

Quality of life outcomes and costs associated with moving from congregated settings to community living arrangements for people with intellectual disability

An evidence review

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Table of Contents

TABLE OF CONTENTS	2
LIST OF TABLES	4
LIST OF FIGURES	5
LIST OF ABBREVIATIONS	6
GLOSSARY	7
EXECUTIVE SUMMARY	8
1 INTRODUCTION	11
1.1 POLICY CONTEXT AND PURPOSE OF REVIEW	11
1.2 RESEARCH QUESTIONS	11
1.3 BACKGROUND.....	12
2 METHODS	15
2.1 ELIGIBILITY CRITERIA.....	15
2.1.1 <i>Types of participants</i>	15
2.1.2 <i>Types of intervention or exposure, and comparator</i>	15
2.1.3 <i>Types of outcomes</i>	15
2.1.4 <i>Types of studies and reports</i>	16
2.2 SEARCH STRATEGY	16
2.2.1 <i>Database search</i>	16
2.2.2 <i>Other sources</i>	16
2.2.3 <i>Search</i>	17
2.3 STUDY SELECTION AND QUALITY ASSESSMENT	19
2.3.1 <i>Screening of titles and abstracts</i>	19
2.3.2 <i>Screening of full-text reports</i>	19
2.3.3 <i>Assessment of methodological quality and risk of bias</i>	19
2.4 DATA ANALYSIS	19
2.4.1 <i>Data extraction</i>	19
2.4.2 <i>Data synthesis</i>	20
3 RESULTS	21
3.1 SEARCH AND SELECTION RESULTS	21
3.1.1 <i>Database search</i>	21
3.1.2 <i>Grey literature search</i>	27
3.2 FINDINGS BY RESEARCH QUESTION	27
3.2.1 <i>Quality-of-life effects</i>	27
3.2.2 <i>Cost-effects</i>	57
3.2.3 <i>Subpopulations with special support needs</i>	62
4 DISCUSSION	65
4.1 MAIN FINDINGS	65
4.1.1 <i>Quality of life literature</i>	65
4.1.2 <i>Cost literature</i>	68
4.2 STRENGTHS AND LIMITATIONS.....	69
4.3 IMPLICATIONS FOR PRACTICE AND RESEARCH	70
REFERENCES	72
APPENDICES	76
APPENDIX 1 GREY LITERATURE	76
APPENDIX 2 UNOBTAINABLE STUDIES	79
APPENDIX 3 STUDIES IN A LANGUAGE OTHER THAN ENGLISH	82
APPENDIX 4 STUDIES EXCLUDED AT QUALITY ASSESSMENT	84

APPENDIX 5 DATA EXTRACTION FORMS..... 86
APPENDIX 6 CASP RISK OF BIAS/QUALITY APPRAISAL TOOL..... 90

List of tables

Table 1 Search terms (example using MEDLINE)..... 18

Table 2 Categories of included studies and reports 22

Table 3 Quality assessment: included quantitative and mixed methods studies 23

Table 4 Quality assessment: included qualitative studies..... 25

Table 5 Summary characteristics of quantitative studies of quality of life outcomes 28

Table 6 Timing of post-move assessments in studies with quantitative quality-of-life data 30

Table 7 Summary characteristics of included studies on quality of life 35

Table 8 Summary of findings: pre-move compared to post-move for quality of life in persons with any level of ID, and for any setting 44

Table 9 Evidence table: quantitative quality of life research 50

Table 10 Summary characteristics of included studies on costs 58

Table 11 Key results from included studies on costs (in pounds sterling) 61

List of figures

Figure 1 Database search and study selection 26

Figure 2 Quality of life for adults with any level of intellectual disability post-move from any institutional setting to any community setting..... 44

Figure 3 Post-move quality of life for people with mild to moderate intellectual disability only..... 46

Figure 4 Quality of life following move from one institution to a different institution 48

Figure 5 Quality of life following move from one institution to a cluster setting 48

Figure 6 Quality of life in community versus cluster settings following a move from an institution..... 49

List of abbreviations

Abbreviation	Term
CASP	Critical Appraisal Skills Programme
CI	confidence interval
GRADE	Grading of Recommendations Assessment, Development, and Evaluation
ID	intellectual disability
IDS-TILDA	Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing
IQ	intelligence quotient
LCQ	Life Circumstances Questionnaire
LEC	Life Experiences Checklist
MD	mean difference(s)
NHS	National Health Service
PEOS	Participants, Exposure, Outcomes, and Study types
PICOS	Participants, Interventions, Comparators, Outcomes, and Study types
QOL	quality of life
QOL-Q	Quality of Life Questionnaire
SMD	standardised mean difference
UK	United Kingdom

Glossary

Term	Definition
confidence interval (CI)	A range of values within which a population parameter falls a specified proportion of the time. The confidence interval therefore expresses the degree of uncertainty associated with a sample statistic.
Life Circumstances Questionnaire (LCQ)	A tool which assesses objective quality of life.
Life Experiences Checklist (LEC)	A tool which assesses both objective and subjective quality of life.
Quality of Life Questionnaire (QOL-Q)	A tool which assesses subjective quality of life.
standardised mean difference (SMD)	A summary statistic in meta-analysis used when studies assess the same outcome (e.g. quality of life) but measure it using different tools or scales. SMD is calculated as difference in mean outcome between groups divided by standard deviation of outcome among subjects. Thus, it standardises the results of the studies to a uniform scale to allow the individual study results to be combined into a single overall result.

Executive summary

Purpose: To systematically evaluate the evidence on quality of life outcomes and costs associated with moving from congregated settings to community living arrangements for people with intellectual disability.

Review questions: The review aimed to answer three research questions:

1. What is the evidence on how deinstitutionalisation for adults with intellectual disability affects quality of life?
2. What is the evidence on how deinstitutionalisation for adults with intellectual disability affects costs?
3. Of the evidence for Questions 1 and 2, what is the evidence on deinstitutionalisation specifically for people who have highly specialised support requirements: people with severe physical and intellectual disability who have complex medical needs (such as people who use ventilators), people who are a forensic risk or who are ex-prisoners, people with dementia, and people with very challenging behaviours?

Methods: Studies were eligible for inclusion if they evaluated the effect of a change in residential setting for adults with intellectual disability on quality of life and/or costs. All study designs were considered. The team searched seven databases for relevant literature (MEDLINE, PsycINFO, CINAHL, EconLit, Embase, Scopus, and CENTRAL) using terms related to decongregation, intellectual disability, quality of life, and costs, without a time limitation. The authors of this review supplemented the articles found with a search of the grey literature in seven countries. Two reviewers independently assessed the retrieved citations for eligibility based on the title/abstract and then, for potentially eligible studies at the title/abstract level, based on the full text. Assessments of the methodological quality of included studies, as well as data extraction, were performed by one team member, with a second team member performing a corroborating review.

Studies measuring overall quality of life at baseline (before a move from an institution) and at some time point after a move were combined in a meta-analysis to ascertain the overall effect of moving on quality of life. Studies that used alternative designs (e.g. retrospective designs) and studies where only subdomains of quality of life were reported were not included in the meta-analysis; their results were reported narratively instead. Cost-effects data were extracted from studies and discussed, but heterogeneity and other limitations in reporting across the studies precluded meta-analysis. We did not define institutional and community settings beforehand – for example, according to the number of residents per unit – but instead made decisions based on the information provided in each study.

Findings: From an initial 19,285 articles (following removal of duplicates), a total of 36 relevant studies were determined to meet the eligibility criteria, of which 15 met the methodological quality threshold for inclusion. Thirteen of the included studies examined quality of life effects: eight quantitative, two qualitative, and three of mixed methods design. Two of the included studies examined cost-effects. The grey literature search identified six potentially eligible studies, but none met the quality threshold for inclusion.

The majority of the included individual studies showed that relocation to the community was associated with improved quality of life, both overall and in most subdomains. When sufficiently similar studies were combined in a meta-analysis, the results at both less than or equal to 12 months post-move and greater than 12 months post-move showed a statistically significant improvement in quality of life in favour of community living arrangements compared to living in institutional settings. Quality of life subdomains assessed in the studies included physical well-being, community access, routines, self-determination, residential well-being, and general life improvements.

Qualitative studies conveyed an overall positive impact on individuals' quality of life, i.e. improved well-being, freedom, and independent decision-making; more careful consideration of housemate compatibility; and increased family contact and social integration opportunities. Studies specifically examining quality of life have also found freedom and self-determination to be meaningful aspects of community living for individuals. However, potentially negative consequences were also reported, including an increased sense of loneliness and challenges in maintaining family contact.

Two eligible studies on costs were included, although the definitions of 'community settings' were unclear and included nursing homes. One study reported that a move from a long-stay hospital to community settings was associated with reduced costs, whereas the other reported that such a move was associated with increased costs. In both cost studies, very limited information was provided on both the people moving and the size and environment of their post-move residences. This precludes meta-analysis and prevents substantive policy recommendations on costs from being drawn.

With respect to high support needs, one study reported on quality of life outcomes longitudinally for up to two years for a sample described as having high support needs (a majority of those in the sample had severe or profound intellectual disability, challenging behaviour, specific health needs, and/or long-term institutionalisation). Quality of life, both overall and across a range of subdomains, improved for the whole group. This included the eldest members of the subgroup of people with severe or profound intellectual disability, although there was no significant improvement in their physical well-being. A second study found a non-significant increase in quality of life for people with a higher dependency level, although post-move destinations varied (e.g. these ranged from single-occupancy apartments to nursing homes).

Conclusions: Although there is a large body of studies examining quality of life outcomes of residential moves by people with intellectual disability, small samples, a lack of systematic design, incomplete data, and variations in what was measured over different time frames mean that few studies were worthy of inclusion in a systematic review, and even fewer met the criteria for meta-analysis. Nevertheless, this evidence review does offer some support for the hypothesis that moving from an institutional residential setting to a community residential setting is associated with improved quality of life for adults with intellectual disability. There is no clear evidence on the cost-effects of residential moves, and few conclusions can be drawn for people who have highly specialised support needs. There were some findings suggesting that people with severe or profound intellectual disability either experienced a generally improved quality of life or experienced a lack of improvement, but not a deterioration in quality of life, following a move to a community setting. There is a need for longitudinal studies – and agreed standardised variables and measures – that examine adequately sized representative samples of people with intellectual disability

where there is the potential to gather baseline (pre-move) data; follow individuals at several time points; examine health-related, community participation, and life satisfaction variables; and control for the effects of changing health and independence needs. Comparison of cost-effects requires measurement from the broadest possible perspective, incorporating both formal (residential, health, and social care, out-of-pocket costs) and informal (unpaid carer) cost domains in ways that illuminate the relationships between specific types of residential settings and associated utilisation. Within Ireland, such a study could be embedded within the pre-existing Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA), where the baseline is already established. Efforts should also be made to link with longitudinal studies in other countries.

1 Introduction

1.1 Policy context and purpose of review

The right to live independently in a place of one's own choosing is a core value of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).¹ Across the world, there have been multiple efforts made since the 1960s to reduce reliance on institutions among people with intellectual disability, not least because of concerns about the standards of care and due to the recognition that people with intellectual disability were being unnecessarily deprived of normal lives.²

Ireland is in the process of implementing a new phase in its efforts to reduce the reliance on institutional residential arrangements for people with intellectual disability. In particular, there has been a focus on moving people from what are widely referred to as 'congregated settings' (institutions with 10 or more residents) to 'community living arrangements' (where each unit contains no more than four residents). This process follows the publication of two major housing policies for people with disabilities: the Health Service Executive's report, *Time to Move on from Congregated Settings: A Strategy for Community Inclusion* (2011),⁴ and the Department of Environment, Community and Local Government and the Department of Health's *National Housing Strategy for People with a Disability 2011-2016* (2012).⁵ These policies seek to reshape where people with a disability live, with community-based living being the goal for all. Changing the residential options for people with intellectual disability is essential not only in the context of current rights, but also in terms of the needs of an ageing and often medically or behaviourally complex population.⁶

Therefore, the Department of Health in Ireland requested this review to inform Ireland's ongoing deinstitutionalisation process. Specifically, it sought evidence on the effects of deinstitutionalisation on quality of life and costs, as well as any specific evidence on the effects of deinstitutionalisation for populations with highly specialised support needs.

The purpose of this review is to systematically evaluate the evidence on quality of life outcomes and costs associated with a move from a congregated setting to a community living arrangement for people with intellectual disability.

1.2 Research questions

The commissioning body – the Health Research Board (HRB) – sought answers to three specific research questions:

1. What are the quality of life outcomes for people with intellectual disability who move from congregated settings to community living arrangements?
2. What are the costs associated with providing supports to people with intellectual disability who move from congregated settings to community living arrangements for three time periods: before the decongregation period, during the decongregation period, and after the decongregation period?
3. What is the evidence on quality-of-life and cost-effects specifically for people who have highly specialised support requirements: people with severe physical and intellectual disability who have complex medical needs (such as people who use ventilators), people who are a forensic risk or who are ex-prisoners, people with dementia, and people with very challenging behaviours?

In designing a systematic review to address these questions, the authors of this review faced a number of considerations. First, we considered matching the definitions of ‘congregated settings’ and ‘community living arrangements’ to the definitions in Irish healthcare policy: settings with 10 or more residents and settings with 4 or fewer residents per unit, respectively. However, we believed that these limits would arbitrarily exclude some studies that might otherwise be relevant to the evidence base, so we resisted hard cut-offs and instead decided to assess each paper on a case-by-case basis.

Second, it was not possible to answer all three research questions with a single systematic review. In consultation with the HRB, we agreed on the following revisions: we would systematically search for all studies that comparatively evaluated the effect of deinstitutionalisation on quality of life (Question 1) and costs (Question 2), and then we would separately assess all included studies for their evidence on Question 3.

We therefore conducted the review based on the following research questions:

1. What is the evidence on how deinstitutionalisation for adults with intellectual disability affects quality of life?
2. What is the evidence on how deinstitutionalisation for adults with intellectual disability affects costs?
3. Of the evidence for Questions 1 and 2, what is the evidence on deinstitutionalisation specifically for people who have highly specialised support requirements: people with severe physical and intellectual disability who have complex medical needs (such as people who use ventilators), people who are a forensic risk or who are ex-prisoners, people with dementia, and people with very challenging behaviours?

We systematically searched the published and grey literature for studies that reported on adults with intellectual disability who experienced a change in residential setting and that evaluated the impact of this move on quality of life and/or costs. We did not restrict our criteria based on study design.

1.3 Background

A body of literature has emerged defining and measuring the components of a quality life, measuring the quality of life and other outcomes for people with intellectual disability when they move from institutions into communities, examining the cost issues in community versus institutional care, and delineating the factors of a successful transition. Prior studies have influenced policy responses, and the assumption is that community living increases quality of life and that, overall, movement out of institutions is at least cost-neutral if not cost-effective.⁷ There have also been concerns raised about the quality of life experienced in the community⁸ and about the quality, drivers, and comparability of the available cost data.⁹ Given that these findings are used to make decisions about the lives of people with intellectual disability, it is important that this literature is well-integrated and understood within a framework that gives due emphasis to rights, outcomes, and costs. Both client experiences and costs need to be clearly understood so that community living services are efficacious and sustainable in the short and long term.⁹

One critical issue in considering policy direction is informing policy choices on appropriate evidence-based outcomes. Much work has already occurred in both defining and measuring quality of life for people with intellectual disability, particularly as it relates to one’s living situation. The United Nations Convention on the Rights of Persons with Disabilities is rooted in a rights perspective, arguing that people with intellectual disability should have a quality of life comparable to that of other community members.¹ An influential academic quality of life framework proposes an eight-domain conceptualisation of quality of life: emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights.¹⁰ In

addition, given that all public policy-making faces the constraints of resource scarcity and that it is imperative to maximise outcomes for available budgets, considerations of economic outcomes must also be integral to decision-making.¹¹

Another important consideration is what constitutes an institutional setting and what constitutes a community setting when decongregation occurs. In current Irish Government policy, best-practice community living arrangements are those with four people or fewer living in a single unit.^{4,5} However, in most of the available literature, the concept of deinstitutionalisation has been applied more broadly and refers simply to leaving an institution (e.g. a long-stay hospital), even if the individual with intellectual disability moves to a setting with more than four beds, and in some older studies this includes settings such as nursing homes.

