either traditional services (Howe et al., 1998) or small group homes (Emerson et al., 2001);
- lower costs in semi-independent living arrangements when compared to group homes (Stancliffe and Keane, 2000);
- higher costs in community-based residences than in campus /cluster housing (Emerson et al., 2000; Emerson et al., 2000) and possibly intentional communities (Emerson et al., 2000);

- lower costs in community-based residences than ICF/MR facilities (Spreat et al., 2005);
- higher costs in community-based residences than “traditional” services for people with severe challenging behaviour (Felce et al., 2000, 2001);
- lower costs in smaller settings (Rhoades and Altman, 2001);
- lower costs in larger settings (Felce et al., 2003; Myles et al., 2000);
- higher costs in congregate settings for people with severe challenging behaviour (Robertson et al., 2004) and dual sensory impairment (Hatton et al., 1995) when compared to non-congregate settings.

3.4. Instruments Used

There are a number of Quality of Life and related instruments in use at various levels of the service system for people with intellectual and other developmental disabilities. Research based on some of these instruments has been included in articles in the peer-reviewed literature and some, such as the **National Core Indicators**, has appeared mainly in publications prepared specifically for state agencies, stakeholders and advocates. These instruments have all been developed for somewhat different purposes. For instance, the **Ask Me! Survey** was developed for use by self-advocates and the unit of analysis is the provider. The **National Core Indicators** survey is meant to be used at the systems level and was designed to guide state-level policy makers and administrators regarding the performance of public intellectual/developmental disabilities systems. **The Personal Outcome Measures** developed by the Council on Quality and Leadership were developed as the core data collection activity leading to agency accreditation.

The following descriptions of instruments used are included in order to indicate to policy makers the rich history surrounding quality of life measurement and the wide range of survey protocols that can be used as a point of departure depending on the context. Because the types of policy, practice and advocacy concerns vary between countries and regions it is important, when beginning the process of selecting and/or adapting a survey to measure outcomes, to outline the primary areas of performance that are of the highest priority. Once these domains have been established, the choice among various approaches will be made much clearer.

Ask Me! Quality of Life Survey (Bonham et al., 2004)

General Description

The 56-item survey instrument includes six questions for each of the following eight core QOL domains: social inclusion, self-determination, personal development, rights, interpersonal relations, emotional well-being, physical well-being and material well-being. Eight items are also included regarding transportation availability. Each question in the survey has three possible responses. The first response is favourable, associated with a happy face and a numeral 1 on a flash card shown to the respondent, and scored +1. The second response is neutral, associated with a neutral face and the numeral 2, and scored as 0. The third answer was unfavourable, associated with a sad face and the numeral 3 on the flash card, and scored as -1. Self-advocates who have been trained as surveyors administer the survey to other self-advocates using the consumer-friendly procedures outlined above. Professional staff are available only to assist with the process when necessary. A detailed description of the training and administration procedures is available in Bonham et al. (2004).

Psychometric Properties

Extensive reliability data (generally Cronbach's alpha and test-retest reliability coefficients) are available and show the reliability of the instrument. Additional analyses have been completed on content and discriminant validity. These data can be found in Schalock et al., (2000), Schalock and Bonham (2003), and Bonham et al., (2004).

General Use

The primary use, thus far, for the **Ask Me! Survey** has been as a basis for the evaluation of the quality of life of service recipients in the US state of Maryland. The information gathered has been used for reporting and quality improvement purposes. Agency staff and administrators have received extensive feedback as to how to interpret and use the data. Agency data are also used as part of statewide provider profiles.

Comprehensive Quality of Life Scale (Cummins, 1997)

General Description

The scale exists in three parallel forms: for adults in the general population (ComQol-A), for adults with an intellectual disability or cognitive impairment (ComQol-I) and for non-disabled adolescents attending school (ComQol-S). These parallel forms mean that the life quality of people with intellectual disabilities can be directly compared with that reported by non-disabled persons. The scale is intended as an operationalisation of the following definition:

> Quality of life is both objective and subjective, each axis being the aggregate of seven domains: material well-being, health, productivity, intimacy, safety, community, and emotional well-being. Objective domains comprise culturally relevant measures of objective well-being. Subjective domains comprise satisfaction weighted by their importance to the individual.

Each objective domain is measured through an aggregate score of three items. For example, the domain of "health" comprises five-point measures of the degree of chronic medication, frequency of physical consultation and presence of chronic disability. Each subjective domain is measured through the product of perceived importance and satisfaction.

Psychometric Properties

The seven domains comprising the ComQol Scale have been demonstrated to represent a high level of content validity and internal reliability (Cummins, 1996, 1997, 2003). Discriminant validity and cross-cultural sensitivity have also been reported (Cummins, 2003).

General Use

The ComQol Scale has been used primarily in research and establishing normative data for levels of satisfaction. A detailed initial screening procedure is used to establish the comprehension of the items by respondents.

Quality of Life Questionnaire (Schalock and Keith, 1993)

General Description

This 40-item scale, which has a parallel form for school-aged adolescents (Keith and Schalock, 1994), contains four sub-scales (each comprising ten questions) to measure the following QOL domains: empowerment/independence, competence/productivity, satisfaction, and social belonging/community integration. The scale is administered by an interviewer reading each question aloud and the respondent uses a three-point Likert scale response format.

Psychometric Properties

This is an extensively studied and evaluated scale, both nationally and internationally, and has been translated into a number of languages. Both factor structure and factor stability have been demonstrated (Schalock and Keith, 2004) as well as high internal consistency, test-retest and inter-observer reliability coefficients. The validity of the scale (in terms of content, construct and discriminant validity) has also been reported across a number of national and international studies (Schalock and Keith, 2004).

General Use

The scale has been used in both research and applied situations. Agencies use the profiles across the four domains to summarise their clients' assessed quality of life and use that information for quality improvement and organisation change. The data are also used as a basis for provider profiles in at least one US state (Nebraska; Keith and Bonham, 2005).

National Core Indicators (NCI) Consumer Survey (Human Services Research Institute, revised 2004)

General Description

The **National Core Indicators Consumer Survey** was developed by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). The **NCI Consumer Survey** has two interview sections: Section I includes subjective questions that can only be answered by the individual receiving services, and Section II contains objective questions that could be answered by a proxy respondent. Section I must be administered as a face-to-face interview, while Section II can be administered either in person or by phone. The survey also includes a background information section containing demographic and some outcome items (e.g. health) that are obtained from a proxy respondent or state database. There are 39 items in the background section and 50 items in Sections I and II combined. Questions have either a yes/no response or three response options.

Psychometric Properties

Inter-rater reliability is over 90%. Approximately 65-70% of individuals are able to respond to Section I of the survey. Each participating state draws a random sample of at least 400 individuals served across settings, including individuals living at home. In order to display the findings of the consumer survey across states, a regression analysis is performed using functional characteristics as independent variables. Reliable scales can be calculated, including community inclusion (alpha = 0.76); supports-related choices (alpha = 0.92); personal choices (alpha = 0.96); and service coordination (alpha = 0.82).

General Use

The survey was designed for use at the state level to assess performance in MR/DD systems. There are currently 25 states and four regional programmes using the **NCI Consumer Survey**. The NCI survey is administered by a variety of interviewers (QA staff, graduate students, self-advocates and family members, community members, etc.). NCI-participating states are provided with train-the-trainer sessions by conference call to review item-by-item coding instructions and interviewing techniques, a trainer's guide and set of slides on interviewing techniques, a set of resource materials on interviewing people with disabilities, and a training video.

The NCI survey was used in a research study in Kentucky to examine differences in outcomes of NCI-survey respondents compared to data collected from individuals in the general population (Sheppard-Jones, Prout and Kleinert, 2005). Additionally, the survey has been used to measure the health status of individuals in two states (Freedman and Chassler, 2004; Havercamp, Scandlin and Roth, 2004).