Current evidence on both personal outcomes and costs is wide-ranging and complex. Many studies report that decongregation is associated with positive impacts across most outcome measures, including competence and personal growth, challenging behaviour, community participation, and engagement in meaningful activity.^{12,13} However, even within these reviews that report on balance improvements from decongregation, there are studies reporting significant deterioration. Other studies and reviews have found limited day-to-day differences following decongregation¹⁴⁻¹⁶ and either mixed or worse comparative outcomes for challenging behaviour, psychotropic medication use, health, and mortality.¹⁷ In short, the balance of evidence appears to favour deinstitutionalisation, but this conclusion must be viewed in the context of limitations in the number and scope of outcome measures, as well as the challenges of managing the variety of client needs and available care packages in resultant analyses. In addition, improvements in outcomes upon moving into the community cannot be assumed to be inevitable.¹⁸

Similarly, it has been argued that community placements are routinely less expensive than institutional settings.⁷ But concerns have been raised about the accuracy of cost calculation methods, including differences in staff and capital costs, regulation, and funding across settings;^{9,19} the comparability of different baskets of services between institutions and community residences;^{20,21} limitations to the perspectives of economic analyses, particularly regarding cost-shifting onto informal family and friend networks;²² and inadequate consideration of both transition costs associated with the process of decongregation and of ongoing institutional costs once institutions are partially or wholly closed as care settings.²⁰

One major concern across this literature is that observed results reflect how the characteristics of the service users differ, including the higher prevalence of poor health, disability burden, and challenging behaviours among residents in institutions compared with those in community living arrangements.²⁰ ²² A second major issue is the question of identifying an appropriate timeframe for assessing the decongregation process: How often and for how long should outcomes be measured in order to ensure that the reported results are robust and accurately reflect people's lives in the long term and are not simply artefacts of the short-term upheaval associated with moves? In addition, early movers and later movers tend to have different profiles and needs, with evidence indicating that early movers tend to be younger and higher functioning than later movers.²³ These limitations are particularly acute where studies do not evaluate a single decongregation process *per se* but rather perform a cross-sectional comparison of the experiences for different cohorts across multiple settings. This means that samples across settings will likely differ systematically in ways that are difficult to control for.

In summary, while some of the literature argues that community living is unambiguously better for people with intellectual disability, other assessments are more nuanced and raise concerns about small sample sizes, the selective use of data, the failure to address differences in populations served and in regulatory environments, and the over-reliance on cross-sectional studies that compare outcomes across settings but not within an overall decongregation process.

As Ireland continues its own decongregation initiatives, reforms ought to be based on how different choices impact on the lives of people with intellectual disability and on the costs of service provision,

reflecting policy-makers' primary goal of getting the best possible outcomes using the available resources. A systematic review of the available moderate- to good-quality evidence on these questions can contribute substantively to decision-making and to future developments within policy and practice.

2 Methods

2.1 Eligibility criteria

The authors of this review included articles of comparative studies that contained either detailed PICOS (which focuses on the Population, Intervention, Comparison, Outcomes and Study design) or PEOS (which focuses on the Population, Exposure, Outcomes, and Study design). The following sections describe the various PICOS and PEOS components that the eligible studies reported on.

2.1.1 Types of participants

The authors of this review examined studies that reported on adults (aged 18 years and older) with different levels of intellectual disability. Additionally, we specified at the outset that we would conduct subsample analyses of the populations of interest in Question 3 – that is, people with severe physical and intellectual disability who have complex medical needs (such as people who use ventilators), people who are a forensic risk or who are ex-prisoners, people with dementia, and people with very challenging behaviours – where a sufficient number of eligible studies that reported on these populations in a way that permitted subsample-specific analysis were included.

2.1.2 Types of intervention or exposure, and comparator

To be eligible for this review, studies had to evaluate a change in residential setting. While the primary focus of this review was specifically on the effect of moving from a congregated setting to a community living arrangement, we were conscious of the different stages of deinstitutionalisation in different parts of the world. We were also conscious of additional distinct concepts such as reinstitutionalisation (where people have left an institution for a community setting but then return to institutional living) and transinstitutionalisation (where people move between two institutions). We therefore took a broad approach to conceiving our intervention, comparator, and exposure variable(s) so as to include all studies that evaluated a change in residential setting irrespective of the specific settings that participants moved from and to. Additionally, we specified at the outset that, where possible, we would conduct subsample analyses of the primary move of interest – from congregated settings to community living arrangements (those with no more than four residents per unit) – if a sufficient number of eligible studies that reported on such moves in a way that permitted subsample-specific analysis were included.

2.1.3 Types of outcomes

The primary pre-specified outcomes of interest for this review were quality of life and costs.

For the purposes of this review, we chose author-defined quality of life, as measured by the study authors (i.e. using a validated or study-specific quality of life measurement instrument, or using subjective measures such as participants' views or experiences), as the sole criterion for identifying quality of life studies. This approach allowed a broad spectrum of quality of life concepts, characteristics, and measurement methods, in order to be eligible for this review. This recognised the evolving nature of quality of life concepts and definitions both within and beyond the field of intellectual disability. There were no restrictions on how quality of life was measured or operationalised, with both subjective and objective measurements being accepted.

We took a broad approach to defining costs. Outcomes of interest included any component of resource use (e.g. costs to payers, service users, and families; informal care costs). We did not require that resource use had to reflect the literal cost of provision for the study to be included, and we considered non-cost measurements of resource use – e.g. insurance programme charges, frequency utilisation combined with unit cost data – to fall within our eligibility criteria. Any study reporting within any cost-consequence framework (e.g. cost-effectiveness analysis, cost-utility analysis) was also deemed eligible.

2.1.4 Types of studies and reports

As different study designs were required to meet the different objectives of this review, we did not restrict our search to any one design. We planned to include the following types of studies: prospective and retrospective before-and-after studies, randomised controlled trials, economic evaluations, qualitative or descriptive studies, and exploratory studies. We excluded studies that did not compare quality of life and/or cost following a move. Cross-sectional quantitative studies were also generally excluded, as they lacked comparative data on moves, although this was not a pre-stated exclusion criterion.

2.2 Search strategy

2.2.1 Database search

In order to ensure a search strategy that was both sensitive and specific, a comprehensive search methodology to identify both published and grey literature (policy reports, national or international guideline documents, etc.) was developed and executed through routine scientific database searches and grey literature retrieval. Language restrictions were not applied to our search strategy; however, given the timeframe available and the challenges with securing translations, the selection of relevant papers was restricted to English-language publications. By searching all languages, we were able to identify the extent of potentially eligible additional papers that were not initially included and assess whether this may have indicated a possible language bias.

The following electronic databases were searched:

- MEDLINE
- PsycINFO
- CINAHL
- EconLit
- Embase
- Scopus
- CENTRAL

Searches were conducted in September 2017. No publication date limit was set, and all databases were searched from their inception dates to the date of the search.

2.2.2 Other sources

The search of grey literature focused on non-academic publications that were readily available online and included a range of different types of documents such as government, statutory organisation, and non-statutory organisation (with a particular focus on national disability organisations and university-based centres of disability studies) policy, guidance, standards, or clinical audit documents which included either primary or secondary data analysis. Books, book chapters, and PhD and Masters theses were excluded from this review. The focus was on reports that were directly relevant to policy, written by or for States where the policy of deinstitutionalisation had been implemented, and which directly captured this experience.

Although specific grey literature databases such as OpenGrey, OpenSIGLE, Open University, and GreyNet are available, subject matter experts on the project team decided to conduct the search for grey literature by country and based on centres of disability studies known to the authors. There was no publication date limit applied to these searches.

The countries searched were those outlined in the International Association for the Scientific Study of Intellectual and Developmental Disabilities Comparative Policy and Practice Special Interest Research Group's position paper on deinstitutionalisation: the United Kingdom (UK), the United States of America, Canada, Australia, Denmark, and Norway.²⁴ These countries have been at the forefront in

implementing policies and conducting research on deinstitutionalisation. Ireland was also included in the search of grey literature, as this is the country of focus for the current review.

2.2.3 Search

The search terms used to guide the review were developed and subsequently finalised by Trinity College Dublin's information specialist (GS), in collaboration with the review team's topic experts, by executing 'scoping' and pilot searches to cross-reference the search terms with prior studies and reviews.

With respect to the intervention, no standardised terminology exists for the concepts of 'deinstitutionalisation' and 'decongregation', but attempts in piloting to capture concepts of 'movement' and its synonyms led to poorly specified searches returning large numbers of irrelevant studies. Category 1 of our search strategy therefore includes vocabulary related not only to transitions but also to different categories of residence (e.g. hospital, home). Similarly, with respect to the population being researched, the language used to describe people with intellectual disability has changed profoundly since the 1960s; category 2 of our strategy is therefore intended to capture both current and historic terminology. In specifying language for quality of life in our search strategy, we considered multiple approaches, including the use of domains from well-established frameworks for quality of life concepts. However, pilot searches suggested that this approach led to large numbers of studies with low relevance. In category 3 of our search strategy, we therefore used 'quality of life', closely related terms such as 'life quality', and the related but distinct term 'adaptive behaviour', which has a prominent history in this field.

A combination of title and abstract keywords and related controlled vocabulary terms were incorporated into the search in order to ensure comprehensiveness. Table 1 presents the search terms with search strings as an example of the executed searches – in this case, using MEDLINE (EBSCO). The separate strings were combined using Boolean operators as follows: 1 AND 2 AND (3 OR 4).

Table 1 Search terms (example using MEDLINE)

	Term	Search terms
1	Living arrangement/setting type	MH("Housing" OR "Group Homes" OR "Nursing Homes" OR "Residence Characteristics" OR "Residential Facilities" OR "Deinstitutionalization" OR "Institutionalization" OR "Hospitals, Psychiatric") OR TI(House OR houses OR housed OR housing OR home OR homes OR domicile OR dwelling OR communit* OR apartment* OR hospital* OR asylum* OR accommodation OR "independent living" OR "semi-independent" OR institutional* OR institution OR institutions OR noninstitutional* OR deinstitutional* OR residence OR residential OR nonresidential OR congregat* OR decongregat* OR "family care" OR "social model" OR "service model" OR placement OR transition* OR campus OR forensic OR prison* OR reinstitutional* OR transinstitutional* OR cluster* OR personalised OR personalized OR "step down facility" OR "step-down facility" OR "supported living" OR relocat* OR resettl*) OR AB(House OR houses OR housed OR housing OR home OR homes OR domicile OR dwelling OR communit* OR apartment* OR hospital* OR asylum* OR accommodation OR "independent living" OR "semi-independent" OR institutional* OR institution OR institutions OR noninstitutional* OR deinstitutional* OR residence OR residential OR nonresidential OR congregat* OR decongregat* OR "family care" OR "social model" OR "service model" OR placement OR transition* OR campus OR forensic OR prison* OR reinstitutional* OR transinstitutional* OR cluster* OR personalised OR personalized OR "step down facility" OR "step-down facility" OR "supported living" OR relocat* OR resettl*)
2	Disability	MH("Intellectual Disability" OR "Developmental Disabilities") OR TI("Intellectual* disab*" OR "developmental* disab*" OR "learning disab*" OR "mental* retard*" OR "mental* handicap*" OR "intellectual* impair*" OR "IDD" OR "intellectual developmental disorder") OR AB("Intellectual* disab*" OR "developmental* disab*" OR "learning disab*" OR "mental* retard*" OR "mental* handicap*" OR "intellectual* impair*" OR "IDD" OR "intellectual developmental disorder")
3	Quality of life	MH("Adaptation, Psychological" OR "Quality of Life") OR TI("well-being") OR wellbeing OR "life quality" OR "quality of life" OR benefit* OR outcome* OR impact OR effect* OR "life satisfaction" OR "lifestyle satisfaction" OR "adaptive behaviour" OR "adaptive behavior") OR AB("well-being" OR wellbeing OR "life quality" OR "quality of life" OR benefit* OR outcome* OR impact OR effect* OR "life satisfaction" OR "lifestyle satisfaction" OR "adaptive behaviour" OR "adaptive behavior")
4	Costs	MH("Health Care Costs" OR "Cost and Cost Analysis" OR "Models, Economic" OR "Budgets") OR TI(Cost OR costs OR costing OR financial OR financials OR efficiency OR expenditure OR budget* OR expenditure* OR utilisation OR utilization OR economic* OR resource OR resources OR spend OR spending OR 1915(c) OR "1915 (c)" OR funding) OR AB(Cost OR costs OR costing OR financial OR financials OR efficiency OR expenditure OR budget* OR expenditure* OR utilisation OR utilization OR economic* OR resource OR resources OR spend OR spending OR 1915(c) OR "1915 (c)" OR funding)

2.3 Study selection and quality assessment

2.3.1 Screening of titles and abstracts

Two reviewers (RLV and EM) independently screened the titles and abstracts of retrieved citations based on this review's eligibility criteria (see Section 2.1). Subsequently, conflicts were resolved between these two reviewers on the basis of consensus. The online reviewer tool Covidence (<https://www.covidence.org/>) was used to manage the screening and selection process.

2.3.2 Screening of full-text reports

The second phase of screening involved accessing and downloading the full-text papers for all of the citations retained from the first phase of screening and applying the eligibility criteria. Two independent reviewers (any two of RLV, EM, and PM) independently screened the full-text papers, with any conflicts or uncertainties being resolved through discussion between the two reviewers. In addition, all of the included papers were checked for references to potentially eligible studies.

2.3.3 Assessment of methodological quality and risk of bias

Following agreement on full-text study eligibility, each study was assessed for methodological quality using one of several standardised instruments developed by the Critical Appraisal Skills Programme (CASP, <http://www.casp-uk.net/casp-tools-checklists>); that is, a CASP-developed tool specific to the design of the included study (e.g. the CASP Case Control Study Checklist, the CASP Economic Evaluation Checklist, the CASP Qualitative Checklist, and so forth).

A pair of reviewers conducted the quality assessment process, whereby one reviewer (either RLV or EM for quality of life studies and PM for cost studies) assessed the studies' methodological quality and a second reviewer (either RLV or EM for quality of life studies and CN for cost studies) performed their own rapid assessment to corroborate the initial quality assessments. Any conflicts were resolved through discussion and consensus.

Given that studies of low methodological quality are known to overestimate the effects of interventions or variables under investigation and to bias the results (usually in favour of the intervention), thereby often providing unreliable data on which to inform policy and practice, we made the decision to exclude studies assessed as being of low methodological quality. In performing our CASP appraisals, reporting on ethical processes was one criterion for determining methodological quality. Notwithstanding our awareness of the divergence between current and historical reporting standards and practices, we viewed whether consent for research participation was obtained as the floor below which ethical consideration should not fall, and as an important aspect of methodological reporting.

2.4 Data analysis

2.4.1 Data extraction

To address each research question, comprehensive data extraction forms were predesigned and piloted to extract relevant data from each study reviewed (see Appendix 5 Data extraction forms). One reviewer (either RLV or EM for quality of life studies and PM for cost studies) extracted the data from the included papers, and a second reviewer (either RLV or EM for quality of life studies and CN for cost studies) performed their own rapid assessment of the extracted data to corroborate the accuracy and comprehensiveness of the extracted data. Any conflicts were resolved by discussion and consensus. Relevant data included, for example, study design features (randomised controlled trial, prospective or retrospective cohort study, etc.), study setting (country of origin), participant details (characteristics, number of participants, etc.), recruitment and sampling, exposure or intervention details, ethical issues (e.g. consent), review question and outcome details (e.g. quality of life outcomes, costs, expenditure, etc.), findings (including summary measures and their standard deviations, as well as qualitative themes), and author-identified implications.

2.4.2 Data synthesis

2.4.2.1 Summary measures

For quality of life, the principal summary measure sought was the effect of a change in residential setting on quality of life. In quantitative investigations, for example, this may have included differences in means (mean differences (MDs), with associated 95% confidence intervals (CIs)) or a proportion of variance in quality-of-life outcomes accounted for by predictor variables. In our meta-analysis of quality-of-life data from studies that measured quality of life in different ways (i.e. using different instruments), we planned to use standardised mean differences (SMDs) and associated 95% CIs. For qualitative studies, this included themes reflecting individuals' quality-of-life experiences following a residential move.

For costs, the principal summary measure sought was the mean estimated effect of a change in residential setting on costs (from whatever perspective the study specified). Mean estimated effects on subcategories of costs, as well as drivers of costs, were secondary measures of interest.

2.4.2.2 Analytical measures

From the outset,, our aim was, as far as it was reasonable and feasible, to perform a meta-analysis of individual studies' data so as to achieve an overall (higher-level) effect estimate of quality of life or cost following a move from an institutional setting to a different institutional setting or to a community-based setting. To be combined in a meta-analysis, studies needed to be sufficiently similar in design (i.e. they had to provide prospectively collected pre-move and post-move data) and had to provide overall quality of life measures. Where studies did not meet these minimum similarity criteria, we reported these results narratively. Furthermore, where studies included in the meta-analysis used different instruments or tools to measure quality of life, we synthesised the data using SMDs, an analytical method that adjusts for variations that can arise from the same outcome being measured in different ways (i.e. using different scales or measurement instruments).

We present a narrative synthesis of the qualitative quality-of-life data using thematic analyses.

For the cost data, statistical pooling of data across studies proved neither feasible nor appropriate due to inadequate information on post-discharge residences and associated costs. We therefore present a narrative synthesis of these data using descriptive statistics and thematic analyses.

3 Results

3.1 Search and selection results

3.1.1 Database search

The database search identified 25,853 citations for consideration against the eligibility criteria for this review. Following removal of duplicates (n=6,568), 19,000 citations were excluded based on title and abstract, as they clearly did not meet the review's pre-specified eligibility criteria. A full-text review of the remaining 285 citations was performed, following which a further 217 citations were excluded and 32 were unobtainable. Reasons for exclusion were: no examination of a change in residential setting (127 articles); no cost or author-defined quality of life as an outcome (46); opinion or commentary articles or overviews (18); not in English language (12); not an adult population with intellectual disability (8); and miscellaneous (6).

This resulted in 36 articles being identified as meeting the eligibility criteria, of which 21 were subsequently excluded following assessment of their methodological quality using the relevant CASP tool (see Appendix 6 CASP risk of bias/quality appraisal tool). Reasons for exclusion following quality assessment included failure to establish consent of the study participants and insufficient or negligible data on participants and/or outcomes.

All published research including people with an intellectual disability is required to include information on the consent agreement with such participants.^{25 26} Guided by the CASP quality assessment tool (see Appendix 6 CASP risk of bias/quality appraisal tool presents one example, the Cohort Study Checklist), studies that did not demonstrate evidence of study participants – or appropriate proxies – providing informed consent were excluded. In addition to ethical concerns, appropriate recruitment is essential in order to minimise bias. The lack of reporting about informed consent could indicate that participants were potentially unaware of the study's aims or the voluntary nature of participation, and could indicate that participants were not given adequate time to evaluate the risks and costs of participation.

Secondary analyses of anonymised data, which typically do not require consent as there is no human participation, were not excluded for failing to demonstrate consent agreement.

Consequently, 15 studies were included from the database search (see Table 2 for categories of included studies and Figure 1 for the PRISMA search and selection flow diagram). The methodological quality of the included quantitative and mixed methods studies was assessed across 11 key parameters using the CASP Cohort Study Check (see Table 3). The methodological quality of the included purely qualitative studies (n=3) was assessed across 10 key parameters using the CASP Qualitative Checklist (see Table 4).

Table 2 Categories of included studies and reports

Type of study	Description	Number included
Longitudinal prospective cohort studies	Studies with more than two data collection time points, with at least one occurring prior to deinstitutionalisation. One longitudinal study also included qualitative interviews.	7
Single prospective cohort before-after studies	Studies which examined outcomes of interest prior to and following deinstitutionalisation	4
Retrospective cohort studies	A study with one data collection point which sought information on changes going back over time. This study also included qualitative interviews.	1
Qualitative studies	Studies employing qualitative methods only, which might be considered primarily exploratory	2
Case studies	An in-depth qualitative study with one participant (in this instance)	1
Total		15

Note: One of the longitudinal studies, as well as the retrospective cohort study, also included additional qualitative data. Thus, five studies in total presented qualitative data. Studies which present both quantitative and qualitative data could be termed mixed methods studies.

Table 3 Quality assessment: included quantitative and mixed methods studies

Study	Screening: Addresses clearly focused issue	Screening Cohort acceptably recruited	Exposure accurately measured (minimal bias)	Outcome accurately measured (minimal bias)	Identified important confounding factors	Account for confounding factors in design/analysis	Follow-up complete enough	Follow-up long enough	Believable results	Applicable to local population	Fit with available evidence	Total Yes	Total No	Total Cannot tell
Ager <i>et al.</i> 2001 ²⁷	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	9	0	2
Barber <i>et al.</i> 1994 ²⁸	Yes	Yes	Cannot tell	Cannot tell	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9	0	2
Bigby 2008 ²⁹	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10	0	1
Cooper and Picton 2000 ³⁰	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10	0	1
Golding <i>et al.</i> 2005 ³¹	Yes	Yes	Cannot tell	Cannot tell	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	8	0	3
Howard and Spencer 1997 ³²	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	9	0	2
O'Brien <i>et al.</i> 2001 ³³	Yes	Yes	Cannot tell	Cannot tell	No	No	No	Yes	Yes	Cannot tell	Yes	5	3	3
Young 2006 ³⁴	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	11	0	0

Study	Screening: Addresses clearly focused issue	Screening Cohort acceptably recruited	Exposure accurately measured (minimal bias)	Outcome accurately measured (minimal bias)	Identified important confounding factors	Account for confounding factors in design/analysis	Follow-up complete enough	Follow-up long enough	Believable results	Applicable to local population	Fit with available evidence	Total Yes	Total No	Total Cannot tell
Young and Ashman 2004a ³⁵	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	11	0	0
Young and Ashman 2004b ³⁶	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	11	0	0
Beecham <i>et al.</i> 1997 ³⁷	Yes	Yes	Cannot tell	Yes	No	No	Yes	Yes	Yes	Cannot tell	Cannot tell	6	2	3
Hallam <i>et al.</i> 2006 ³⁸	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Cannot tell	Cannot tell	7	2	2

Note: Bigby (2008) and O'Brien *et al.* (2001) are both mixed method studies, i.e. they present both quantitative and qualitative data. Beecham *et al.* (1997) and Hallam *et al.* (2006) are economic studies and were appraised with the CASP Cohort Study Checklist; this was considered more appropriate than the CASP Economic Evaluation Checklist, since both studies are cohort studies where cost is the outcome of interest, rather than full cost-effectiveness analyses in the economic evaluation tradition.

Table 4 Quality assessment: included qualitative studies

Study	Aims clearly stated	Qualitative method appropriate	Research design appropriate	Appropriate recruitment strategy	Appropriate data collection method	Relationship between researcher and participant considered	Ethical issues considered	Data analysis sufficiently rigorous	Findings clearly stated	Research useful to review question(s)	Total Yes	Total No	Total Cannot tell
Di Terlizzi 1994 ³⁹	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes	9	0	1
Kilroy <i>et al.</i> 2015 ⁴⁰	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10	0	0
Sheerin <i>et al.</i> 2015 ⁴¹	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10	0	0

Note: Quality assessments for both Bigby (2008) and O'Brien *et al.* (2001), which present both quantitative and qualitative data, are presented in Table 3.

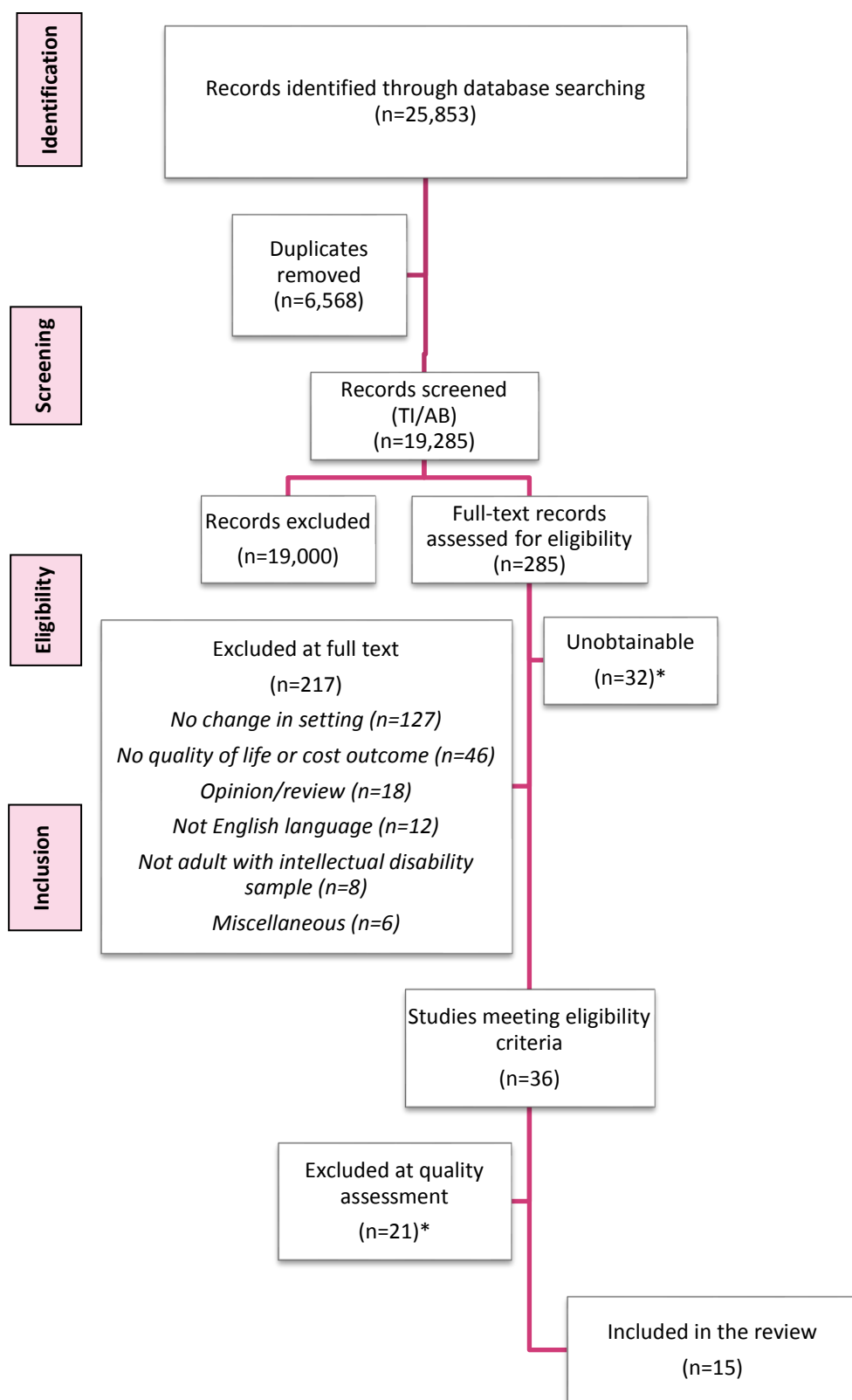


Figure 1 Database search and study selection

* For details of unobtainable papers and those excluded at quality assessment, see Appendix 2 Unobtainable studies and Appendix 4 Studies excluded at quality assessment, respectively.

3.1.2 Grey literature search

A total of 74 specific reports were identified from the grey literature search. Most studies were found from reviews of the websites of relevant research centres, advocacy organisations, and governmental agencies. Following a detailed review, 30 reports were identified as relevant to deinstitutionalisation from a cost and/or quality of life perspective. Of these, six included data on pre- and post-move measures, and so were eligible for this review.

Following a quality assessment of each of the six reports that met the eligibility criteria and focused on both pre- and post-move data, none of the reports was included in the final analysis. A major concern which was common across all six reports was the lack of reporting on ethical procedures and consent from participants. This could be due to a number of factors:

- The study was conducted at a time when reporting on ethics was not common practice.
- For work commissioned by the State or a particular disability service, consent may have preceded the researchers' work or may have been deemed unnecessary due to the fact that it was an evaluation rather than a research project *per se*.
- Some of the institutional closures were due to court orders, and thus tracking and evaluating outcomes for the residents may have been an incumbent part of the deinstitutionalisation order.

A detailed overview of the grey literature methodology and a list of the retrieved studies/reports is provided in Appendix 1 Grey literature.

3.2 Findings by research question

3.2.1 Quality-of-life effects

3.2.1.1 Description of included quality of life studies

3.2.1.1.1 Quantitative quality of life studies

Nine quantitative studies, comprising 10 papers, addressed the review question of quality of life outcomes.²⁷⁻³⁶

All of the included studies with quantitative data examined a move from an institution to a non-institutional setting, while two also specifically examined moves to either another institution or to cluster centres. Six studies originated in Australia, three in the United Kingdom (UK), and one in New Zealand. Of the six from Australia, two report different analyses of the same sample; these are discussed simultaneously where it is more meaningful to do so. Study characteristics are reported in detail in the text, with summaries of study characteristics provided in Table 5 and Table 7, and post-move data collection time points described in Table 6.

Quality of life was assessed in a range of ways, with some consequent diversity in measurement tools. Three studies used the Life Experiences Checklist (LEC),⁴² a tool which assesses both objective and some more subjective experiences of quality of life, and for which validity and reliability data are available. Three studies used the Life Circumstances Questionnaire (LCQ), a nonstandardised tool used to assess objective quality of life which was developed by the authors of the studies in which it was used.⁴³ Two studies used the Quality of Life Questionnaire (QOL-Q), a validated tool for providing information on subjective quality of life.⁴⁴ Other ways of measuring quality of life included aspects of informal social relationships (one study) and family ratings of quality of life (one study). Five of the included research studies attempted to assess quality of life using multiple post-move assessments.

Table 5 Summary characteristics of quantitative studies of quality of life outcomes

Author and year	Location	Description of study sample			Quality-of-life tool or proxies
		Number in institutions	Number moving to community	Intellectual disability (ID) level	
Ager <i>et al.</i> 2001 ²⁷	UK	76	76	Not reported	LEC
Barber <i>et al.</i> 1994 ²⁸	Australia	15	15	Mild=53%, moderate=40%, severe=7%	QOL-Q
Bigby 2008 ²⁹	Australia	24	24	Mild=0%, moderate=62.5%, severe or profound=25%, unknown=12.5%	Analysis of social networks
Cooper and Picton 2000 ³⁰	Australia	45	26	Moving to community: mild=24%, moderate=52%, severe or profound=24% Moving to other institutions: mild=5%, moderate=47%, severe or profound=47% The authors report no significant difference between groups, though no statistics were reported.	QOL-Q
Golding <i>et al.</i> 2005 ³¹	UK	6	6	Mild to moderate (with challenging behaviour)=100%	LEC
Howard and Spencer 1997 ³²	UK	10	10	Not reported	LEC
O'Brien <i>et al.</i> 2001 ³³	New Zealand	54	54	Not reported by ID level. Total sample=54; high support needs=75.5%, medium=6%, low=18.5%	Family ratings of changes in quality of life

Author and year	Location	Description of study sample			Quality-of-life tool or proxies
		Number in institutions	Number moving to community	Intellectual disability (ID) level	
Young 2006 ³⁴	Australia	60	30	Mostly moderate or severe or profound. Numbers by category were not reported.	LCQ
Young and Ashman 2004a and 2004b ^{35 36}	Australia	104	104	Mild=14%, moderate=25%, severe=61%	LCQ

Note: Two studies, by Young and Ashman (2004a, 2004b), are grouped for the purposes of this table as they report different analyses of the same cohort of participants.

Table 6 Timing of post-move assessments in studies with quantitative quality-of-life data

Study	Timing of post-move assessment									
	1 month	3 months	6 months	9 months	1 year	1.5 years	2 years	3 years	5–9 years	
Ager <i>et al.</i> 2001 ²⁷			Yes ^a							
Barber <i>et al.</i> 1994 ²⁸	Yes									
Bigby 2008 ²⁹					Yes			Yes	Yes	
Cooper and Picton 2000 ³⁰			Yes					Yes		
Golding <i>et al.</i> 2005 ³¹		Yes		Yes						
Howard and Spencer 1997 ³²					Yes					
O'Brien <i>et al.</i> 2001 ³³									Yes	
Young 2006 ³⁴					Yes		Yes			
Young and Ashman 2004a and 2004b ^{35 36}	Yes		Yes		Yes	Yes	Yes			
Total	2	1	3	1	4	1	2	2	2	

^a Between six and nine months

Quantitative studies may be usefully grouped according to those that address the following issues: a comparison of different resettlement destinations;^{27 30 34} a focus on subpopulations or particular samples with high support needs or challenging behaviour;^{31 34-36} an examination of one particular subcomponent of quality of life;²⁹ and other studies which studied moving from an institution to community more generally.^{28 32 33}

Ager *et al.* (2001) studied 76 movers aged 21 to 92 years (mean=53 years of age) at baseline and at six to nine months post-move.²⁷ This sample was drawn from a group of 95 people who relocated due to a hospital closure in the UK. Length of stay in the institution ranged from 1 to 66 years (mean=29 years). Participants' level of intellectual disability was not reported. Participants moved to any of 19 community-based homes (18 receiving voluntary funding, 1 receiving private funding), either of two nursing homes (receiving private funding), or any of five older people's homes (receiving local authority funding). Participants' quality of life was measured pre-move and between six and nine months post-move using the LEC. Participants had a range of dependency levels which did not appear to have an obvious relationship with their post-move accommodation, although their individual dependency levels were not reported by the authors. No data were provided on participants' health status or condition.

Barber *et al.*'s (1994) Australian study was concerned with outcomes almost immediately following a move.²⁸ They studied the short-term (one month) outcome for a sample of 15 people (8 females, 7 males) with intellectual disability who were moving from institutions to community-based group

homes in 1991. This cohort was reportedly a subset of a larger, stratified random sample of 31 participants from a paper that remained unpublished by the time Barber *et al.*'s 1994 study went to press and which could not be located within the time frame of the present review. The subsample ranged in age from 30 to 57 years (mean=42.4 years, standard deviation=8.5 years) with the following levels of intellectual disability: mild=8, moderate=6, and severe=1. No information was reported on the participants' health status or conditions.