Participant Experience Survey (Medstat Group, 2003)

General Description

The **Participant Experience Survey (PES)** was developed by MEDSTAT for the Centers for Medicare and Medicaid Services (CMS). The purpose of the instrument was to assess that level of satisfaction of status of individuals receiving home and community-based services as part of the federal Medicaid programme. There are two versions of the instrument: one designed for use with elderly and/or physically disabled individuals and another one for people with developmental disabilities. The survey contains 99 direct interview questions that translate to 51 performance indicators. The interview takes approximately 30 minutes to administer. Eight "core questions" are identified for individuals with severe cognitive impairments.

Psychometric Properties

Approximately 80% of people interviewed in the field tests were able to respond to the survey. Inter-rater reliability was not available for the MR/DD version of the PES. However, an inter-rater reliability test of the PES elderly/disabled version found that three reviewers recorded the same response to 90% or more of the items. No scales or composite measures have been identified.

General Use

The **PES** is administered in-person with consumer respondents only. The tool comes with a user's guide, which provides general interviewing guidelines for trainers and interviewers, as well as detailed instructions for coding responses. The elder/disability version is used much more widely in the US than the MR/DD version.

3.5. Discussion and Recommendations

As noted above, very few studies have appeared in the peer-reviewed literature on the quality and costs of supported accommodation services for people with intellectual disabilities in Ireland. The results of this limited literature are broadly consistent with those of the predominantly UK and US-based literature. Specifically:

- The overall quality of life of people with intellectual disabilities has been reported to be greater in community-based settings when compared to campus-type settings (McConkey et al., 2007; McConkey et al., 2005; Walsh et al., 2001) and in supported living arrangements when compared with community-based group homes (McConkey et al., 2007);
- People living in campus-type settings were more likely to receive psychoactive medication and to have access to some specific health screening (Walsh et al., 2004);
- Costs were greater in campus-style than community-based settings (Walsh et al., 2001).

Based on the literature review, gaps in the evidence include a significant lack of information on:

- some aspects of quality of life (e.g. material circumstances, employment and physical health), although efforts to measure employment and health status are ongoing by those leading the National Core Indicators initiative;

- some forms of supported accommodation (e.g. supported living);
- people with intellectual disabilities who have particular needs (e.g. people with severe and complex disabilities, people with mild intellectual disabilities, people with intellectual disabilities and autistic spectrum disorders and older people with intellectual disabilities);
- potentially important determinants of quality (e.g. poverty and income, organisational culture, geographical variation);
- evidence collected using more participatory approaches to research.

There is little evidence in the literature of any consensus regarding what outcomes should be measured. This is likely to reflect the absence of a clear conceptual framework to guide the selection of outcome indicators. In addition, there is little evidence of a consensus within the evaluation literature regarding the use of specific measures to operationalise the collection of information relevant to outcome domains.

Specific Outcomes

As noted in the summary of the literature review, the existing literature fails to provide a sufficient volume of evidence to draw any clear conclusions between type of accommodation setting and material circumstances, employment, physical health and personal life satisfaction.

Forms of Supported Accommodation

With few exceptions (Emerson et al., 2001; Howe et al., 1998), most of the post-deinstitutionalisation studies have tended to evaluate outcomes associated with group homes for people with more severe disabilities. There is a dearth of contemporary evidence on the outcomes associated with supported living arrangements (Emerson et al., 2001; Howe et al., 1998).

People with Intellectual Disabilities with Particular Needs

Most studies have employed modestly sized samples of heterogeneous groups of people with intellectual disabilities. As a result, there is little available information on the costs and benefits of differing forms of supported accommodation for people with intellectual disabilities who have particular needs (e.g. people with severe and complex disabilities, people with mild intellectual disabilities, people with intellectual disabilities and autistic spectrum disorders, and older people with intellectual disabilities).

Understanding the Determinants of Quality

Many previous reviews (Emerson and Hatton, 1994; Felce, 2000; Hatton and Emerson, 1996), and many of the studies included in this review, have illustrated the variation in quality that is apparent within any particular approach to providing supported accommodation for people with intellectual disabilities. Understanding the determinants of this variation opens up the possibility of identifying factors that could prove critical in enhancing quality across different approaches to providing supported accommodation. Research to date has indicated the importance of staff support and, to an extent, institutional climate as key factors that influence quality. Studies have also repeatedly shown that indicators of basic resources (e.g. costs, staffing ratios, staff qualifications and staff skills) have little or no association with quality.

Three types of factors are notable in their absence from the list of variables that have been investigated to date: poverty and income, organisational culture, geographical variation.

Poverty and Income

More general analyses of the key determinants and dimensions of social exclusion have drawn attention to the critical importance of poverty (Gordon, Levitas and Pantazis, 2005; Hills, Le Grand and Piachaud, 2002). A recent national survey in England illustrated the widespread impact that poverty has on the life experiences of adults with intellectual disabilities (Emerson et al., 2005). To date, however, the issue of income poverty as a determinant of quality in supported accommodation services has received no attention.

Organisational Culture

As noted above, previous research has demonstrated the importance of staff activity and support in enhancing the quality of life of people with intellectual disabilities in several domains. However, there is still much to be learned about the conditions under which appropriate staff action is likely to be facilitated and maintained. One markedly under-explored area is the potential importance of "organisational culture" in staff teams (Gillet and Stenfert-Kroese, 2003).

Neighbourhood and Community Characteristics

Again, more general analyses of the key determinants and dimensions of social exclusion have drawn attention to the critical importance of neighbourhood and community characteristics (e.g. deprivation and social capital, and rurality) and the possible influence of regional variations (Hills et al., 2002; Putman, 2000). Indeed, a recent national survey in England illustrated the impact that neighbourhoods have on the life experiences of adults with intellectual disabilities (Emerson et al., 2005). To date, however, the issue of neighbourhood characteristics as determinants of quality in supported accommodation services has received no attention.

Participatory Approaches

It is notable that virtually no studies demonstrated any commitment to more participatory approaches to research (Ramcharan et al., 2004). The few exceptions involved the participation of people with intellectual disabilities in the selection of measures (Emerson, 2004; Emerson and McVilly, 2004; Gardner and Carran, 2005). No instances of emancipatory research were identified. It is clear, however, that more participatory approaches are both viable and beneficial in gaining a better understanding of the nature and determinants of the quality of life and life experiences of people with intellectual disabilities (Bonham et al., 2004; Bradley and Kimmich, 2003; Emerson et al., 2005; Gardner and Carran, 2005; Human Services Research Institute and National Association of State Directors of Developmental Disabilities Services, 2003).

Representativeness

Very few studies indeed have adopted a sampling strategy that allows conclusions to be drawn about the quality or costs of supported accommodation services for people with intellectual disabilities in a given jurisdiction. The reasons for this are twofold. First, the majority of samples appear to be convenience samples, rather than samples drawn by random or quasi-random processes from the total universe of services within a jurisdiction. Given the ready availability of administrative records of provision, the latter is clearly a possible option (Emerson et al., 2005). Second, as noted above, sample sizes are often small. As a result, they are underpowered in relation to detecting "real" effects and any attempt to generalise to the sampled universe of supported accommodation services would involve considerable confidence limits.

Recommendations

Recommendations are based on general conclusions drawn from the systematic review of the existing evidence-base regarding the comparative outcomes and costs of different approaches to providing supported accommodation for people with intellectual disabilities and on the gaps in evidence that were identified. Future research to address the gaps identified is required. Research approaches might employ:

- more participatory approaches. The minimum standard should be to involve people with intellectual disabilities as key informants (wherever possible) and in deciding what to measure, how to measure it, what sense to make out of the results and how to disseminate the findings,
- a more comprehensive strategy for measuring indicators of the quality of life or life experiences of people with intellectual disabilities. Given the paucity of information in the existing literature, particular attention should be paid to measuring

indicators of material circumstances, employment and physical health,

- a more comprehensive strategy for measuring indicators of potential determinants of the quality of life or life experiences of people with intellectual disabilities. Again, given the paucity of information in the existing literature, particular attention should be paid to measuring indicators of poverty, organisational culture and potentially salient aspects of geographical factors (e.g. rurality, neighbourhood deprivation and social capital),
- a sampling strategy that assures that attainment of a sufficiently large (and consequently powerful) sample that will allow analysis by sub-populations of people with intellectual disabilities of particular policy interest (e.g. elderly people with intellectual disabilities, adults with intellectual disabilities and autistic spectrum disorders) and also allow for the exploration of regional variations in outcome,
- a sound methodology for determining both the direct and indirect costs of provision.

There is also a need for efficiency in data collection with large-scale studies so that future directions could lead to a blurring of the boundaries between activities that are traditionally thought of in terms of evaluation research and performance measurement systems.

4. QOL Measurement – The Way Forward

4.1 Organising Principles and Guidelines

Quality of life (QOL) research and evaluation efforts between 1995 and 2005, the time frame of this project, have been based largely on a group of organisation principles (Schalock, 2005; Schalock et al., 2002) that relate to the conceptualisation and measurement of the quality of life construct and include:

- Conceptualisation: Quality of life: (a) is multi-dimensional and influenced by personal and environmental factors and their interaction; (b) has the same components for all people; (c) has both subjective and objective components.
- Measurement: Measurement in quality of life: (a) involves the degree to which people have life experiences that they value; (b) reflects the domains that contribute to a full and interconnected life; (c) considers the contexts of physical, social and cultural environments that are important to people.

Based on these principles, a consensus is emerging regarding five guidelines that can serve as a framework for organising and identifying quality indicators/outcomes. These five guidelines (Schalock et al., 2006): (a) recognise the multi-dimensionality of quality of life; (b) develop indicators for the respective quality of life domains; (c) base the assessment on objective aspects of quality of life on life experiences, circumstances and lifestyles; (d) focus on the predictors of quality indicators/outcomes; (e) use quality indicators as a basis for quality improvement, monitoring social inequality and making normative comparisons.

4.2 QOL Models: Core Domains and Indicators

Current quality of life models are based on two essential components: quality of life domains and respective indicators (Schalock et al., 2006; Schalock and Verdugo, 2002).

QOL domains

These are defined as: "The set of factors composing personal well-being. The set represents the range over which the QOL concept extends and thus defines quality of life." Although the specific listing of domains varies somewhat across investigators (Schalock and Verdugo, 2002), most quality of life investigators suggest that the actual number of domains is less important than the recognition that: (a) any proposed QOL model must recognise the need to employ a multi-element framework; (b) persons know what is important to them; (c) any set of domains must represent in aggregate the complete QOL construct. It is also important to realise that the relative importance of the respective QOL domains and indicators may well vary across individuals, cultures and one's life span (Schalock, 2005; Schalock et al., 2005).

QOL indicators

Quality of life domains are operationalised through quality indicators that are defined as: "QOL-related perceptions, behaviours and conditions that give an indication of a person's well-being." The consistent suggestion found in the QOL literature is the need to develop specific quality indicators for each quality-of-life domain and to use best practice measurement methodology for their assessment. This suggestion provides a firm conceptual and empirical basis for the measurement of quality indicators (Section 2: Key Aspects of Available Measures).

The most frequently used measurement instruments show considerable variability in both the QOL domains and indicators assessed. These instruments are discrete, typically addressing only one aspect or QOL domain. This situation suggests the need in the field for both a clear conceptual QOL model and specific criteria for selecting quality indicators.

Each of the QOL assessment instruments reviewed in this report was developed for different purposes and on the basis of different QOL conceptual models. Thus, any potential user of a QOL assessment instrument should understand clearly the answers to the following questions: (a) Is the instrument based on a clearly articulated QOL conceptual model (e.g. factors, domains and indicators)? (b) Is the conceptual model explained clearly in the Standardisation Manual? (c) What are the psychometric (reliability and validity) properties of the instrument? (d) Do the scores answer the questions being asked by the potential user? (e) Do the resultant items/ item scores meet the following criteria? Do they reflect the domains outlined in the QOL model? Do they represent what people want in their lives? Are they ones that the service/supports provider has some control over? Do they relate to current or future policy issues? And, finally, can they be used for reporting and quality improvement purposes?

A set of possible indicators grounded in the core Quality of Life domains and how each of these indicators might be operationalised is suggested in Column 3 of Table 2. For example, personal skills is an exemplary indicator of independence, a core domain of Quality of Life. Each indicator must be operationalised and suitable measures must be selected.

Table 2: Proposed indicators mapping onto quality of life domains

Core QOL Domains	Exemplary indicators	Person can/has opportunity to:
Independence	Personal skills (e.g. adaptive behaviour)	Access life-long learning
	Material well-being (e.g. income, possessions)	Access income, resources required to have good diet, housing, participation in family and community life
	Choice and self-determination	Choose, control services Manage risk in personal life

Table 2: Proposed indicators mapping onto quality of life domains (continued)

Social inclusion/ Civic participation	Social networks and friendships	Develop range of friendships, activities, relationships
	Community-based activities	Take part in local affairs, decisions Vote Act as volunteer
	Employment	Access equal opportunities for education, training, employment
Well-being	Emotional well-being/mental health (including challenging behaviour)	Receive protection from abuse, exploitation Access support in managing long-term conditions
	Physical health	Experience clean, ordered living environment Access health screenings and care Undertake physical activity
	Personal life satisfaction	Access leisure Experience security at home Enjoy a full, purposeful life

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Appendices

Appendix 1: Deinstitutionalisation Studies - Methodology

Key	PP - Pre/post no comparison group PPC - Pre/post with comparison group MG - Matched group comparison SC - Statistically controlled comparison Participants column records whether the study included information on the participants with respect to age (A), gender (G), ethnicity (E), severity of intellectual disability (ID), presence of autistic spectrum disorders (ASD).

N & Author/Date	Year	Country	Design	Participants
1 (Ager et al., 2001)	2001	UK	PP	N=76. Continent, ambulant & not behaviour disordered. Elderly dependent/elderly low dependency, older people home/nursing home. A/ID
2 (Myles et al., 2000)	2000	UK	PP	As above
3 (Baker, in press)	in press	UK	PPC	N=28 movers, N=34 comparison group (community based). Severe/profound ID. A/G/ID
4 (Beadle-Brown & Forrester-Jones, 2003)	2003	UK	PP	N=250. A No disability and then mild/mod/severe/very severe
5 (Bowen & Gerry, 1995)	1995	AUS/NZ	PP	N=10. Severe/profound intellectual disabilities. G
6 (Bramston & Cummins, 1998)	1998	AUS	PP	N=4. Mild ID. G/A
7 (Brook & Bowler, 1995)	1995	UK	PP	N=50. A/G/IDE
8 (Bryan et al., 2000)	2000	UK	PP	N=121. A/G/ID

N & Author/Date	Year	Country	Design	Participants
9 (Conroy & Adler, 1998)	1998	USA	SC	N=1,154.
10 (Conroy et al., 2003)	2003	USA	PP	N=254. People with severe disabilities. E/G/ID
11 (Cullen et al., 1995)	1995	UK	SC	N=100. 50=movers; 50 stayers. A/G/ID
12 (Dagnan et al., 1998)	1998	UK	PP	N=29. Older, relatively able people with ID. G/A
13 (Donnelly et al., 1997)	1997	UK	PP	N=283. A/G
14 (Donelly et al., 1996)	1996	UK	PP	N=214.
15 (Beecham et al., 1997)	1997	UK	PP	N=192.