Bigby (2008) examined informal social relationships, using quantitative methods, as a component of quality of life in an Australian sample.²⁹ At baseline, 27 participants (selected from a group of 55 residents moving from an institution to small houses in the community) agreed to take part in the study; however, three died during the five-year study period. Data were collected from a final sample of 24 residents at the following time points: pre-move and at one, three, and five years after moving from a large institution to small group homes in the community. Demographic information was drawn from institutional records. The participants' levels of intellectual disability were recorded as follows: moderate=15, severe or profound=6, and unknown=3. Seventeen of the participants had identified health issues, seven had psychiatric diagnoses, and six had mobility impairment. The author used a structured interview which included questions on formal and informal social networks, including the relationships of identified persons to the resident, nature of contact, frequency of contact, residents' location, and whether friends were close or intimate. Contacts were categorised as: friends with and without intellectual disability, close friends, intimate friends, co-residents (or not), and relatives.

Cooper and Picton (2000) compared two groups of people with intellectual disability moving from the same institution which had been decommissioned.³⁰ Participants in both groups were selected quasi-randomly from all movers at the institution, with the aim of creating similar groups. One group comprising 26 participants moved to a number of community group homes accommodating six or fewer residents, while the other group of 19 participants moved to refurbished units within another institution. The two groups' quality of life and experiences were measured at pre-move baseline, and at six months and three years following the move. The study authors reported that the demographic characteristics of the group moving to the community homes (mean age=52 years, standard deviation=15 years; 52% male) were similar to the group moving to other institutions (mean age=55.2 years, standard deviation=12; 53% male, 47% female), but no inferential statistics results were reported. Cooper and Picton also reported that the levels of intellectual disability were similar between the two groups; however, the authors of this review observed that the groups appear to differ in terms of distribution of intellectual disability level (community homes group: mild=24%, moderate=52%, severe or profound=24%; other institutions group: mild=5%, moderate=47%, severe or profound=47%), with the group moving to other institutions containing a lower proportion of people with mild intellectual disability and a higher proportion with severe or profound intellectual disability than the group moving to community homes. No information was provided on the participants' health status.

Golding *et al.* (2005) examined changes in quality of life using the LEC total and domain scores from three months pre-move and from three months and nine months post-move for a sample of six males with mild to moderate intellectual disability and challenging behaviour in the UK.³¹ It was not specified why these participants were selected, e.g. whether or not a convenience sampling method was employed. The post-move community living arrangement consisted of two separate houses managed by a specialist challenging behaviour residential service with an on-duty staffing ratio of four staff to six residents between 7.00am and 10.00pm. Although information on pre-move adaptive behaviour was provided, no information was provided on the participants' health status or conditions.

Howard and Spencer (1997) examined the quality-of-life outcomes of 10 people – all of whom participated in the study – who moved from a large rural group home with institutional features to one of two houses in a rural setting. The group comprised three males and seven females, and the mean age of the participants was 61 years. The 10 participants were movers who chose to live in a rural setting in the UK. Neither their level of intellectual disability nor their health status were reported. The study authors examined quality of life outcomes at one year post-move using the LEC.

O'Brien *et al.* (2001) examined family ratings of quality of life changes for relatives with intellectual disability following a move from a psychiatric hospital to community homes in New Zealand.³³ The study authors used a retrospective design to study the participants' quality of life outcomes at nine years post-move. The overall sample of people with intellectual disability in the study was reported as 54 (sampled from 61 residents in total who moved); this sample comprised 31 females and 23 males aged between 36 and 65 years (mean=48 years of age) who had been in the long-stay hospital for between 2 and 42 years (mean=22 years) before the move. Level of support need was determined by a checklist used by the community service agency in applications for funding. High support needs equated to physical assistance to move around and assistance in toileting, feeding, dressing, and bathing. The authors identified 41 participants as having high support needs, 3 as having medium support needs, and 10 as having low support needs. For these 54 participants with intellectual disability, 21 family members and one advocate were asked to rate participants' quality of life in the institution before the move and at nine years after the move, with both ratings collected at the same time. The study did not explain whose relatives provided information and whose did not. Ratings were given on seven five-point Likert scales, which represented seven domains derived from the Quality-of-life Scale designed by Cummins.⁴⁵ Data were only presented for between 11 and 14 participants for each subscale, but this was also not explained in the study. This study also provided qualitative data, which is discussed in Section 3.2.1.1.2.

Young (2006) undertook a longitudinal study of 60 participants with intellectual disability and challenging behaviour sampled from an original population of 160 in an institution in Australia.³⁴ Participants ranged in age from 27 to 81 years, with 38 males and 22 females, and with levels of intellectual disability described as mostly moderate, or severe or profound. The 60 participants were allocated to one of two groups of 30 that were matched afterwards based on a range of demographic, health, impairment, and adaptive behaviour variables. After initial baseline assessment, one group of 30 remained in the institution for an extended period, then moved to interim community housing, and finally to cluster centres. The cluster centres each accommodated between 20 and 25 people and consisted of seven or eight houses and an administration centre, which were built in outer suburban locations and resembled surrounding houses (although one centre had a fenced perimeter and electric gates). Houses were modified as required (e.g. non-glass windows, kitchens enclosed by security panels, accessible showers). The second group of 30 moved within six months of the baseline assessment to pre-existing outer suburban houses accommodating two or three residents each. These houses were generally unmodified except where wheelchair access was required. The cluster centres group had 6 to 10 hours of community recreation time per week, whereas the community group had 10 to 15 hours. The post-move assessments of quality of life using the LCQ were undertaken when each participant had been living in the community for 12 months, and again at 24 months. The participants' health status or conditions were not reported.

Young and Ashman (2004a, 2004b) researched a group of 104 participants (57 males and 47 females) moving to the community following the closure of an institution in Australia.^{35 36} The people in the sample were aged between 21 and 84 years (mean=47 years of age). The authors considered this sample to require high levels of support, due to the majority of participants having severe intellectual disability (severe=61%, moderate=25%, and mild=14%), challenging behaviours, and specific health needs or impairments (50 participants had visual, hearing, or mobility impairment), as well as many participants having lived in institutions for most of their lives (between 2 and 70 years; mean=26 years). Additionally, 61% were considered older adults (aged 40 years and older). All relocated residents moved into modern, brick, freestanding public housing, which was typical of the surrounding neighbourhoods in outer suburban areas, and which had more favourable staff-to-resident ratios than was the case in the institution. Each household was responsible for house management, and there were 15 hours of funded day activities per week for each person. Quality of life was assessed using the LCQ at the following time points: approximately 6 months pre-move, and then at 1, 6, 12, 18, and 24 months post-move.

3.2.1.1.2 Qualitative quality-of-life studies

Qualitative methods were employed in five studies – two originating in Ireland (both used a qualitative design only),^{40,41} one case study in the UK,³⁹ one retrospective mixed methods study in New Zealand,³³ and one mixed methods study in Australia²⁹ – and ranged in publication year from 1994 to 2015 (Table 5).

Both Irish studies qualitatively investigated the impact of a move from a residential centre to the community on the quality of life for a small sample of people with intellectual disability: Kilroy *et al.* (2015)⁴⁰ interviewed eight participants and Sheerin *et al.* (2015)⁴¹ interviewed seven participants. All eight of Kilroy *et al.*'s participants had limited capacity to communicate; six individuals with mild to moderate levels of intellectual disability consented to be interviewed, and key workers were interviewed as proxies for the other two participants.⁴⁰ The participants' mean age was 37 years (ranging from 26 to 44 years of age) and seven participants had specific health conditions: one person had autism, two had bipolar affective disorder, one had bipolar affective disorder and epilepsy, one had bipolar affective disorder and autism, one had epilepsy, and one had syndrome. Sheerin *et al.* presented less detailed information than Kilroy *et al.*, reporting that participants were middle to older age individuals (aged ranged from 26-44) with no details on health conditions.⁴¹

In these two studies, participants shared the experience of moving from a residential campus, where they were supported in all areas of life, to two different types of community living arrangements. Kilroy *et al.*'s participants moved into a new housing located within a Dublin commuter belt,⁴⁰ whereas Sheerin *et al.*'s participants moved to two community houses in a rural location in the west of Ireland.⁴¹ The Dublin community setting included a number of self-contained living spaces with shared living areas within staffed houses. Given the nature of a commuter belt, home dwellers generally commuted in the early morning and late evening, which limited participants' opportunities for contact with neighbours. Access to amenities was less convenient for these participants, and the opportunity to independently return to the community setting after visiting friends was restricted by public transport availability. Sheerin *et al.* presented a more detailed picture of the community setting in the west of Ireland, describing five-bedroomed detached houses, each with its own private access, a shared garden, and amenities accessible within approximately five minutes by car.⁴¹ Transport was allocated to each individual, along with staffing hours. Following the move, personal bank accounts were set up and a monetary disability benefit was allocated to each individual.

Based on a thematic analysis of the data, 10 themes were presented in Kilroy *et al.*: (i) indicators of change, (ii) improvement in living conditions, (iii) compatibility with housemates, (iv) house as home, (v) importance of support strategies, (vi) move as catalyst for organisational change, (vii) community participation versus integration, (viii) staff as key to quality of life, (ix) sense of freedom, and (x) ongoing difficulties affecting quality of life.⁴⁰ Sheerin *et al.* (2015) outlined six themes that overlapped with Kilroy *et al.*'s themes, which were: (i) moving to and living in the community house, (ii) personal space and privacy, (iii) independence, (iv) loss of security, (v) differing expectations of staff, and (vi) social integration.⁴¹

O'Brien *et al.*'s (2001) retrospective mixed methods study, which took place in New Zealand, had a larger sample of 54 participants, and included interviews with staff and family members of the participants in order to examine quality of life outcomes following a move from an institution to the community.³³ Forty-one people were perceived as having high support needs, 3 as having medium support needs, and 10 as having low support needs. Interviews were conducted with three groups of people: (i) staff from the community service agency, (ii) family members, and (iii) members of the focus group with sufficient communications skills:

- (i) Forty-four staff members working for the community service agency and two who worked for an alternative provider were interviewed as part of one focus group. Staff had known each individual with intellectual disability about whom they were being interviewed for approximately five years. Seven staff members provided information on more than one individual. Staff roles included community service managers (n=8) and

- community service workers (n=38).
- (ii) Twenty-two people agreed to be interviewed about a relative or friend with an intellectual disability in the second focus group. The interviewees' relationship with the person with intellectual disability about whom they were being interviewed included mother (n=9), father (n=3), sister (n=3), brother (n=3), cousin (n=3), and advocate (n=1).
- (iii) Nine (mean age=53 years; range=37–65 years of age) of the 13 people who were reported as having low or medium support needs made up the third group of participants that were interviewed. Community staff considered all nine people to be capable of holding a conversation. Length of stay within the hospital ranged from 9 to 31 years, with a mean length of stay of 17 years. Seven participants lived in group homes and two lived in apartments. Two people attended centre-based day programmes, four worked in sheltered workshops, and three were in supported work groups. Two of the people also held part-time jobs in the community. The experiences of individuals with severe intellectual disability and/or challenging behaviour were not included in the qualitative analysis or discussion.

O'Brien et al.'s (2001) qualitative results are focused on three main topics, which also overlap with the topics in the Irish studies: (i) staff members' early recollections of individuals, (ii) perceived changes in the individuals following deinstitutionalisation, and (iii) advantages and disadvantages of the move into a residential home as they relate to quality of life.³³

These three studies share a number of similar themes, such as the changes experienced during the move from an institution to the community, changes in staff roles, and increases in opportunities for independence and freedom of choice. In addition, each study found that individuals' emotional well-being, privacy, health, and material well-being were all perceived to have improved following the move from an institution to the community.^{33 40 41}

Di Terlizzi (1994) presented an in-depth case study of the life of one woman with severe intellectual disability and challenging behaviour who had experienced several residential settings before her eventual move to a community setting that was in closer proximity to her family.³⁹ The key themes in this case study that were related to quality of life focused on this individual's lack of access to appropriate individualised support in the residential setting and the improvement in access to this type of tailored support in the community. In particular, improved contact with family contributed to improved quality of life outcomes for this individual; previously, the lack of access to appropriate support and training impeded this individual's ability to engage in any meaningful way with life in general. The case study depicts a disturbing picture of this individual's dramatic regression in all areas of her life when appropriate support for her challenging behaviour was not provided in residential institutions. Most notably, in the absence of appropriate support at the residential settings, her challenging behaviour became more severe. The answer was not to simply move her to a setting with fewer residents, but rather to provide her with individualised support and training to meet her specific needs. The move to a community setting included access to appropriate training and support for her individual needs, which positively impacted her overall quality of life. Most significantly, the new location was much closer to her family home, which meant that her family visited more regularly and that she could then visit them at home, which positively impacted the development of relationships with family members that had previously been stunted.

Bigby's 2008 study (which took place in Australia) also focused on the significance of maintaining social relationships, particularly with family, following a move into a small group home in the community five years after moving out of an institution.²⁹ Participants' levels of intellectual disability ranged from moderate (n=15) to severe or profound (n=6), with three participants' details not reported. Only 11 of these participants were involved in the qualitative aspect of the study. The nature of social relationships as they related to the individuals' quality of life was the sole focus of the study.

Table 7 Summary characteristics of included studies on quality of life

Study	Location	Aim	Study design	Participants	Pre-move setting	Post-move setting
Ager <i>et al.</i> 2001 ²⁷	UK	To examine levels of social integration for individuals resettling into community provision following the phased closure of Gogarburn Hospital, Edinburgh, UK, and the personal and service-related characteristics which were influenced social integration.	Prospective cohort Pre-post Pre-move: baseline Post-move: 6–9 months Measure: LEC	Total sample=76 Mean age=53 years (range=21–92 years) Gender: not reported Intellectual disability (ID) level: not reported Time in institution: 1–66 years Health status: not reported	1 hospital	19 community-based homes (18 receiving voluntary funding, 1 receiving private funding), OR 1 of 2 nursing homes (receiving private funding), OR 1 of 5 older people’s homes (receiving local authority funding)
Barber <i>et al.</i> 1994 ²⁸	Australia	To report the immediate effects of relocation on those clients who were relocated during the first year of the deinstitutionalisation project.	Prospective cohort Pre-move: baseline Post-move: 1 month Measure: QOL-Q (subjective)	Total sample=15 Mean age=42.4 years (standard deviation=8.51, range=30–57 years) Gender: female=8, male=7 ID level: mild=8, moderate=6, severe=1	1 institution	Community-based group homes
Bigby 2008 ²⁹	Australia	To examine changes in the nature of the residents’ informal relationships 5 years after	Mixed methods Pre-move: baseline	Total sample=24 Mean age=51.5 years	1 large institution	Small group homes in the community

Study	Location	Aim	Study design	Participants	Pre-move setting	Post-move setting
		leaving an institution.	Post-move: 1, 3, and 5 years Qualitative interviews Measure: Structured interview, social network analysis (size, relationship type, etc.)	(range=39–68 years) Gender: not reported ID level: mild=0, moderate=15, severe or profound=6, unknown=3 Mean time in institution prior to move=38 years (range=10–54 years) Identified health issues=17 (psychiatric diagnosis=7, mobility impairment=6; some residents had multiple health issues)		
Cooper and Picton 2000 ³⁰	Australia	To examine the long-term effects of relocation on a sample of 45 adults with ID who moved from a State residential institution to small group homes and to units within other institutions.	Prospective cohort Pre-move: baseline Post-move: 6 months and 3 years Measure: QOL-Q	Total sample=45 Group moving to community=26 (mean age=52 years, standard deviation=15.3; gender: male=52%, female=48%) Group moving to refurbished institution=19 (mean age=55.2 years, standard deviation=12; gender: male=53%, female=47%)	1 institution – closure order	Community group homes housing no more than 6 people (n=26) Refurbished institution (n=19)

Study	Location	Aim	Study design	Participants	Pre-move setting	Post-move setting
				ID level: not reported Time in institution: not reported Health status: not reported		
Di Terlizzi 1994 ³⁹	UK	To describe the life history of a woman with severe learning disabilities and communicative impairment.	Case study	Total sample=1 Age=36 when she moved to community house ID level: severe learning disability and challenging behaviour Time in institution: not reported Health status: not reported	Residential hospital institution	Small community-based staffed house. Shared with 3 other highly independent co-tenants with mild learning disabilities. Service provided was a 1:1 staff ratio throughout the day.
Golding <i>et al.</i> 2005 ³¹	UK	To evaluate the effects of relocation from institutional to specialised community-based care provision for people with severe challenging behaviour.	Prospective cohort (and an additional comparison group that was already living in the community, which has not been discussed in this review as the findings for this group are not relevant) Pre-move: baseline	Total sample=6 males with mild to moderate ID and challenging behaviour An additional 6 participants who were already in the community were also included in this study but are not reported on for the purposes of this review.	Institution operated by the National Health Service (NHS)	2 separate houses managed by a specialist challenging behaviour residential service with an on-duty staffing of 4 staff to every 6 residents between 7.00am and 10.00pm