N & Author/Date	Year	Country	Design	Participants
16 (Dudley et al., 1997)	1997	USA	PP	N=98. Mental illness and ID. A/G/ID/E
17 (Dudley et al., 1999)	1999	USA	PP	N=239. A/G/E/ID
18 (Felce et al., 1995)	1995	UK	MG	N=16. Severe intellectual disabilities and severely challenging behaviour (8=traditional hospitals and 8=community settings). A/G
19 (Golding et al., 2005)	2005	UK	PP	N=12. Challenging behaviour. A/G
20 (Gabre et al., 2001)	2001	Sweden	PP	N=57. A/G/ID
21 (Gabre et al., 2002)	2002	Sweden	PP	N=55. A/G/ID
22 (Howard & Spencer, 1997)	1997	UK	PP	N=10. A/G/D

N & Author/Date	Year	Country	Design	Participants
23 (Hughes, McGinnity, Kell, Kennedy, & Donnelly, 2003)	2003	IRE	PP	N=71. A/G/ID
24 (Hundert et al., 2002)	2002	CAN	PP	N=17. A/G/ID
25 (Jahoda & Cattermole, 1995)	1995	UK	UC	N=24 (N=12 long stay hospital, N=12 community based hospital). A/G/ID
26 (Janssen et al., 1999)	1999	NLD	MG	N=199. Mild/moderate ID.
27 (Lerman et al., 2003)	2003	USA	PPC	N=300. Movers N=150; Non-movers N=150. A/G/ID
28 (Lerman et al., 2005)	2005	USA	PPC	N=300. Movers N=150; Non-movers N=150. A/G/ID
29 (Macleod et al., 2002)	2002	UK	PP	N=4.

N & Author/Date	Year	Country	Design	Participants
30 (Maisto & Hughes, 1995)	1995	USA	PPC	N=80. 42 deinstitutionalised and living in a group home; 38 group home residents, not previously institutionalised. A/G/ID
31 (Mansell et al., 2004)	2004	UK	PP	N=35. Severe ID, severe challenging behaviour. A/G
32 (McConkey et al., 2003)	2003	UK	other	N=39. Less severe ID. A/G/ID
33 (Nøttestad & Linaker, 1999)	1999	Norway	PP	N=109. A/G/ID
34 (Nøttestad & Linaker, 2002)	2002	Norway	PP	N=64. A/G/ID
35 (Nøttestad & Linaker, 2001)	2001	Norway	PP	N=48. A/G/ID
36 (Nottestad et al., 2000)	2000	Norway	PP	N=23. Elderly. A/G/ID

N & Author/Date	Year	Country	Design	Participants
37 (O'Brien & Zaharia, 1998)	1998	USA	SC	N=7,923.
38 (Spreat & Conroy, 2002)	2002	USA	PP	N=177. A/G/E/ID
39 (Stancliffe & Abery, 1997)	1997	USA	SC	N=127. (N=56 movers, N=71 stayers). A/E/ID
40 (Stancliffe et al., 2002)	2002	USA	PPC	N=148. A/G/ID
41 (Strauss & Kastner, 1996)	1996	USA	SC	N=18,362. G/A
42 (Strauss et al., 1998)	1996	USA	SC	N=1,878. A/G/ID
43 (Shavelle & Strauss, 1999)	1998	USA	PP	N=1,878.

N & Author/Date	Year	Country	Design	Participants
44 (Wehmeyer & Bolding, 2001)	2001	USA	SC	N=31. A/G
45 (Young, 2003)	2003	AUS	PP	N=104.
46 (Young & Ashman, 2004)	2004	AUS	PP	N=104. A/G/ID
47 (Young et al., 2001)	2001	AUS	PP	N=95. G/A/ID
48 (Young et al., 2000)	2000	AUS	PP	N=32. A/G/ID
49 (Yu & Jupp, 1996)	1996	AUS	SC	N=49. A/G/ID

Appendix 2: Deinstitutionalisation Studies - Results

N	Links	Outcome/Cost Measures	Results
1	2	Independence: Choice & self-determination	Independence: Choice & self-determination. Increase on deinstitutionalisation.
		Civic Participation/Social Inclusion: Community-based activities	Civic Participation/Social Inclusion: Community-based activities. Increase on deinstitutionalisation.
		Civic Participation/Social Inclusion: Social networks & relationships	Civic Participation/Social Inclusion: Social networks & relationships. Increase on deinstitutionalisation.
		Other: composite quality of life	Other: Composite quality of life. Increase on deinstitutionalisation.

N	Links	Outcome/Cost Measures	Results
2	1	Costs	Costs: Increased costs associated with greater dependency and smaller-sized settings. No association between costs and outcomes.
3		Independence: Other (home-based leisure activities) Civic Participation/Social Inclusion: Community-based activities	Independence: Other (home-based leisure activities). No impact of deinstitutionalisation. Civic Participation/Social Inclusion: Community-based activities. Significant increase following deinstitutionalisation.
4		Independence: Personal skills	Independence: Personal skills. Deinstitutionalisation associated with significant increase in conversation & social mixing, initiation of conversation and social interaction. Significant decrease over time in community settings in conversation & social mixing, non-verbal communication, initiation of conversation and social interaction (no comparison group).

N	Links	Outcome/Cost Measures	Results
5		Independence: Personal skills Well-being: Emotional & mental health	Independence: Personal skills. Deinstitutionalisation associated with no change in adaptive behaviour. Well-being: Emotional and mental health. Deinstitutionalisation associated with increases in challenging behaviour.
6		Well-being: Emotional & mental health	Well-being: Emotional & mental health. Transition into the community was not perceived as a stressful event.
7		Independence: Personal skills Civic Participation/Social Inclusion: Community-based activities Well-being: Emotional & mental health	Independence: Personal skills. No overall systematic change on deinstitutionalisation. Civic Participation/Social Inclusion: Community-based activities. Significant increase in frequency and, to an extent, range of community-based activities following deinstitutionalisation. Well-being: Emotional & mental health. Reduction in challenging behaviour on deinstitutionalisation.

N	Links	Outcome/Cost Measures	Results
8		Well-being: Physical health	Well-being: Physical health. Deinstitutionalisation associated with significant increases in risk relating to food groups and unintended weight gain and loss.
9		Well-being: Physical health	Well-being: Physical health. No evidence of increased mortality following deinstitutionalisation.
10		Independence: Personal skills Civic Participation/Social Inclusion: Social networks & relationships, community-based activities, employment	Independence: Personal skills. Deinstitutionalisation associated with increased skills Civic Participation/Social Inclusion: Social networks & relationships. Deinstitutionalisation associated with increased contact with families. Civic Participation/Social Inclusion: Community-based activities. Deinstitutionalisation associated with increased use of community facilities.

N	Links	Outcome/Cost Measures	Results
10 Continued			Civic Participation/Social Inclusion: Employment. Deinstitutionalisation associated with increased employment.
		Well-being: Emotional & mental health	Well-being: Emotional & mental health. Deinstitutionalisation associated with decrease in challenging behaviour.
11		Independence: Personal skills	Independence: Personal skills. Evidence of increase in some specific skill areas following deinstitutionalisation.
		Well-being: Personal life satisfaction, emotional & mental health	Well-being: Personal life satisfaction. Increase following deinstitutionalisation. Well-being: Emotional & mental health. Significant reduction in challenging behaviour following deinstitutionalisation.
		Other: composite quality of life measure	Other: composite quality of life measure. Increase following deinstitutionalisation.