Study	Location	Aim	Study design	Participants	Pre-move setting	Post-move setting
			Post-move: 3 months and 9 months Measure: LEC			
Howard and Spencer 1997 ³²	UK	To provide local management and staff with some insight into the effect of service changes (a move from a group home to community living arrangements) on the lives of the residents.	Prospective cohort Pre-move: baseline Post-move: 1 year Measure: LEC (mostly objective quality-of-life items, some subjective)	Total sample=10 participants who had a preference to remain in a rural setting post-move Mean age=61 years Gender: female=7, male=3	Large rural group home with institutional features	1 of 2 rural community houses
Kilroy <i>et al.</i> 2015 ⁴⁰	Ireland	To explore key workers' perceptions of the impact of a move to Dublin commuter belt housing on the QoL of individuals with an ID.	Qualitative Proxy participants Measure: Key workers perceptions of residents quality of life One time point	Total sample=8 people with severe intellectual disability who had moved from a residential campus to the community over the previous 4 years Mean age=37.4 years (range=26–44 years) Gender: male=6, female=2	1 institution	2 community houses that are owned by 2 housing associations, which were set up by family of the individuals and staff of the disability organisation but run as independent entities
O'Brien <i>et al.</i> 2001 ³³	New Zealand	To investigate the outcomes of the move into community homes	Mixed methods	Total sample=54 Mean age=48 years (no	1 long-stay hospital	Group homes located in the community with a 1:1 on-duty staff ratio to assist

Study	Location	Aim	Study design	Participants	Pre-move setting	Post-move setting
		for the 61 people who left the psychiatric hospital in 1988, including an exploration of the perceptions of the people who had been deinstitutionalised, their family members, and staff about the effects of the move into the community.	Retrospective cohort Qualitative Measure: interviewees perceptions of the effects of the move Single point in time after the move	standard deviation reported; range=36–65 years) Gender: female=31, male=23 High support needs=41, medium support needs=3, low support needs=10 Time in institution: not reported Health status: not reported		with integration
Sheerin <i>et al.</i> 2015 ⁴¹	Ireland	To explore whether, and to what extent, the move to the community led to the achievement of individualised and personal outcomes for tenants. In addition, it sought to understand the significance of the move in terms of where tenants had moved from and to examine the extent to which this had resulted in their integration in the local community.	Qualitative Proxy participants Measure: Self or key workers perceptions of residents quality of life	Total sample=7 (5 people with ID, 2 relatives of other tenants) Age: not reported Gender: female=3, male=2 ID level: not reported Time in institution: not reported Health status: not reported	1 institution	New residence Participants moved to housing in the west of Ireland

Study	Location	Aim	Study design	Participants	Pre-move setting	Post-move setting
Young 2006 ³⁴	Australia	To monitor changes in skills and life circumstances as residents of an institution that was to be permanently closed were progressively relocated into either dispersed homes in the community or cluster centres and to record any changes in adaptive and maladaptive behaviour, choice-making and objective life quality.	Prospective cohort Pre-move: baseline Post-move: 12 months and 24 months Measure: LCQ	Total sample=60 Age range: 27–81 years Gender: male=38, female=22 ID level: mostly moderate or severe or profound Two groups of 30 matched after the study according to demographic, health, impairment, and adaptive behaviour variables Time in institution: not reported Health status: not reported	1 institution	Cluster centres: accommodating 20–25 people, comprising 7–8 houses and an administrative centre, located in outer suburbs, resembling the surroundings, modified as required Community: pre-existing outer-suburban houses, each accommodating 2–3 residents
Young and Ashman 2004a and 2004b ^{35 36}	Australia	To monitor changes in skills and life circumstances as the participants were progressively relocated from an institution to community homes and to record any changes in quality of life that might be considered equivalent to the experiences of others without mental	Prospective cohort Pre-move: baseline, 6 months pre-move Post-move: 1, 6, 12, 18, and 24 months Measure: LCQ (objective quality of life (QOL))	Total sample=104 Mean age=47 years (range=21–84 years) Gender: male=57, female=47 ID level: severe=61%, moderate=25%, mild=14% The majority had challenging behaviours, specific health needs or impairments (50 with	1 institution	Modern, brick, freestanding public housing which was typical of the surrounding neighbourhood in outer suburban areas and had more favourable staff-to-resident ratios

Study	Location	Aim	Study design	Participants	Pre-move setting	Post-move setting
		retardation in the community.”		visual, hearing, or mobility impairment), and had experienced long-term institutionalisation, in many cases most of their lives (range=2–70 years, mean length of stay=26 years)		

3.2.1.2 Key quantitative and qualitative quality of life results

3.2.1.2.1 Quantitative studies: quality of life

To address the question of quality of life outcomes in people with intellectual disability who move from an institutional setting to a community setting, the analyses have been divided into two discrete yet complementary comparisons. The two comparisons are:

- Comparison 1: Quality of life experienced by people with any level of intellectual disability who move from any type of institutional setting to any type of community setting, providing a 'whole group' answer to this review question; nine quantitative studies measured quality of life outcomes, of which five were suitable for inclusion in a meta-analysis. Three associated subgroup analyses were included in this comparison which explored quality of life subscale scores, quality of life by level of intellectual disability, and quality of life stratified by age.
- Comparison 2: Quality of life experienced by people with any type of intellectual disability following a move from one type of institutional setting to an alternative type of institutional/congregated setting (two studies).

3.2.1.2.2 Comparison 1: Quality of life experienced by people with any level of intellectual disability following a move from any institutional setting to any community setting

The quantitative study characteristics are presented in Table 5. All nine of the included studies assessed quality of life at some point following a move from an institutional setting to a community setting, although these settings were variously described as, for example, an NHS hospital, a State residential centre, a large group home (19 residents) or a large institution, a small group home, a terraced city house, a community unit (four or fewer residents), and private or local authority housing. Follow-up time points also varied across the studies, from one month post-move²⁸ to nine years post-move³³ (Table 6).

As per our described methods (Section 2.4.2.2), only those five studies that met a reasonable level of homogeneity (similarity) in terms of study design were included in meta-analyses; that is, they had to have measured quality of life both prospectively (before the move as a pre-test measure) and at a minimum of one follow-up time point after the move (as a post-test measure). For studies that used repeated post-test measures, we selected quality of life measures at one time point for inclusion in the meta-analysis in order to avoid over-counting, and we described all other time point results narratively. To further reduce characteristic variances in the meta-analysis, we subgrouped the data according to follow-up at either less than one year post-move or at more than one year post-move from any type of institutional setting to any type of community setting. In addition, while subscales of quality of life might be chosen as a proxy measure of overall quality of life, in order for a study to be included in the meta-analysis, an overall quality-of-life scale score had to be provided; where only subscale results were provided, we presented the results for these studies narratively. To further offset the anticipated subtle differences across the studies (e.g. varying degrees of intellectual disability, challenging behaviour, etc.), we meta-analysed the data using a random effects model rather than a fixed effects model.⁴⁶ Lastly, because the instruments used to measure quality of life across the included studies differed, we calculated the standardised mean difference (SMD) in quality

of life as per recommended meta-analytical methods.⁴⁶ The summary results of meta-analysed data are narratively presented in text and visually presented using forest plot graphs.¹

Overall quality of life: meta-analysed data

Overall, quality of life for people with any level of intellectual disability was significantly increased at less than one year following a move to a community setting (SMD: 2.03; 95% CI: 1.21–2.85, five studies, 492 participants) and beyond one year post-move (SMD: 2.34; 95% CI: 0.49–4.20, three studies, 320 participants), with total quality of life change scores higher at 24 months compared to the scores at 12 months (Figure 2). There was a high level of statistical heterogeneity in the analysis, which is likely due to elements of clinical variation across the included studies (e.g. participants with varying levels of ID across studies, along with differing age profiles) rather than to study design issues. For this reason, we used a random effects model in the analysis, which incorporates these random variation issues in the meta-analysis. Using this model, we interpreted the results as an average of the effect of a move from an institutional setting to a community setting rather than as a ‘best estimate’ of the effect (as provided by a fixed effects model). This is why the random effects model is the model of choice where concerns exist over random characteristic variation (known as heterogeneity and often found in observational studies), as it provides a more meaningful method of analysing and interpreting the results of pooled data.

As all of the studies included in this review – and thus the pooled average estimate of the effect of a move from any institutional setting to any community setting on quality of life in people with any level of ID – met a minimum threshold for methodological quality using the CASP quality assessment tool (that is, they were deemed to be of either good or high quality), the strength of these results and the confidence we can have in them is increased. Furthermore, in order to assess the level and quality of the evidence for quality of life, we performed a GRADE (Grading of Recommendations Assessment, Development, and Evaluation) assessment of the summary results (Table 8). GRADE provides a system for rating the quality of the evidence (based on a collective assessment of study design, risk of bias, imprecision, inconsistency, indirectness, and magnitude of effect) on the results of meta-analysed data. For both quality of life measures – that is, less than one year post-move and more than one year post-move – the quality of evidence is moderate (downgraded by two levels due to observational study designs and statistical heterogeneity), indicating moderate confidence that the average effect estimates are reflective of ‘true’ estimates and that the addition of further studies is unlikely to substantially change these results.

¹ A forest plot displays results for both individual studies and for all studies combined, thus providing summary effect evidence based on larger numbers. The green square represents an individual study’s result, with the horizontal line through the middle of this representing the 95% confidence interval (CI) around this result (the narrower the line, the greater precision in the result). The size of the green square represents the size of the sample, that is, the bigger the sample size the bigger the green square. The large black diamond represents the overall result for all of the data combined, with a narrower diamond indicating greater precision in the overall summary effect. All of the green squares and the diamonds to the right of the graph indicate higher quality-of-life scores for community settings compared to institutional settings, and vice versa – the squares and diamonds to the left of the line indicate higher quality-of-life scores for institutional settings. Where an individual study’s horizontal line (95% CI) does not touch the vertical line down the middle of the graph, this means that the result is **statistically significant**. Similarly, where a point on the horizontal plane of the diamond does not touch the graph’s middle vertical line, this indicates a **statistically significant** result, with increasing significance the further away the diamond is from the *line of no difference*. In Figure 2, for example, all of the studies’ results favour community settings; that is, the quality-of-life scores are higher for community settings compared to institutional settings, and the overall diamonds show statistically significant improvement in quality of life following a move to a community setting.

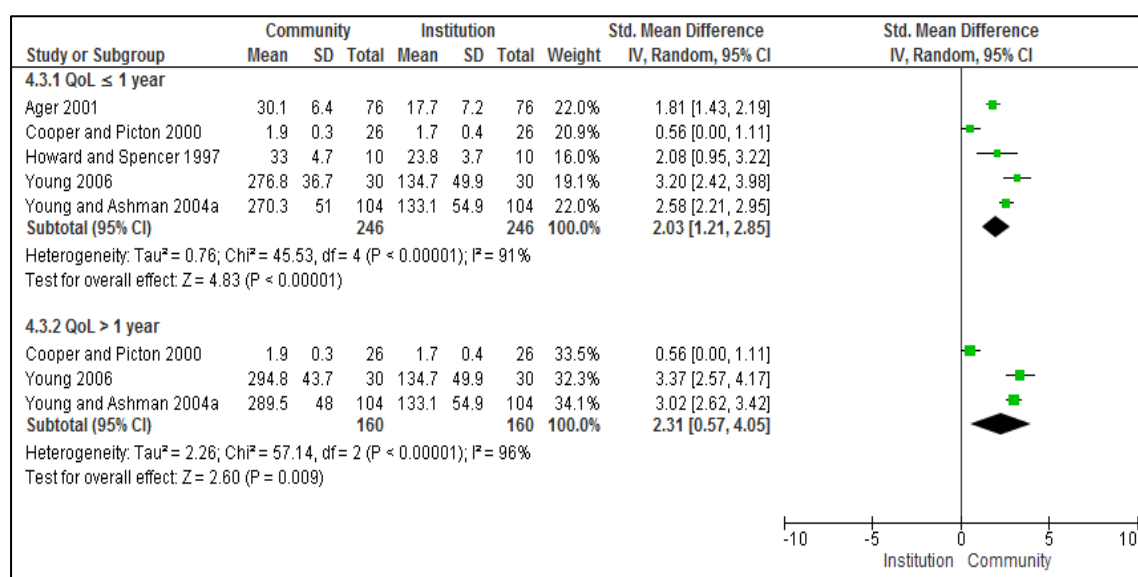


Figure 2 Quality of life for adults with any level of intellectual disability post-move from any institutional setting to any community setting

Table 8 Summary of findings: pre-move compared to post-move for quality of life in persons with any level of ID, and for any setting

Patient or population: quality of life; Setting: institutional and community			
Intervention: post-move; Comparison: pre-move			
Outcomes	No. of participants for metaanalysis (No. of studies)	Certainty of the evidence (GRADE)	Comments
Quality of life: less than or at 1 year post-move	492 (5 observational studies)	⊕⊕⊕○ MODERATE ^{a, b}	a. Observational (pre/post) studies b. Statistical heterogeneity
Quality of life: after 1 year post-move	320 (4 observational studies)	⊕⊕⊕○ MODERATE ^{a, b}	a. Observational (pre/post) studies b. Statistical heterogeneity
GRADE Working Group grades of evidence			
High certainty: We are very confident that the true effect lies close to that of the estimated effect.			
Moderate certainty: We are moderately confident in the effect estimate. The true effect is likely to be close to the estimated effect, but there is a possibility that it is different.			
Low certainty: Our confidence in the effect estimate is limited. The true effect may be substantially different from the estimate of the effect.			
Very low certainty: We have very little confidence in the effect estimate. The true effect is likely to be substantially different from the estimate of the effect.			

Overall quality of life: narrative results

Bigby (2008) reported informal social relationship outcomes as a proxy for quality of life in a sample of 24 residents with moderate to severe intellectual disability, both pre-move and at one, three, and five years after moving from a large institution to small group homes in the community.²⁹ Bigby used a structured interview which included questions about formal and informal social networks, including the relationships of identified persons with the resident, nature of contact, frequency of contact, residents' location, and whether friends were close or intimate. Due to study heterogeneity, these data were not included in the meta-analysis and are instead reported narratively. The reported results demonstrated a slight downward trend from baseline to five years post-move in the number of residents who were in contact with family members. The proportion of residents in contact at least annually fell from 85% (20 residents) pre-move to 75% (18 residents) at the five-year follow-up. While this finding was not significant ($p>0.05$), there was a significant fall in the mean number of family members in contact with residents between one and five years post-move ($p<0.05$). Residents' mean informal network size increased between baseline and one year post-move, but then decreased at three years post-move and again at five years post-move; the overall decrease, however, was not significant ($p>0.05$). Reasons cited by family members (20 telephone interviews) for low levels of contact or changes in the level of contact included changing circumstances, such as ill health or movement for retirement; limited availability of service staff to support family visits with residents; lack of knowledge of a resident's daily life; frequent staff changes which were a barrier to building a relationship with staff; and being unknown by staff when they telephoned. Staff turnover was the reason most frequently cited. Additionally, some family members also cited their own ill health or other demands on time, while others cited aggressive behaviour or lack of acknowledgement by the resident when contact was made. Often, telephone contact replaced physical visits. The study's author also cited a lack of specific goals or strategies relating to maintenance of contact in residents' individual programme plans, or a lack of implementation of these plans, as a reason for contact with family and friends not being maintained.

O'Brien *et al.* (2001) reported retrospectively on quality of life at nine years post-move in individuals who moved from a psychiatric hospital to community homes.³³ Due to this extended timeframe, because higher scores represent a lower quality of life (which is in direct contrast to other studies), and because overall quality of life scores were not provided, data from this study were not included in the meta-analysis. In this study, 21 family members and one advocate were asked to rate participants' quality of life both in the institution (nine years retrospectively) and at the time of the study on five-point Likert scales representing seven dimensions. Mean scores were significantly lower (with lower scores indicating better quality of life) in all domains at follow-up (mean scores at baseline versus at follow-up: material possessions: 1.74 versus 3.69 ($p<0.001$); health: 2.06 versus 2.91 ($p<0.01$); productivity: 2.25 versus 3.77 ($p<0.001$); intimacy: 2.35 versus 3.9 ($p<0.05$); safety: 2.10 versus 3.30 ($p<0.01$); place in community: 2.48 versus 4.16 ($p<0.001$); and well-being: 2.27 versus 4.06 ($p<0.001$)). Data were only presented for between 11 and 14 participants for each subscale, but this inconsistency was not explained in the study.

Quality of life subscale scores

While the majority of studies included in this comparison provide overall quality-of-life scale scores, one study only provides quality of life subscale scores.²⁸ Others provide subscale scores in addition to overall quality-of-life scores.^{27 31 32 34}

Barber *et al.* (1994) used the QOL-Q, which assesses four major quality of life domains: i) satisfaction, ii) competence/productivity, ii) empowerment/independence, and iv) social belonging/integration.²⁸ The study authors provided subscale mean and standard deviation scores only, and the study was thus not included in the meta-analysis (Figure 2). Although mean quality-of-life scores increased in all four domains at one month post-move compared to the pre-move scores, none of these differences reached statistical significance (satisfaction: MD: 1.9; 95% CI: -1.685-4.8; competence/productivity: MD: 2.40; 95% CI: -3.77-8.57; empowerment/independence: MD: 2.0; 95% CI: -0.56-4.56; and social belonging/integration: MD: 0.80; 95% CI: -2.86-4.46

Howard and Spencer (1997), using the LEC, reported subscale scores in addition to overall quality-of-life scores.³² Domain areas in the LEC include home, leisure, relationships, freedom, and opportunities. LEC scores for all domain areas, other than relationships, had increased significantly at one year post-move compared to pre-move scores ($p < 0.01$ or $p < 0.001$). Using the same quality-of-life instrument, Ager *et al.* (2001), at nine months post-move, also reported significant post-move improvements to pre-move scores in all five of the LEC subscales (all $p < 0.005$).²⁷ Interestingly, Howard and Spencer’s (1997) study was the only study to examine a move from a large rural institutional setting to one of two houses in a rural setting where all 10 participants expressed a preference for a specific setting – in this case a rural setting.³² Young (2006) provided a further study where subscale scores were presented in addition to overall scores.³⁴ Using the LCQ, the participants’ post-move scores in the domains of community access, physical well-being, routine, self-determination, residential well-being, and general factors were all significantly improved at 24 months post-move compared to their pre-move scores.

Quality of life stratified by degree or level of intellectual disability

The included studies varied in their descriptions of the levels of intellectual disability in their sample, with some simply referring to populations of people with intellectual disability while others provided exact numbers of participants with mild, moderate, and severe or profound intellectual disability. In attempting to explore quality of life specific to certain levels of intellectual disability, we were able to extrapolate data explicitly relating to people with mild to moderate intellectual disability from four studies,^{27 31 32 35} two of which were suitable for inclusion in a sensitivity analysis (Figure 3).^{32 36} Follow-up time points across the two studies were 12 and 24 months.

In Young and Ashman’s (2004b) study, data were stratified by age (20–39 years, 40–59 years, and 60 years and older), and thus we calculated average mean quality-of-life scores for all participants with mild or moderate intellectual disability, regardless of age.³⁶

Overall quality of life experienced by people with mild or moderate intellectual disability did not significantly improve following a move from an institutional setting to any community setting (MD: 0.99; 95% CI: -0.41–0.46, two studies, 51 participants) (Figure 3). It should be noted, however, that this result is likely to be influenced by the 60 years and older age group demonstrating a (non-significant) reduction in quality-of-life scores at follow-up.⁴⁷ For this reason, we further explored intellectual disability data, stratified by age (see section titled *Quality of life stratified by level of intellectual disability and age*).

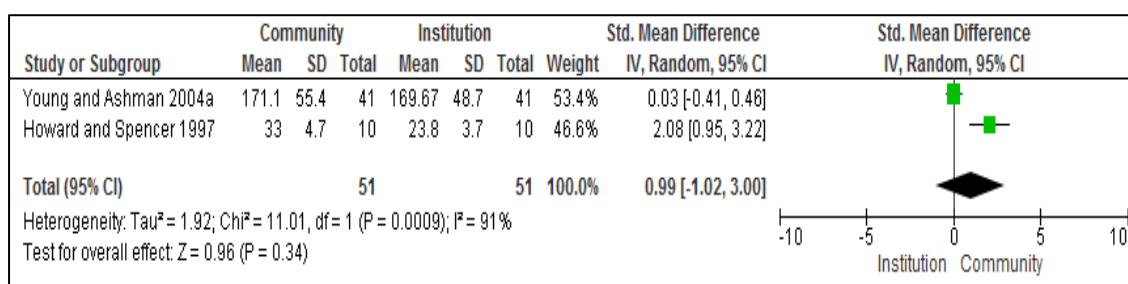


Figure 3 Post-move quality of life for people with mild to moderate intellectual disability only

Young and Ashman (2004b) is the only included study to provide data explicitly on a group of people with severe or profound intellectual disability.³⁶ These data are also stratified by age (20–39 years, 40–59 years, and 60 years and older), but, using the average mean and standard deviation scores across the three age groups, the results demonstrated significantly increased quality-of-life scores at 24 months post-move in this cohort (MD: 170.1; 95% CI: 158.4–181.8; $p < 0.0001$).

Golding *et al.* (2005), in a small study of six participants, assessed quality of life in a hospital group described as having mild or moderate intellectual disability and severe challenging behaviour (baseline data) prior to a move to community houses, and reassessed participants at three and nine

months post-move using the LEC.³¹ The authors do not provide pre- and post-move mean and standard deviation scores, thus we were unable to include this study in the meta-analysis. However, the study authors narratively describe significant improvements in overall LEC scores at both three and nine months post-move – with a 49% increase between baseline and three months and a further 24% increase between three months and nine months – and in all five LEC domain scores (home: 51% increase; leisure: 51%; freedom: 46%; opportunities: 48%; and relationships: 53%); all increases, other than leisure, were maintained at nine months post-move ($p < 0.05$). In addition to pre- and post-move measures in the six participants, Golding *et al.* also compared these participants' baseline data with scores from six individuals who had already been living in the community for 15 months. The results showed significantly higher quality-of-life scores in the community group (MD: 2.42; 95% CI: 0.78–4.05). While these results do not address the direct impact of a move *per se*, they are useful in highlighting the significant differences in quality of life between people with intellectual disability who are living in an institution compared with those who have been living in the community for some time.

In Ager *et al.* (2001), while minimal data are provided, the study authors do provide mean LEC change scores stratified by dependency level.²⁷ These change scores increase (representing improved quality of life) as levels of dependency increase – from 11.0 for low-dependency individuals to 13.5 for medium-dependency individuals to 17.0 for high-dependency individuals – although these increases were not statistically significant.

Quality of life stratified by level of intellectual disability and age

The study by Young and Ashman (2004b) was the only included study that stratified intellectual disability by age (20–39 years, 40–59 years, and 60 years and older) and by level of intellectual disability together (mild or moderate and severe or profound).³⁶ As precise numbers of participants in each age category are not provided, the results are narratively presented. In people with mild or moderate intellectual disability, quality-of-life scores improved following a move to the community at 24 months post-move in both the 20–39 and 40–59 age categories, but these changes were not statistically significant ($p > 0.05$). Conversely, mean quality-of-life scores decreased for those with mild or moderate intellectual disability in the 60 years and older age category (institution: mean=167.7, standard deviation=±50.1; community: mean=154.6, standard deviation=±59.5), but again, this difference was not significant. For people with severe or profound intellectual disability, quality-of-life scores improved across all age categories, and these results were all statistically significant ($p < 0.001$ for both the 20–39 and 40–59 age categories and $p < 0.01$ for the 60 years and older age category). Furthermore, when comparing levels of intellectual disability, there was a significant difference in quality-of-life scores between the groups ($p < 0.01$), with participants with severe or profound intellectual disability having lower total scores at both baseline and at follow-up than those with mild or moderate intellectual disability. Participants in all three age groups and at both levels of intellectual disability had increased scores in the following domains: material well-being, physical well-being, community access, routines, self-determination, social-emotional well-being, residential well-being, and general factors. The only exceptions were a lack of significant improvement in physical well-being for the youngest age group of participants with mild or moderate intellectual disability and for the oldest age group of participants with severe or profound intellectual disability.

Repeated measures

Some of the studies included in this main comparison measured quality of life as a repeated measure over a number of time points. Young and Ashman (2004a), for example, measured quality of life at 1, 6, 12, 18, and 24 months post-move in a sample of 104 individuals with mixed levels of intellectual disability (mild=15, moderate=26, and severe or profound=63) who moved from State centres to community-based dwellings.³⁵ While the data from the 12- and 24-month follow-ups were included in the meta-analysis (Figure 2), all of the follow-up measurements demonstrated a linear increasing trend for improved quality of life across all time points, with mean overall quality-of-life scores increasing. There were also significant linear and quadratic trends in quality-of-life scores over time

($p < 0.01$) which suggest an increase over time, but also indicate that quality-of-life scores were beginning to plateau at 24 months post-move.³⁶

3.2.1.2.3 Comparison 2: Quality of life experienced by people with any type of intellectual disability after moving from one type of institutional/congregated setting to a second type of institutional/congregated setting

In addition to evaluating quality of life following a move from an institutional to a community setting, two studies also evaluated quality of life following a move from one type of institutional setting to another type of institutional or congregated setting, although the new institutional settings were more integrated with a community.^{30 34} Due to considerable differences in the types of settings the participants moved to, we have not combined data in a meta-analysis; rather, we have reported them separately.

Cooper and Picton (2000) compared quality of life for a subgroup of 19 individuals who moved from a large State residential institution to refurbished units in a different institution at six months and again at three years post-move.³⁰ The results demonstrated a significant improvement in overall quality of life, as measured by the QOL-Q, both at six months and at three years following the move (Figure 4).

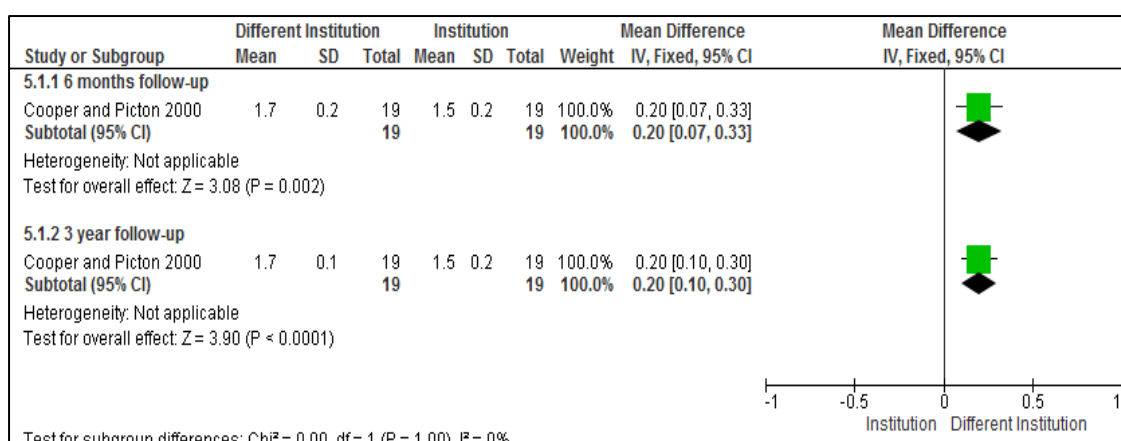


Figure 4 Quality of life following move from one institution to a different institution

Alternatively, Young (2006) compared quality of life for subgroups of 30 people with challenging behaviour who were moved from an institution to a cluster housing arrangement.³⁴ The results demonstrated that individuals who moved from institutions to cluster housing had significantly higher quality-of-life scores at 12 months (MD: 97.8; 95% CI: 68.16–127.44) and at 24 months (MD: 103.5; 95% CI: 75.77–131.23) post-move (Figure 5).

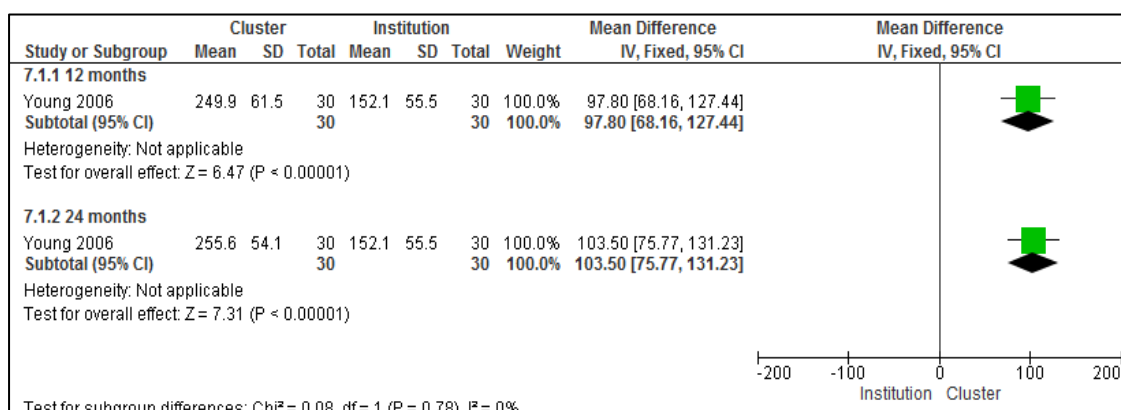


Figure 5 Quality of life following move from one institution to a cluster setting

When a direct comparison of the two alternative settings was made, the results demonstrated that individuals who moved from institutions to small group homes (which were pre-existing outer-suburban homes that housed two to three people) compared to cluster housing had significantly higher quality-of-life scores at 12 months (MD: 26.9; 95% CI: 1.27–52.53) and at 24 months (MD: 39.2; 95% CI: 14.31–64.09) post-move (Figure 6).

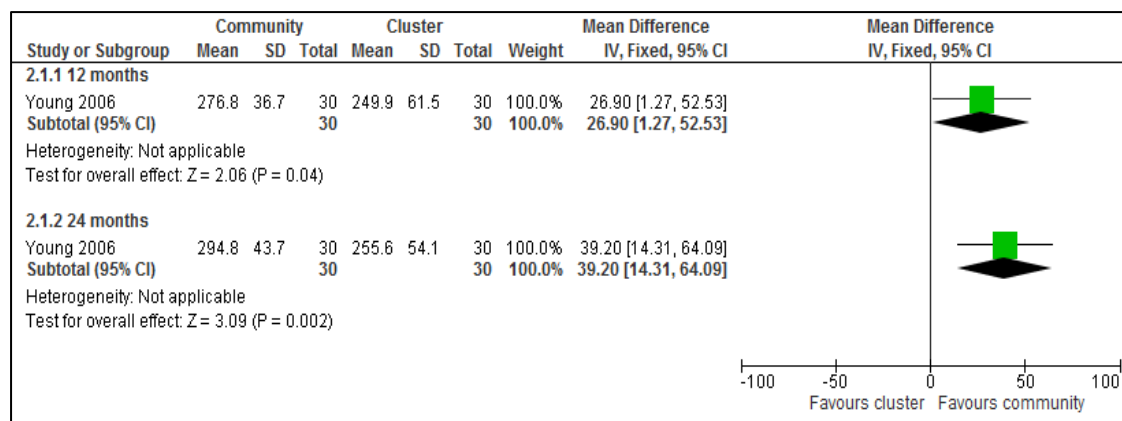


Figure 6 Quality of life in community versus cluster settings following a move from an institution

Quality of life following move to congregated settings: narrative results

As well as the significant improvement in overall quality-of-life scores in the study conducted by Young (2006), all quality of life subdomains improved significantly, with a linear trend from pre-move to both 12 and 24 months following a move to cluster housing (all $p < 0.001$): material well-being, physical well-being, community access, routines, self-determination, social-emotional well-being, residential well-being, and general factors.³⁴ When quality of life subdomain outcomes were compared between community and clustered settings over time, those who relocated to community living arrangements demonstrated significantly better improvements in physical well-being ($p < 0.005$), community access ($p = 0.001$), routines ($p < 0.01$), self-determination ($p < 0.01$), residential well-being ($p < 0.01$), and general factors ($p < 0.001$) than those who relocated to clustered settings. The groups did not differ on material well-being or social-emotional well-being.