N	Links	Outcome/Cost Measures	Results
12		Independence: Other (participation in domestic activities) Civic Participation/Social Inclusion: Social networks & relationships, community-based activities Other: composite quality of life	Independence: Other (participation in domestic activities). Increased on deinstitutionalisation. Civic Participation/Social Inclusion: Social networks & relationships. Increased on deinstitutionalisation. Civic Participation/Social Inclusion: Community-based activities. Increased on deinstitutionalisation. Other: composite quality of life. Increased on deinstitutionalisation.
13	14, 15	Independence: Material well-being Well-being: Personal life satisfaction	Independence: Material well-being. Community settings (physical and social characteristics) rated as more pleasant than institutions. Well-being: Personal life satisfaction. At follow-up participants reported being happier and in better health than they had been while institutionalised.

N	Links	Outcome/Cost Measures	Results
14	13, 15	Independence: Personal skills, material well-being	Independence: Personal skills. No overall change on deinstitutionalisation.
			Social Inclusion: Social networks & friendships. No overall change on deinstitutionalisation.
		Well-being: Personal life satisfaction, emotional & mental health	Well-being: Emotional & mental health. No overall change in challenging behaviour scales scores, but significant decrease on single global rating.
			Well-being: Personal life satisfaction. No overall change on deinstitutionalisation.
15	13, 14	Costs	Costs: Deinstitutionalisation associated with significant increase in overall costs.
16		Well-being: Personal life satisfaction	Well-being: Personal life satisfaction. Deinstitutionalisation associated with increased satisfaction with accommodation, food and level of freedom.

N	Links	Outcome/Cost Measures	Results
17		Independence: Personal skills, choice & self-determination Well-being: Emotional & mental health, other (safety)	Independence: Personal skills. Increase following deinstitutionalisation. Independence: Choice & self-determination. Increase following deinstitutionalisation. Well-being: Emotional & mental health. No change. Well-being: Other (safety). No change.
18		Independence: Other (participation in domestic activity)	Independence: Other (participation in domestic activity). No differences between institutional and community-based settings.
19		Independence: Personal skills, other (participation in domestic and social activities) Well-being: Emotional & mental health Other: Composite quality of life measure	Independence: Personal skills. Limited increase in adaptive behaviour on deinstitutionalisation. Independence: Other (participation in domestic and social activities). No change in participation. Well-being: Emotional & mental health. Reduction in observed but not reported challenging behaviour on deinstitutionalisation. Other: Composite quality of life measure. Increase on deinstitutionalisation.

N	Links	Outcome/Cost Measures	Results
20	21	Well-being: Physical health	Well-being: Physical health. Better oral health and diet following deinstitutionalisation.
21	20	Well-being: Physical health	Well-being: Physical health. No change in oral health following deinstitutionalisation.
22		Independence: Choice & self-determination Other: Composite quality of life measure	Independence: Choice & self-determination. Increase following deinstitutionalisation. Other: composite quality of life measure. Increase following deinstitutionalisation.
23		Costs	Costs: Estimated (modest) costs of staff input into resettlement process.
24		Civic Participation/Social Inclusion: Social networks & relationships, community-based activities	Civic Participation/Social Inclusion: Social networks & relationships. Increased family contact and friendship activities. Civic Participation/Social Inclusion: Community-based activities. Increased social/recreational activity.

N	Links	Outcome/Cost Measures	Results
24 Continued		Well-being: Emotional & mental health	Well-being: Emotional & mental health. No significant difference between institutional and community setting.
25		Independence: Other (participation in leisure & occupational activities)	Independence: Other (participation in leisure & occupational activities). People in hostels engaged in more activities than people in institutions.
26		Other: Composite quality of life measure	Other: Composite quality of life measure. People living in community experience greater quality of life in most domains than people living on periphery of institutions.
27	28	Well-being: Physical health	Well-being: Physical health. No change in mortality following deinstitutionalisation.
28	27	Independence: Personal skills	Independence: Personal skills. Deinstitutionalisation associated with significant gains in independence and household skills. Non-movers incurred losses in social skills and cognitive competencies.

N	Links	Outcome/Cost Measures	Results
29		Well-being: Emotional & mental health	Independence: Other (participation in adaptive and communicative activities). Significant decrease in participation in adaptive and significant increase in participation in communicative activities following deinstitutionalisation. Well-being: Emotional & mental health. Significant increase in time spent engaged in challenging behaviour following deinstitutionalisation.
30		Independence: Personal skills	Independence: Personal skills. Significant increase in adaptive behaviour subsequent to relocation into group homes.
31		Independence: Other (participation in adaptive and social activities) Well-being: Emotional & mental health	Independence: Other (participation). Significant increase in participation in adaptive activities on deinstitutionalisation. No change in social activities. Well Being: Emotional & mental health. No statistically significant changes in time engaged in challenging behaviour following deinstitutionalisation.

N	Links	Outcome/Cost Measures	Results
32		Well-being: Personal life satisfaction	Well-being: Personal life satisfaction. Expressed preference for post-deinstitutionalisation living situation.
33	34, 35, 36	Well-being: Emotional & mental health	Well-being: Emotional & mental health. Deinstitutionalisation associated with no change in mental health but reported increase in aggressive, disruptive and passive behaviours.
34	33, 35, 36	Well-being: Emotional & mental health	Well-being: Emotional & mental health. Deinstitutionalisation associated with increase in aggression toward other people.
35	33, 34, 36	Well-being: Emotional & mental health	Well-being: Emotional & mental health. Deinstitutionalisation associated with no significant change in prevalence of self-injurious behaviour.

N	Links	Outcome/Cost Measures	Results
36	33, 34, 35	Well-being: Physical health	Well-being: Physical health. No difference in mortality between institutions and community-based residences.
37		Independence: Personal skills Well-being: Emotional & mental health	Independence: Personal skills. No change in activities/daily living skills. Well-being: Emotional & mental health. No significant changes in the frequency of psychiatric disorders. Significant increase in ‘other’ disruptive behaviours. Decrease in percentage of people with no challenging behaviour.
38		Civic Participation/Social Inclusion: Social networks & relationships	Civic Participation/Social Inclusion: Social networks & relationships. Increased contact with family members following deinstitutionalisation.
39		Independence: Choice & self-determination	Independence: Choice & self-determination. Deinstitutionalisation associated with increase in choice & self-determination.

N	Links	Outcome/Cost Measures	Results
40		Independence: Personal skills	Independence: Personal skills. Move to ICF/MR associated with decline in adaptive behaviour. Move to community-based residences associated with no change in adaptive behaviour.
		Well-being: Emotional & mental health	Well-being: Emotional & mental health. Deinstitutionalisation associated with initial increases in challenging behaviour, but no difference between pre-move and follow-up.
41	42, 43	Well-being: Physical health	Well-being: Physical health. Higher mortality in community-based than institutional settings.
42	41, 43	Well-being: Physical health	Well-being: Physical health. Higher mortality in community-based than institutional settings.
43	41, 42	Well-being: Physical health	Well-being: Physical health. Deinstitutionalisation associated with increased mortality.
44		Independence: Choice and self-determination	Independence: Choice and self determination. Deinstitutionalisation associated with increased self-determination, autonomous functioning and life choices.

N	Links	Outcome/Cost Measures	Results
45	46, 47, 48	Independence: Personal skills, choice and self-determination	Independence: Personal skills. Significant increase in adaptive behaviour following deinstitutionalisation. Independence: Choice and self-determination. Significant increase following deinstitutionalisation.
		Well-being: Personal life satisfaction, emotional & mental health	Well-being: Personal life satisfaction. Significant increase following deinstitutionalisation. Well-being: Emotional & mental health. No change in challenging behaviour.

N	Links	Outcome/Cost Measures	Results
46	45, 47, 48	Independence: Personal skills, choice & self-determination	Independence: Personal skills. Increase following deinstitutionalisation for people with more severe ID, no change for people with less severe ID.
			Independence: Choice & self-determination. Deinstitutionalisation associated with increased choice & self-determination.
		Well-being: Emotional & mental health	Well-being: Emotional & mental health. Deinstitutionalisation associated with no changes in informant reports of challenging behaviour.
		Other: Composite quality of life	Other: Deinstitutionalisation associated with increase on composite quality of life measure.

N	Links	Outcome/Cost Measures	Results
47	45, 46, 48	Independence: Personal skills, choice & self-determination	Independence: Personal skills. Increase following deinstitutionalisation. Independence: Choice & self-determination. Deinstitutionalisation associated with increased choice & self-determination.
		Well-being: Emotional &mental health	Well-being: Emotional & mental health. Deinstitutionalisation associated with no changes in informant reports of challenging behaviour.
		Other: Composite quality of life	Other: Deinstitutionalisation associated with increase on composite quality of life measure.

N	Links	Outcome/Cost Measures	Results
48	45, 46, 47	Independence: Personal skills, choice & self-determination, other	Independence: Personal skills. No change with deinstitutionalisation. Independence: Choice & self-determination. Deinstitutionalisation associated with increased choice & self-determination. Independence: Other. Deinstitutionalisation associated with increased engagement in domestic activities.
		Well-being: Emotional & mental health	Well-being: Emotional & mental health. Deinstitutionalisation associated with reductions in observed challenging behaviour, no changes in informant reports of challenging behaviour.
		Other: Composite quality of life	Other: Deinstitutionalisation associated with increase on composite quality of life measure.
49		Other: Composite quality of life	Other: Composite quality of life. Increased satisfaction with community, friends and free time (but not services) among participants living in group homes.

Appendix 3:
Post-Deinstitutionalisation Studies - Methodology

N & Author/Date	Country	Design	Participants	Participatory?
Key	PP - Pre/post no comparison group PPC - Pre/post with comparison group MG - Matched group comparison SC – Statistically controlled comparison Participants column records whether the study included information on the participants with respect to age (A), gender (G), ethnicity (E), severity of intellectual disability (ID), presence of autistic spectrum disorders (ASD).			

N & Author/Date	Country	Design	Participants	Participatory?
50 (Conroy, 1996)	USA	Matched	N=102. 51 matched pairs. ICF/MR, community-based residences. A, G, ID	No
51 (Egli et al., 2002)	USA	SC	N=36. Community-based residences. A, G, ID	No
52 (Emerson, 2004)	UK	SC	N=910. Community-based residences (n=741), campus/cluster housing (n=169). A, G, E, ID	M (in previous study)
53 (Emerson & McVilly, 2004)	UK	SC	N=1542. Community-based residences. A, G, E, ID	M (in previous study)
54 (Emerson et al., 2000)	UK	Matched	N=40. 20 matched pairs. Participants with profound/multiple disabilities. Campus/cluster housing, community-based residences. A, G, E, ID, ASD	No
55 (Emerson et al., 2000)	UK	Matched & SC	N=500. Intentional communities (n=86), campus/cluster housing (n=133), community-based residences (n=281). A, G, E, ID, ASD	No

N & Author/Date	Country	Design	Participants	Participatory?
56 (Robertson et al., 2000)	UK	SC	N=500. Intentional communities (n=86), campus/cluster housing (n=133), community-based residences (n=281). A, G, E, ID, ASD	No
57 (Robertson et al., 2001)	UK	SC	N=281. Community-based residences. A, G, E, ID, ASD	No
58 (Emerson et al., 2001)	UK	SC	N=281. Supported living (n=63), small community-based residences (n=55), larger community-based residences (n=152). A, G, E, ID, ASD	No
59 (Gregory et al., 2001)	UK	SC	N=96. Self-report. Community-based residences (n=51), intentional communities (n=45).	No
60 (Felce et al., 2003)	UK	SC	N=163. Community-based residences. A, G, ID, ASD	No

N & Author/Date	Country	Design	Participants	Participatory?
61, 62 (Felce et al., 2000, 2001)	UK	SC	N=34. Community-based residences (n=17), traditional services (n=17). People with severe ID and extreme challenging behaviour. A, G, ID, ASD	No
63 (Felce et al., 2002)	UK	SC	N=97. Community-based residences. A, G, ID, ASD	No
64 (Felce et al., 1999)	UK	SC	N=56. Community-based residences. A, G, ID	No
65 (Felce & Perry, 1995)	UK	SC	N=54. Community-based residences. ID	No
66 (Gardner & Carran, 2005)	USA	UC/SC	N=3,630. Across 552 organisations. A, G, ID, ASD	M – Focus groups used to derive measures
67 (Gillet & Stenfert-Kroesse, 2003)	UK	UC	Comparison of two high and two low-functioning units. A, G	No

N & Author/Date	Country	Design	Participants	Participatory?
68 (Hatton et al., 1995)	UK	SC	N=40. Specialised campus/cluster housing (n=16), specialised community-based residences (n=8), ordinary community-based residences (n=8). A, G, ID	No
69 (Heller et al., 1998)	USA	PPC/SC	N=232. Three year follow up of people who moved from nursing homes to community-based residences (n=67) and people who stayed in nursing homes (n=165). A, G, E, ID	No
70 (Heller & Miller, 1999)		SC	N=58. Community-based residences. A, G, E, ID	
71 (Heller & Miller, 1998)		PPC/SC	N=268. Three year follow up of people who moved from nursing homes to community-based residences (n=201) and people who stayed in nursing homes (n=67). A, G, E, ID	

N & Author/Date	Country	Design	Participants	Participatory?
72 (Heller et al., 2002)		PPC/SC	N=186. Eight year follow up of people who moved from nursing homes to community-based residences (n=133) and people who stayed in nursing homes (n=53). A, G, E, ID	
73 (Howe et al., 1998)	USA	Matched	N=40. 20 matched pairs in supported living and 'traditional' services. A, G, ID	No
74 (Mansell, Beadle-Brown, Macdonald & Ashman, 2003)	UK	SC	N=343. In 76 community-based residences. A, G, E, ID, ASD	No
75 (McConkey et al., 2005)	UK/IRE	SC	N=106. Campus/cluster housing (n=55) & community-based residences (n=51).	No
76 (Walsh et al., 2004)	UK/IRE	SC	N=106. Campus/cluster housing (n=55) & community-based residences (n=51).	No
77 (Perry & Felce, 2005)	UK	SC	N=154 in 47 community-based residences. A, G, ID, ASD	No

N & Author/Date	Country	Design	Participants	Participatory?
78 (Rhoades & Altman, 2001)	USA	SC	N=3,920. In 665 facilities. A, G., E, ID	No
79 (Robertson et al., 2004)	UK	Longitudinal matched groups	N=50. 25 people with severe challenging behaviour in congregate settings (most co-residents have challenging behaviour), 25 people with severe challenging behaviour in non-congregate settings (most co-residents do not have challenging behaviour). A, G, E, ID, ASD	No
80 (Saloviita & Åberg, 2000)	Finland	SC	N=54. Community based group homes (n=22), community-based apartments (n=12), institution (n=20).	No
81 (Schwartz, 2003)	Israel	SC	N=247. Group homes (n=147), semi-independent apartments (n=57), independent apartments (n=43). A, G, E, ID	No

N & Author/Date	Country	Design	Participants	Participatory?
82 (Spreat et al., 2005)	USA	Matched	N=348. Community-based residences (n=174), ICF/MR (n=174). A, G, E, ID	No
83 (Stancliffe, 1997)	AUS	SC	N=65. Community-based residences. A, G, ID	No
84 (Stancliffe et al., 2000)	USA	SC	N=74. Community-based residences. A, G, E, ID	No
85 (Stancliffe & Lakin, 1998)	USA	Longitudinal SC	N=126. Institutional settings and community-based residences. G, E, ID	No
86 (Stancliffe & Keane, 2000)	AUS	Matched pairs & SC	N=54. 27 matched pairs in either group homes or semi-independent living. A, G, ID, ASD	No
87 (Thompson et al., 1996)	USA	SC	N=80. Community-based residences. A, G, ID	No
88, 89 (Tossebro, 1995, 1995)	Norway	SC	N=591. Range of settings. G, ID	No