Table 9 Evidence table: quantitative quality of life research

Author/year	Evidence
Ager <i>et al.</i> 2001 ²⁷	Significant post-move improvements (compared with pre-move baseline measures) in overall quality of life and on all five of the LEC subscales (all $p < 0.005$). In terms of LEC change scores stratified by dependency level, post-move changes were greater as dependency level increased, but not to a statistically significant extent.
Barber <i>et al.</i> 1994 ²⁸	No statistically significant change in quality of life one month post-move, as measured on four QOL-Q subscales (satisfaction, competence/productivity, empowerment/independence, and social belonging/integration). Overall quality of life was not investigated.
Bigby 2008 ²⁹	Slight, but not statistically significant, downward trend in the number of residents in contact with family members annually or more frequently from pre-move to five years post-move (85% [20 individuals] to 75%). Significant drop in the mean number of family members in contact with residents from one year post-move to five years post-move ($p < 0.05$). The mean informal network size increased from pre-move to one year post-move, but then decreased at three years post-move and again at five years post-move, although the overall decrease was not statistically significant ($p > 0.05$). Reasons cited by family members for changes in/lower levels of contact: changing circumstances (e.g. ill health or movement for retirement), limited availability of service staff to support family visits, lack of knowledge of a resident's daily life, frequent staff changes (the most frequently cited reason), being unknown by staff, and aggressive behaviour or lack of acknowledgement by the resident when contact was made. Often, telephone contact replaced physical visits. The author also cited a lack of specific goals or strategies relating to maintenance of contact in residents' individual programme plans, or a lack of implementation of these plans, as a reason for contact with family and friends not being maintained.
Cooper and Picton 2000 ³⁰	Significant improvement in quality of life (measured with the QOL-Q) at both six months and at three years following a move to the community. A subgroup of 19 individuals who moved from one institution to refurbished units in a different institution also showed significant improvement in overall quality of life at both six months and at three years following the move.
Golding <i>et al.</i> 2005 ³¹	A small sample of six participants with mild to moderate intellectual disability and severe challenging behaviour showed improvement in overall LEC scores at both three months and nine months post-move, with a 49% increase between baseline and three months and a further 24% increase between three months and nine months post-move. The participants also showed improvement in all five LEC domain scores (home, leisure, freedom, opportunities, and relationships), and all increases, other than leisure, were maintained at nine months post-move ($p < 0.05$).
Howard and Spencer 1997 ³²	There was an overall improvement in quality of life (LEC) for a small sample of 10 participants who moved to rural settings (as was their preference). Aside from relationships, all other domain areas (home, leisure, freedom, and opportunities) increased significantly at one year post-move compared to pre-move scores ($p < 0.01$ or $p < 0.001$).
O'Brien <i>et al.</i> 2001 ³³	Quantitative data was provided for a small subsample in this study (11 to 14 participants, depending on the subscale). At nine years post-move, the movers had better family ratings of quality of life compared to a nine-year retrospective estimation of quality of life in the institution across all of the included domains.
Young 2006 ³⁴	Individuals (with mostly moderate or severe or profound ID) who moved to either small group homes or cluster housing had significantly higher quality-of-life scores at both 12 and 24 months post-move compared to pre-move (in an institution). Those who moved to the community also had significantly better outcomes than those who moved to clustered settings at 12 months (MD: 26.9; 95% CI: 1.27–52.53) and at 24 months (MD 39.2; 95% CI 14.31 to 64.09) post-move. All quality of life subdomains (material well-being, physical well-being, community access, routines, self-determination, social-emotional well-being, residential well-being, and general factors) improved significantly, with a linear trend from pre-move to 12 and 24 months post-move for both groups (all $p < 0.001$). Those in community living arrangements demonstrated significantly better improvements in physical well-being ($p < 0.005$), community access ($p = 0.001$), routines ($p < 0.01$), self-determination ($p < 0.01$), residential well-being ($p < 0.01$), and general factors ($p < 0.001$) compared to those in clustered settings. The groups did not differ on material well-being or social-emotional well-being.
Young and Ashman (2004a, 2004b) ^{35 36}	Improved quality of life for people described as having generally higher support needs was reported at both 12 months and 24 months post-move. There was a significant linear increase in quality-of-life scores, but there was also a significant quadratic trend, suggesting a plateauing of quality-of-life scores at 24 months post-move. Overall quality of life experienced by people with mild or moderate intellectual disability did not significantly improve following a move to a community setting for 20–39-year-olds or 40–59-year-olds, and those aged 60 years and older showed a non-significant reduction. There was a significant increase in overall quality-of-life scores at 24 months post-move for those with severe or profound intellectual disability for all three age categories ($p < 0.01$ or $p < 0.001$). Participants with severe or profound intellectual disability had lower total quality-of-life scores both pre-move and at follow-up than

those with mild or moderate intellectual disability. Participants in all three age groups and both levels of intellectual disability had increased post-move scores in the following domains: material well-being, physical well-being, community access, routines, self-determination, social-emotional well-being, residential well-being, and general factors. The only exceptions were a lack of significant improvement in physical well-being for the youngest age group with mild or moderate intellectual disability and for the oldest age group with severe or profound intellectual disability.

3.2.1.2.4 Qualitative studies: quality of life

This section addresses key results from five studies which used a qualitative design.^{29 33 39-41} In reporting these findings, the key results are synthesised to cover the main themes which emerged in the majority of these studies. These themes included: i) positive changes experienced following the move to the community; ii) a sense of freedom and independence living in the community increased quality of life; iii) considering compatibility among housemates; iv) differing expectations of staff's role in supporting community living; v) social integration and family contact; and vi) ongoing challenges for individuals' quality of life.

O'Brien *et al.* (2001) report that staff recollections of their first encounters with individuals were coded as negative, mixed, or positive.³³ Negative recollections dominated 35 participants' accounts, and while there was a range of mixed recollections in 14 accounts, only a very small number of positive accounts (5) were reported. Negative recollections related to physical appearance, withdrawal, and aggressive behaviour. Perceived changes in the individuals following deinstitutionalisation were also coded into three categories: positive, mixed, and negative. In this case, two staff members did not have adequate prior knowledge of an individual, so only 52 participants' insights were reported. Thirty-nine staff and 16 family members perceived the changes in residents to be overwhelmingly positive. Key areas of positive change highlighted by both staff and families included: affect (referred to by 79% of staff and 68% of family members), self-help skills (79% of staff and 68% of family members), and social skills (72% of staff and 32% of family members). Prior to the move, the individuals were reportedly living in inappropriate accommodations.^{33 40 41} Positive outcomes for individuals' well-being following the move, in contrast to their previously more restricted – and sometimes harrowing – experiences, are exemplified in the following quotations:

She is happier since the move, more responsive and willing, now that she trusts other people. (O'Brien et al., 2001 p 75)³³

It is a hugely positive, yeah, he has totally changed in his character, in his, the whole, his whole wellbeing has totally changed. He is totally content now. (Kilroy et al., 2015 p 72)⁴⁰

We actually came down to have a look and I said my God this is like a palace ... Oh I loved it, yeah. (Sheerin et al., 2015: Tenant 6 p 271)⁴¹

(The community) feels alright. (In hospital I used) to scream, they hit me. Now I do the bath and basin, toilets and the floor and washing. I do the cups and that. (O'Brien et al., 2001 p 79)³³

3.2.1.2.5 A sense of freedom and independence living in the community increased quality of life

O'Brien *et al.*, Kilroy *et al.* and Sheerin *et al.* explored the experience of freedom and independence and its positive association with quality of life.^{33 40 41} In contrast to the experience of living in an institutional setting, the individuals' new living arrangement in the community was perceived as a more suitable environment, as it was more private, less noisy, and had more space – including a garden area^{40 41} – and wheelchair access.⁴⁰ The residents also had responsibility for household tasks, due to access to a kitchen and a garden, and all individuals had improved dietary choice and were

more involved in decisions relating to excursions.^{33 40} Independence reportedly seemed to improve for five individuals in Kilroy *et al.*'s study,⁴⁰ and they were more involved in decisions relating to excursions. Increased independence regarding money management gave participants the freedom to make every day, personal choices that positively impacted these participants' quality of life.⁴¹ This included the potential to take charge of their own daily meal preparation, which was identified as having a positive impact on their quality of life.⁴¹ Compared with their previous experiences living in more restricted residential environments, moving to the community was perceived as giving all participants in three studies a sense of freedom.^{33 40 41} Having the freedom to leave the premises independently increased individuals' well-being, as indicated in the following quotations:

My life is better, it's changed a lot because I have much more freedom...I can get away from others but at the hospital I couldn't get away ... Here I can go out with the staff and I behave myself. (O'Brien et al., 2001 p 79)³³

He couldn't go outside unless he was accompanied. Here, although he needs to be accompanied going out the front door, there is so much space in the back – once the gates are closed he can go on his own. You could see the joy on his face the first day he walked out on his own and he realised that nobody was following him. It was superb. (Kilroy et al., 2015 p 74)⁴⁰

A move to the community was also associated with increased personal space and privacy, resulting in improved quality of life, as demonstrated in the following quotations:

There is more space to move around in. Life has changed. (O'Brien et al., 2001 p79)³³

It's big, my room is big...much more room. Yeah, my room was small...terrible in [institutional service setting]. (Sheerin et al., 2015: Tenant 1 p 272)⁴¹

You have your own space, and then you have your own bedroom, and no one comes into your room without your permission. (Sheerin et al., 2015: Tenant 2 p 272)⁴¹

3.2.1.2.6 Considering compatibility among housemates increased quality of life

More careful consideration of the impact of individuals' compatibility with housemates when placing individuals in community houses is reported as positively impacting individuals' quality of life.^{33 40} Kilroy *et al.* report that six individuals were perceived to have been affected by housemates creating noise disturbances or engaging in self-injurious behaviour.⁴⁰ These behaviours were noted to be significantly more frequent when the self-injuring individuals were living on campus and they resulted in distress, with other individuals having to be relocated within or outside the house regularly due to their limited space. As a result of considering individuals' compatibility with other housemates before they relocated and compared with their experience of living in the residential campus setting, less frequent noise disturbances and self-injurious behaviour were reported in community houses.

For example, in a residential campus setting, one individual experienced such distress from a fellow resident's behaviour that it inhibited his capacity to go on group outings;⁴⁰ for other individuals, exposure to bullying behaviour caused stress that was alleviated by their move to a community setting:³³

Once...what we used to have to do was, when he was screaming, we used to have to bring X out of the house, to another house to settle him because he got so traumatised by it. He actually used to go really pale and he'd start sweating and he just wasn't able to cope with the noise, so we used to have to leave the house without him. (Kilroy et al., 2015 p 72)⁴⁰

I am happy with my life...I've got lovely friends. Why I am really happy is that nobody is picking on me or nasty to me. My life has really changed -because I am much more happier and not so stressed out ... I go out more on my own and I'm more independent. (O'Brien et al., 2001 p 80)³³

I am more independent...I had less independence when I was in [institutional service setting], now I have more independence to myself...I do my own shopping...I wasn't allowed to go and do my own shopping...people would have to go with you. (Sheerin et al., 2015: Tenant 5 p 273)⁴¹

3.2.1.2.7 Differing expectations of staff's role in supporting community living

Staff's support role was mostly perceived as contributing to individuals' quality of life.^{40 41} Permanent staff familiar with individuals' interests and choices were found to improve individuals' participation in the community and alleviate some individuals' stress related to staff turnover.^{40 41} However, other participants had higher expectations of staff support and involvement,⁴¹ which subsequently negatively impacted the individuals' perceived quality of life, as demonstrated in the following quotations:

I suppose that there's probably the same regular staff as well always here now, whereas in the centre it may have changed ... so I think that has made a huge improvement too, that he knows exactly ... who's with him and the fact that the staff know him very well, and they know what he will and won't do, so I think that's kind of, he kind of trusts people I think. (Kilroy et al. 2015 p 73)⁴⁰

I think that the staff up there are A1, and then that they'll do anything for you...but...they might not come near you all night and check on you to see if you're, you're okay. One time I was out of work ... sick ... and then I saw the staff in the morning but in the afternoon no one came near me. I, I didn't see anyone till about seven, seven or eight o'clock at night ... but they stay upstairs in their own bedroom and then they have their own office up there ... (Sheerin et al., 2015: Tenant 2 p 276)⁴¹

3.2.1.2.8 Social integration and family contact

Interpreting the social integration outcomes for individuals following a move into the community was a common theme in the five qualitative studies.^{29 33 39-41} Di Terlizzi's study presents the life history of a woman with intellectual disabilities and severe challenging behaviour who, after 30 years in UK institutions, experienced an increase in quality of life following her eventual move to a small staffed house in the community.³⁹ In particular, access to individualised day programmes demonstrated perceived positive changes in social integration outcomes and her quality of life. Increased contact with her family due to the community home's significantly closer proximity to her family ultimately meant that she could attend family events, get to know her siblings after years of separation, and, most significantly, visit her family more regularly. This increased integration into her family's life had a perceived positive impact on her quality of life, as noted especially by her mother.

Social contact in the form of increased family integration was also associated with improved quality of life in Sheerin *et al.*'s study, as highlighted in the following quotations:⁴¹

They ... are involved more now that I'm up [here]. (Sheerin et al., (2015) Tenant 5 p 277)⁴¹

I wouldn't have visited her too much in [institutional living setting] ... I picked up going back up to visit her on a fairly regular basis. (Sheerin et al., (2015) Relative of Tenant 4 p 277)⁴¹

Bigby's mixed methods study specifically focused on the significance of the role of informal social networks on quality of life for a random sample of 24 participants from a group of 55 residents who moved to small group homes in a community in Melbourne, Australia.²⁹ In-depth qualitative case studies were conducted with a purposive subsample of 11 residents: twice while living in the institution, then at 4-month intervals for the first 12 months after the move, and then after 3 years living in the community. An observation checklist – including details such as the resident's personal appearance, use of space, social interactions with staff and other residents, community participation/integration, personal autonomy/decision-making, and social networks – guided visits and field note taking. The size of each resident's informal social network was calculated based on the number of people with whom they had at least annual contact, who lived outside the residence, and who did not know the resident in a paid capacity. Four types of informal networks for residents were identified: i) non-existent (for 4 participants); ii) special occasion family (6); iii) engaged family (9); and iv) friendship-based (5). An example of improved engaged family contact is an increased number of phone calls and visits from family after moving to the community compared with when the individual was living in an institution. Bigby notes that while one of the community house staff's key responsibilities is to support residents in maintaining contact with family and friends following relocation, this was not substantiated in residents' individual plans. For example, only four residents' plans included strategies or goals related to maintaining family and friendship contacts. In one case, the lack of implementation led to one resident losing contact with a sibling.²⁹ In Sheerin *et al.*'s (2015) study, relatives' perspectives on the degree of social integration varied, with some experiences being more positive than others. A positive experience is exemplified by the following quotation:⁴¹

Yeah, the neighbours seemed to have welcomed them, I was talking to a couple of them. They said really that they know the girls and that they are quite integrated in the area. They made them feel welcome. (Sheerin et al., 2015: Relative of Tenant 4 p 276)⁴¹

In Kilroy *et al.*'s study, it was perceived that all eight participants were accessing more services within the community and also "getting out into the community" (p 73) more as a result of the move.⁴⁰ However, they were not necessarily more integrated with people in the community, and instead showed a preference for being with people with whom they were more familiar (i.e. those from the community house). It was generally reported that most local service providers were very welcoming towards the residents and, as a result of this, two individuals became more sociable in public. Similarly, Sheerin *et al.* (2015) report that through involvement in community-based activities, some tenants indicated that they had begun the process of social integration:⁴¹

Yeah I do more things... Going to the library...getting to know the people up here in [my new residence]. Sometimes I say hello to them and ... They can be friendly yeah, but again if I say hello, certain people might say 'hello' and ask you 'how are you', you know but other people I think just ignore you. (Sheerin et al., 2015: Tenant 5 p 276)⁴¹

However, most of the tenants in Sheerin *et al.*'s (2015) study indicated that they did not feel integrated into the local community and stated that they did not know anyone there,⁴¹ as shown in the following quotations:

No they [the neighbours] said they would come down but sure, that's up to them like, I can't ask them, you know. (Tenant 6 p 276)⁴¹

Oh I'd say they're not integrated at all...I wouldn't say they are ... I wouldn't say they know any of those people in those apartments around them. (Relative of Tenant 1 p 276)⁴¹

3.2.1.2.9 Ongoing challenges for individuals' quality of life

In general, all five qualitative studies reported positive outcomes for individuals with intellectual disability moving into the community, but ongoing challenges to individuals' quality of life were also reported. Adjustment to the move could reportedly take months, depending on the specific circumstances of the transition. Ongoing difficulties included the day programmes being described as too cramped, with poor consideration of the individuals' needs, particularly in relation to challenging behaviours; unavailability of speech and language therapy or communication aids suitable for some individuals, which remained problematic; amenities not being as convenient due to the rural location of the home; lack of family contact still not being addressed; and lack of adequate funding, meaning reduced night-time staffing and no overnight trips.⁴⁰ Some participants also experienced a loss of security following the move; this was related to changes in staffing routines leading to loneliness and insecurity, as reported in the following quotations⁴¹:

*I'm afraid I might fall and there's nobody there and I might get a pain in my heart. (Sheerin *et al.*, 2015: Tenant 6 p 275)⁴¹*

*It's just that when I get lonely like when the staff go off...I kind of felt a bit lonely today because I was sitting ... it can be fairly lonely here ... you can't blame the staff with the cut backs, you can't blame them, I don't blame them at all ... (Sheerin *et al.*, 2015: Tenant 6 p 275)⁴¹*

Kilroy *et al.* (2015) report that, although individuals living in the community were getting breast checks annually, staff members had not received training to facilitate the female residents' capacity to regularly self-check.⁴⁰ Ethical concerns were also raised as to how the decision-making process gave rise to some individuals with intellectual disability having the opportunity to move, whereas others were not given such an opportunity.⁴⁰

From the studies that provided qualitative data, two studies included participants with challenging behaviour: Di Terlizzi,(1994)³⁹ which followed one participant, and Kilroy *et al.*,(2015)⁴⁰ in which seven out of the eight participants had comorbidities which were related to challenging behaviour. These studies highlighted the need for specific tailored supports for these individuals – in particular, in Kilroy *et al.*'s 2015 study, participants (and proxies for participants) criticised the lack of consideration and planning for individuals with challenging behaviour; for example, placing large numbers of individuals into a single day care programme, leading to heightened levels of distress, and lack of access to specific supports to meet these individuals' needs, such as speech and language therapy.⁴⁰ It is also noteworthy that in this study, interviews were conducted with proxy participants who were very familiar with individuals who had lived in a residence for between 6 and 30 years prior to the move. Moreover, although five of the individuals with intellectual disability were in an earlier phase of

transition (they had lived in the new setting for less than one year when the interview was carried out), three of the individuals with intellectual disability had been living there for four years. Therefore, there is an indication that some of these criticisms regarding neglect of the individuals' challenging behaviour had persisted past the initial adjustment phase to cause considerable impacts on their quality of life in the community.