Appendix 4: Post-Deinstitutionalisation Studies - Results

N		Outcome/Cost Measures	Results
50		Independence: Personal skills, choice & self-determination	Independence: Personal skills. Greater skill gain in community-based residences. No difference in change in challenging behaviour. Independence: Choice & self-determination. Greater in community-based residences.
		Civic Participation/Social Inclusion: Community-based activities, employment	Civic Participation/Social Inclusion: Community-based activities. Greater in community-based residences. Civic Participation/Social Inclusion: Employment. No difference.
		Well-being: Physical health	Well-being: Physical health. No difference.
51		Civic Participation/Social Inclusion: Community-based activities	Architectural features (homelikeness) & staff attitudes were associated with more staff-initiated interactions that were in turn associated with increased community-activities.

N		Outcome/Cost Measures	Results
52	53	Civic Participation/Social Inclusion: Social networks & friendships, community-based activities, employment	Civic Participation/Social Inclusion: Social networks & friendships. No difference. Civic Participation/Social Inclusion: Community-based activities. Increased rate and variety in community-based residences. Civic Participation/Social Inclusion: Employment. No differences.
		Well-being: Physical health	Well-being: Physical health. Increased use of dental services in campus/cluster housing. Increased prevalence of being underweight in campus/cluster housing. Increased exercise in community-based residences. No difference on nine other indicators.
53	52	Civic Participation/Social Inclusion: Social networks & friendships.	Civic Participation/Social Inclusion: Social networks & friendships. Lower rates of friendship activities involving friends with ID in Nursing Homes than other forms of community-based residences. Higher rates of friendship activities involving friends without ID in settings in which residents hold legal tenancies.

N		Outcome/Cost Measures	Results
54	55, 56, 57, 58, 59	Costs	Costs: Greater costs in community-based residences.
		Independence: Choice & self-determination, other (engagement)	Independence: Choice & self-determination. Greater in community-based residences.
			Independence: Other (engagement). Greater in community-based residences.
		Civic Participation/Social Inclusion: Social networks & friendships, community-based activities	Civic Participation/Social Inclusion: Social networks & friendships. Greater size of social network in community-based residences. No difference in contact with families.
			Civic Participation/Social Inclusion: Community-based activities.

N		Outcome/Cost Measures	Results
55	54, 56, 57, 58, 59	Costs	Costs: Greater in community-based residences than campus/cluster housing. Greater in community-based residences than intentional communities for statistically controlled comparisons, but not for matched comparisons.
		Independence: Choice & self-determination.	Independence: Choice & self-determination. Greater in community-based residences than intentional communities and campus/cluster housing. Greater in intentional communities than campus/cluster housing.
		Civic participation/Social Inclusion: Social networks & friendships, community-based activities	Civic Participation/Social Inclusion: Social networks & friendships. Greater size of social networks in community-based residences and intentional communities than campus/cluster housing.
			Civic Participation/Social Inclusion: Community-based activities. Greater number of activities in community-based residences than intentional communities and campus/cluster housing.

N		Outcome/Cost Measures	Results
55 Continued			Greater variety of activities in community-based residences and intentional communities than campus/cluster housing.
		Well-being: Physical health, other (accidents & risks)	Well-being: Physical health. Men more physically active in community-based residences than campus/cluster housing. No difference for women or body mass index. Well-being: Other (accidents & risks). No differences in accidents. Less risk of crime, verbal abuse and exploitation in community in intentional communities than community-based residences and campus/cluster housing. No differences in five other risk variables.

N		Outcome/Cost Measures	Results
56	54, 55, 57, 58, 59	Well-being: Physical health (diet, physical activity, smoking)	Well-being: More likely to have sufficient milk-based foods in diet in community-based residences and campuses than intentional communities (when controlling for participant characteristics). More likely to smoke and have a generally poor or fatty diet in community-based residences and campuses than intentional communities (when controlling for participant characteristics). No differences on six other measures of diet. More likely to smoke in community-based residences and campuses than intentional communities (when controlling for participant characteristics). More likely to exercise in community-based residences than intentional communities and (in turn) campuses (when controlling for participant characteristics).

N		Outcome/Cost Measures	Results
57	54, 55, 56, 58, 59	Independence: Choice & self-determination	Independence: Overall low levels of choice in relation to major and minor areas of life. Self determination in community residences related to higher ability, smaller size of home, increased homeliness and internal working practices (active support).
58	54, 55, 56, 578, 59	Costs Independence: Choice & self-determination. Civic Participation/Social Inclusion: Social networks & friendships, community-based activities Well-being: Physical health, other (accidents & risks)	Costs: No differences in total costs. Independence: Choice & self-determination. Greater in supported living than community-based residences. Civic Participation/Social Inclusion: Social networks & friendships. Larger social network in supported living and small community-based residences than larger community-based residences. No differences in contact with family.

N		Outcome/Cost Measures	Results
59	54, 55, 56, 57, 58, 59	Independence: Choice & self-determination. Civic Participation/Social Inclusion: Social networks & friendships, community-based activities Well-being: Physical health, other (accidents & risks)	Civic Participation/Social Inclusion: Social networks & friendships. Increased expressed satisfaction with friendships. No differences in expressed satisfaction across other six domains. Increased satisfaction with accommodation associated with more organised staff practices(active support) and more hours per week of regularly scheduled activity.
60		Costs Independence: Other (engagement in activity)	Costs: Costs related to resident adaptive behaviour, size of residence, date of establishment of service. Independence: Other (engagement in activity). Related to resident adaptive behaviour and receipt of staff attention (which was itself related to resident adaptive behaviour, staffing ratios, staff practices).

N		Outcome/Cost Measures	Results
61, 62		Costs Independence: Choice & self-determination, other (engagement in activity)	Costs: Higher in community-based residences. Independence: Choice & self-determination, other (engagement in activity). Higher in community-based residences and among more able participants. Independence: Other (engagement in activity). Higher among more able participants and higher staff contact. Civic Participation/Social Inclusion: Community-based activities. Higher among more able participants and in smaller settings.
63		Independence: Other (engagement in activity) Civic Participation/Social Inclusion: Social networks & friendships, community-based activities	Independence: Other (engagement in activity). Greater among more able participants, larger group size, more staff assistance. Civic participation/Social Inclusion: Social networks & friendships. Greater when person had a key worker. Civic participation/Social Inclusion: Community-based activities. Greater in less institutional settings.

N		Outcome/Cost Measures	Results
64		Independence: Choice & self-determination, other (engagement in domestic/social activity)	Independence: Choice & self-determination. Higher among more able participants. Independence: Other (engagement in domestic/social activity). Higher among more able participants and with greater levels of staff assistance for reported but not observed measures.
		Civic Participation/Social Inclusion: Community-based activities	Civic Participation/Social Inclusion: Community-based activities. Higher among more able participants.
65		Independence: Other (engagement in domestic/social activity)	Independence: Other. Lower levels of ID associated with higher rates of engagement.

N		Outcome/Cost Measures	Results
66		Range across all domains (but only total score and some factor scores reported)	People supported in small to medium sized organisations achieved a greater number of personal outcomes (including in the 'identity' and 'affiliation' domains). For people with mild/moderate ID, people supported in individualised settings achieved a greater number of personal outcomes than people in supported settings who (in turn) achieved a greater number of personal outcomes than people in supervised settings. For people with severe/profound ID, people supported in supported settings achieved a greater number of personal outcomes than people in individualised or supervised settings.
67		Organisation selected on basis of high/low performance across range of outcome domains	Organisational culture (specifically aggressive/defensive cultural style) discriminated between organisations.

N		Outcome/Cost Measures	Results
68		Costs	Costs: greater for specialised services, no difference between campus and community-based.
		Civic Participation/Social Inclusion: Community-based activities; Social networks & friendships	Civic Participation/Social Inclusion: Community-based activities. Greater for community-based services, no difference between specialised or ordinary. Civic Participation/Social Inclusion: Social networks & friendships: No differences.
		Independence: Other (scheduled activity)	Independence: Other (scheduled activity). Greater in specialised community-based than specialised campus.

N		Outcome/Cost Measures	Results
69	70, 71, 72	Independence: Personal skills	Independence: Personal skills. Increase on move from nursing home to community-based residences.
		Civic Participation/Social Inclusion: Community-based activities, employment.	Civic Participation/Social Inclusion: Community-based activities. Increase on move from nursing home to community-based residences. Civic Participation/Social Inclusion: Employment. No difference. Well-being: Physical health. Increase in general health and mobility on move from nursing home to community-based residences.
		Well-being: Physical health, mental health (challenging behaviour), life satisfaction	Well-being: Mental health (challenging behaviour). No difference. Well-being: Life satisfaction. Increase on move from nursing home to community-based residences.

N		Outcome/Cost Measures	Results
70	69, 71, 72	Civic Participation/Social Inclusion: Community-based activities	Civic Participation/Social Inclusion: Community-based activities. Smaller size of setting (plus adaptive behaviour and involvement in decision making) associated with increased community integration.
71	69, 70, 72	Independence: Personal skills Civic Participation/Social Inclusion: Community-based activities Well-being: Physical health	Independence: Personal skills. Greater gains over time in smaller settings. Civic Participation/Social Inclusion: Community-based activities. Greater among people who moved from nursing home to community-based residences. Well-being: Physical health. No effect of moving or size.

N		Outcome/Cost Measures	Results
72	69, 70, 71	Independence: Personal skills, choice and self-determination	Independence: Personal skills. Increased on moving to community-based residences. Independence: Choice and self-determination. Increased on moving to community-based residences.
		Civic Participation/Social Inclusion: Social networks and activities, community-based activities	Civic Participation/Social Inclusion: Social networks and activities (contact with family). No effect of moving. Civic Participation/Social Inclusion: Community-based activities. Increased on moving to community-based residences.
		Well-being: Physical health	Well-being: Physical health. No effect of moving.
73		Costs	Costs: No difference between supported living and traditional services.
		Civic Participation/Social Inclusion: Social networks and activities, community-based activities	Civic Participation/Social Inclusion: Social networks and activities. Higher frequency and variety in supported living services. Civic Participation/Social Inclusion: Community-based activities. Higher frequency and variety in supported living services.

N		Outcome/Cost Measures	Results
74		Costs Independence: Other (engagement)	Independence: Other (engagement). Related to ability and staff practices (active support).
75	76	Independence: Choice & self-determination Civic Participation/Social Inclusion: Social networks & friendships, community-based activities	No differences for separate measures when controlling for participant characteristics, but overall QOL greater in community-based settings (uncontrolled comparisons and when controlling for participant characteristics).
76	75	Well-being: Physical health	Well-being: Increased use of medication in campus settings (when controlling for participant characteristics). Increased use of health checks & blood pressure checks in campus settings. Increased use of mammography, vision and hearing checks in community settings (all uncontrolled comparisons).

N		Outcome/Cost Measures	Results
77		Independence: Choice and self-determination, other (engagement)	Independence: Choice and self-determination. Higher for self-report (but not staff report) in smaller settings. Also associated with participant characteristics (adaptive behaviour, challenging behaviour) and individual planning. Independence: Other (engagement). Primarily related to participant characteristics (adaptive behaviour). Small effect for extent of physical integration.
		Civic Participation/Social Inclusion: Community-based activities	Civic Participation/Social Inclusion: Community-based activities. Higher in larger sized settings. Also associated with participant characteristics and not being supported by a private (for profit) organisation.
78		Costs	Costs: Lower costs associated with less severe ID and smaller size living unit.

N		Outcome/Cost Measures	Results
79		Costs	Costs: Greater in congregate than non-congregate settings.
		Independence: Choice and self-determination, other (engagement).	Independence: Choice and self-determination. No difference between settings.
			Independence: Other (engagement). No difference between settings.
		Civic Participation/Social Inclusion: Social networks & friendships, community-based activities	Civic Participation/Social Inclusion: Social networks & friendships. No difference between settings.
			Civic Participation/Social Inclusion: Community-based activities. Greater in non-congregate than congregate settings.
		Well-being: Physical health, mental health (challenging behaviour)	Well-being: Physical health. Injuries from co-tenants greater in congregate than non-congregate settings.
			Well-being: Mental health (challenging behaviour). Increase over time in congregate settings. No change in non-congregate.

N		Outcome/Cost Measures	Results
80		Independence: Choice & self-determination	Independence: Choice & self-determination. Greater self-determination in single occupancy apartments than group homes (uncontrolled and for people with ‘moderate’ ID).
81		Well-being: Personal life satisfaction	Well-being: Personal life satisfaction. Weak association between living in group homes or independent apartments (rather than semi-independent apartments) and increased life satisfaction.
82		Costs Civic Participation/Social Inclusion: Social networks & friendships, community-based activities Well-being: Physical health	Costs: Higher in ICF/MR than community-based residences. Civic Participation/Social Inclusion: Social networks & friendships. More contact with family in community-based residences. Civic Participation/Social Inclusion: Community-based activities. Greater in community-based residences. Well-being: Physical health. No difference in general health.

N		Outcome/Cost Measures	Results
83		Independence: Choice & self-determination	Independence: Choice & self-determination. Greater self-determination associated with participant characteristics and living in smaller settings.
84		Independence: Choice & self-determination	Independence: Choice & self-determination. Greater self-determination in community-based residences and smaller size living units than ICF/MR facilities.
		Civic Participation/Social Inclusion: Social networks & friendships	Civic Participation/Social Inclusion: Social networks & friendships. No difference.
85		Independence: Personal skills	Independence: Personal skills. No relationship between presence/absence of IHP goals and outcomes.
		Civic Participation/Social Inclusion: Social networks & friendships, community-based activities	Civic Participation/Social Inclusion: Social networks & friendships. No relationship between presence/absence of IHP goals and outcomes. Civic Participation/Social Inclusion: Community-based activities. No relationship between presence/absence of IHP goals and outcomes.

N		Outcome/Cost Measures	Results
86		Costs	Costs: Lower in semi-independent living.
		Independence: Choice & self-determination, other (domestic activity)	Independence: Choice & self-determination. Higher in semi-independent living. Independence: Other (participation in domestic activity). Higher in semi-independent living.
		Civic Participation/Social Inclusion: Social networks & friendships, community-based activities	Civic Participation/Social Inclusion: Social networks & friendships. Greater satisfaction with social networks in semi-independent living. No difference in frequency of contact with friends or family. Civic Participation/Social Inclusion: Community-based activities. Greater frequency of use of community facilities (including independent use) semi-independent living.
		Well-being: Personal life satisfaction, other (risks)	Well-being: Personal life satisfaction. No difference between settings. Well-being: Other (risks). No difference between settings.

N		Outcome/Cost Measures	Results
87		Well-being: Mental health (challenging behaviour)	Well-being: Mental health (challenging behaviour). Less stereotyping and aggression in more homelike settings.
88, 89		Independence: Choice & self-determination	Independence: Choice & self-determination. Greater in smaller settings, but little association with size above five people per setting.

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