In the other Irish qualitative study, participants had mild or moderate challenging behaviour and there was no discussion about the implications of moving other individuals with severe and/or challenging behaviour to a community setting.⁴¹

In the qualitative aspect of O'Brien *et al.*'s study, nine participants with medium or low support needs (the majority had low support needs) participated in the interviews.³³ Community staff considered all nine people capable of holding a conversation. Length of stay within the hospital had ranged from 9 to 31 years, with a mean length of stay of 17 years. Seven participants lived in group homes and two lived in apartments. Two people attended centre-based day programmes, four worked in sheltered workshops, and three were in supported work groups. Two of the participants also held part-time jobs in the community. There was no discussion of individuals with severe intellectual disability and/or challenging behaviour included in the qualitative analysis.

3.2.1.2.10 Summary and conclusion on qualitative research

In the wider literature, there is debate regarding whether or not those who reside in the community are truly integrated into their community in line with the ethos of 'inclusion'. Five studies in our review provide qualitative insights into the lived experiences of individuals' moves into the community. Individuals with intellectual disability and proxy participants' perspectives on the move conveyed an overall positive impact on individuals' quality of life: improved well-being, freedom, and independent decision-making; more careful consideration of housemate compatibility; increased family contact; and social integration opportunities. Studies specifically examining quality of life have also found freedom and self-determination to be meaningful aspects of community living for individuals.

Following a move into the community, people's expectations of available staff support differed, which could lead to negative quality of life outcomes. In particular, changing staff roles and the move to an unfamiliar setting could contribute to a sense of insecurity and fear of having an accident in isolation. Furthermore, differing expectations could contribute to both poor participation in the new community and limited support of participants returning to the institution in order to maintain friendships with people who still reside there. Consequently, there is a risk of increased loneliness for deinstitutionalised individuals. An ongoing challenge to individuals' quality of life that was reported was ensuring that family contact was maintained.

3.2.2 Cost-effects

3.2.2.1 Description of included cost studies

Two studies evaluated the impact on costs for people with intellectual disability who experienced a change in residential setting. Each study follows a single cohort of people moving from long-stay hospitals in the UK NHS, to a variety of settings detailed in Table 10. Beecham *et al.* examined costs at 12 months for adults moving from intellectual disability institution and psychiatric hospitals to each type of settings in Northern Ireland between 1990 and 1992;³⁷ Hallam *et al.* longitudinally examined costs after 1, 5, and 12 years for adults moving from 12 different sites in England between 1984 and 1987.³⁸

Both studies constitute parts of larger studies published in book form: Donnelly *et al.* (1994)⁴⁸ is the companion to Beecham *et al.*, and Knapp *et al.* (1992)⁴⁹ and Cambridge *et al.* (1994)⁵⁰ present the main study for Hallam *et al.* A review of these papers and books revealed limited information on the characteristics of the samples studied in the cost papers. Beecham *et al.* do not report any sample characteristics, although cost analyses are performed on a subset of the overall study's analytic sample of 497 individuals, and the indicative age, intelligence quotient (IQ) level, and time in hospital pre-move are provided for this larger group. Hallam *et al.* report participants' age and time in hospital pre-move, but no baseline information on level of disability or disease burden.³⁸

An additional shared limitation was the use of the term 'community care'. In the Beecham *et al.* study, only one person (total sample=192; 0.5%) is reported as moving to an independent living arrangement.³⁷ Of the other settings examined, Beecham and colleagues differentiate the categories according to provider (statutory, voluntary, or private) but not according to setting characteristics, such as specifying how many people lived in a single unit. A large majority of study participants (141; 73%) moved from hospital to residential and nursing homes by private bodies. It is therefore possible that a significant number of people ended up in community living as now understood in Irish healthcare policy, with four or fewer people per unit, but it is not reported as such. In the Hallam *et al.* study, settings are delineated more clearly by characteristics, but independent living is again highly unusual, with two residents (2%) in independent living settings after one year, four (4%) after five years, and none after 12 years.³⁸ At each post-move time point, approximately half of the participants were living in established homes via foster care or sheltered housing, or in group homes with two to five residents per unit; 30–40% of participants were living in either nursing homes or in hospices with six or more residents.³⁸

Based on the information provided in the Beecham *et al.* study, only the one person living independently can be said for certain to have moved to a community living setting by the definitions of either the Irish Department of Health or the wider academic literature in 2018.³⁷ In the Hallam *et al.* study, more than half of the participants moved to an established home or small group home, while most others moved to larger institutional settings such as nursing homes and hospices.³⁸

Table 10 Summary characteristics of included studies on costs

Author and year	Location (country); dates of study	Aim	Study design	Description of study sample	Description of congregated setting	Description of community setting
Beecham <i>et al.</i> 1997 ³⁷	Northern Ireland; 1990–1993	To evaluate the effect on costs of discharging people with ID from long-stay hospitals to community care settings.	One cohort was assessed prior to leaving hospital and again 12 months after doing so.	Adults with intellectual disability. Of 214 adults moving during the study period, 22 could not be located for follow up interview or withdrew from the study at follow up interview, leaving a sample of 192. Male=57% [§] Median age=47 years [§] Median hospital stay prior to move=20 years [§] Severe/profound intellectual disability (IQ <20)=7%, moderate intellectual disability (IQ 20–49)=52%, mild intellectual disability (IQ 50–69)=33%... [§]	Intellectual disability institutions=3 Psychiatric hospitals=4	Residential facilities provided by statutory bodies=30 Residential facilities provided by voluntary bodies=20 Residential and nursing homes provided by private bodies=141 Independent living arrangements=1
Hallam <i>et al.</i> 2006 ³⁸	England; 1984–1999	To evaluate community care for people moving from intellectual disability institution.	One cohort was assessed prior to leaving hospital and at 1, 5, and 12 years post-move.	Adults moving from intellectual disability institutions, Of 397 recruited in the institution, 103 have cost data from all three time points. Male=47% Mean age at move=44 years Mean length of hospital stay pre-	Long-stay institutions across different regions=12	Residential/nursing home or hospice=45 [#] Group home=42 [#] Adult foster care or sheltered housing=15 [#] Hospital=1 Independent living=0

Author and year	Location (country); dates of study	Aim	Study design	Description of study sample	Description of congregated setting	Description of community setting
				move=27 years		

[§] Data presented for 497 people moving between 1987 and 1992; analytic cost sample of 192 is a subset of these for whom no specific data on characteristics are provided.

[#] All sample sizes for 12-year time point, some small divergence from these at one and five years. Categories grouped for this review according to number of residents: residential/nursing homes or hospices had six or more residents; group homes had two to five residents; adult foster care and sheltered housing do not specify number of residents living in each of the two types of accommodation in this group.

3.2.2.2 Key results

Both studies examined the same cost perspective: formal costs to the payer of a broad basket of hospital, community, and accommodation services associated with each specific individual.^{37,38} This therefore implies that both studies have the same limitations, particularly an absence of reporting on informal care costs and out-of-pocket costs that may arise when people leave institutions for settings where on-site care is less comprehensive. While both overall studies – to which the cost papers were attached – did examine client outcomes, no cost-consequence analysis or ratio is reported in either study.

Mean costs for hospital and community care for each study are presented Table 11. In the Beecham *et al.* study, mean costs are reported as being lower for community settings than for hospital settings, but this difference is not tested significantly (and it is not possible to conduct testing as part of this review using the reported data³⁷). Differences between the hospital and the various types of post-move residences (as a group) are large and found to be statistically significant, but comparisons of specific types of residences with the pre-move hospital or institution are not reported. 'Community' settings are characterised by the sector of the provider but not by any other descriptive data, making it impossible to infer the characteristics of services that offer cost savings compared to hospital or institution, beyond the fact that public facilities are more expensive and voluntary and private facilities are cheaper (Table 10). These differences may reflect different levels of need among individuals with intellectual disability and/or different characteristics between providers (e.g. number of residents, environment), or they may reflect true differences in the effect that provider type has on the cost of residential care for this population of individuals with intellectual disability.

In the Hallam *et al.* study, mean costs are reported as higher for community care than for hospital care at 12 years, and this difference is a statistically significant difference.³⁸ This conclusion is consistent with analyses at one and five years. In the comparison between hospital and community care costs, all community care costs were pooled, meaning that no cost comparison of an established home or small group home versus a hospital was reported and it is not possible to conduct testing as part of this review using the reported data (established home or small group home costs cannot be separated from nursing home and hospice costs). Secondary analysis shows that accommodation accounts for 81–86% of post-move community care costs.

Lack of detail about the type of community care that participants moved to, as well as limitations in reporting of cost data and their characteristics, precludes meta-analysis of these studies.

Table 11 Key results from included studies on costs (in pounds sterling)

Author and year	Mean (standard deviation) weekly costs in pounds sterling (GBP)*, by residential location						Evidence
Beecham <i>et al.</i> 1997 ^{37#}	Pre-move Mean costs: community setting (long stay hospital)	Post-move community settings Mean costs: community setting (long stay hospital)					Mean costs are lower in community settings than in long-stay hospitals, although considerable variation is observable between different community settings. Secondary analysis finds that post-move costs are associated with both client and residence characteristics.
	Hospital (n=192)	Public (n=30)	Voluntary (n=20)	Private (n=141)	Ind. living (n1)	All (n=192)	
	574 (-)	517 (165)	351 (72)	323 (45)	133	356 (106)	
Hallam <i>et al.</i> 2006 ^{38§}	Pre-move (n=103) Mean costs: community setting (long stay hospital)	Post-move, all community settings (n=103) Mean costs: community setting (long stay hospital)				Mean costs are higher in community settings than in long-stay hospitals at 1, 5, and 12 years post-move, and cost differences are statistically significant in each case. No presentation or analysis of post-move costs by type of residence is provided. Secondary analysis shows that accommodation accounts for 81–86% of post-move community care costs.	
	Hospital	1 year	5 years	12 years			
	736 (136)	899 (260)	871 (301)	765 (324)			

* Both studies assessed formal costs per client (payer perspective) for hospital, community, and accommodation services.

Costs in GBP, 1994–1995 levels.

§ Costs in GBP, 2002–2003 levels.

3.2.3 Subpopulations with special support needs

Few studies addressed the quality of life outcomes of subpopulations with special support needs. All of the studies that did have been included in the general overview of results provided in the Section 3.2.1; however, a narrative summary of the findings of these studies is provided here. Young and Ashman considered a sample that they described as having high support needs,^{35 36} while Ager *et al.* (2001) analysed quality of life outcomes according to level of dependency.²⁷ Additionally, O'Brien *et al.*'s (2001) whole sample included a large number of people with higher support needs/dependency – although, with respect to this, the composition of the subsample for which family ratings of quality of life changes were provided is unclear.³³ Both Golding *et al.* (2005)³¹ and Young (2006)³⁴ investigated outcomes for people with challenging behaviour.

3.2.3.1 High support needs

Young and Ashman (2004a, 2004b) considered the sample in their study to require high levels of support. There were significant linear ($F(1, 92)=166.42, p<0.001$) and quadratic ($F(1, 92)=28.07, p<0.001$) trends in quality-of-life scores, which suggested that quality of life was increasing over time but that it was beginning to plateau by two years post-move.^{35 36} A similar pattern indicated that quality of life improved significantly for all of the quality of life subdomains: material well-being, physical well-being, community access, routines, self-determination, social-emotional well-being, residential well-being, and general factors. The authors examined whether participants in three age groups (20–39 years, 40–59 years, and 60 years and older) and in either one of two ID level groupings (mild or moderate and severe or profound) differed in quality of life outcomes over two years, from baseline to 24 months post-move. There was a significant difference in quality-of-life scores according to level of ID, with participants with severe or profound ID having lower total scores over time ($F(1, 87)=4.38, p<0.01$; monotonic linear trend $F(1, 87)=13.25, p<0.001$). However, participants in all three age groups and at both levels of ID showed increased scores over time in all eight quality-of-life subdomains: The only exceptions were a lack of statistically significant improvement in physical well-being for the youngest age group with mild or moderate ID and for the oldest age group with severe or profound ID.

A study in the UK researched 76 of the 95 consecutive movers aged 21 to 92 years (mean age=53 years) following a hospital closure.²⁷ Participants' quality of life was measured using the LEC both pre-move and between six and nine months post-move. Participants had a range of dependency levels, assessed with the Wessex Mental Handicap Register. No data were provided on participants' health status *per se*. LEC scores increased significantly from pre-move (mean=17.7, standard deviation=7.2) to post-move (mean=30.1, standard deviation=6.4, $t=15.1, p<0.005$). Improvements were also evident for all five subsections of the LEC (home, freedom, opportunities, relationships, and leisure) following the move to community accommodation (all $p<0.005$). There was no statistically significant association between LEC scores and level of dependency (Kruskal–Wallis $\chi^2=5.24, p>0.05$).

O'Brien *et al.* (2001) presented family ratings of changes in quality of life nine years after a move from an institutional setting to the community, describing 41 participants as having high support needs, 3 as having medium support needs, and 10 as having low support needs.³³ Despite having a sample of 54 participants with intellectual disability, and having ratings provided by 21 family members and one advocate, data for a range of quality of life subdomains were only presented for 11 to 14 participants per subdomain. These discrepancies were not explained by the study authors. Using paired sample *t*-tests with one-tailed tests of significance, O'Brien *et al.* found that ratings for each aspect of quality of life – material possessions, health, productivity, intimacy, safety, place in community, and well-being – were significantly better at the nine-year follow-up than at baseline. As O'Brien *et al.* did not report on which participants from the full sample of 54 these data were available for, it is not possible to determine whether or how these data might apply to people with high support needs. Indeed, it is conceivable that all of the data for some of the scales might relate only to people with low or medium support needs.

Kilroy *et al.*'s study included eight people (mean age=37.4 years, range=26–44 years; male=6,

female=2) with severe intellectual disability who had moved from a residential campus to the community over the previous four years.⁴⁰ Interviews were conducted with eight key workers with this group, who served as proxy participants. Of the eight people with intellectual disability about whom proxy participants were interviewed, six were non-verbal and all eight had limited capacity to communicate their experiences. Only one participant did not have any comorbid diagnoses; the comorbid diagnoses for the other seven participants included autism (n=1); autism and bipolar affective disorder (n=1); bipolar affective disorder (n=2); bipolar affective disorder and epilepsy (n=1); epilepsy (n=1); and Down syndrome (n=1). All eight participants reported perceiving the move to the community as having positive impacts generally, described in contrast with 'old' life and 'new' life. Following the move to the community, emotional well-being, privacy, health, and material well-being were all perceived to have improved for individuals. Specifically related to the experience of challenging behaviour, the authors criticise the day programme: "interpersonal dynamics in the day programmes had not been properly considered and that challenging behaviour sometimes resulted from this poor fit" (p 74).⁴⁰ It was also noted that, for this group with communication difficulties, there was poor consideration of these needs – for example, the lack of access to speech and language therapy or communication aids suitable for some individuals was an ongoing issue.

3.2.3.2 Challenging behaviour

One study from Australia undertook a longitudinal study of 60 participants with intellectual disability and challenging behaviour.³⁴ Participants ranged in age from 27 to 81 years, with 38 males and 22 females, and with levels of ID described as mostly 'moderate' or 'severe or profound'. Two groups of 30 were matched afterwards based on a range of demographic, health, impairment, and adaptive behaviour variables. After initial baseline assessment, one group remained in the institution for an extended period, then moved to interim community housing, and finally to cluster centres with accommodation modified as required. The second group moved to pre-existing outer-suburban houses that accommodated two to three residents each within six months of the baseline assessment. These houses were generally unmodified except where access was required for a wheelchair. The cluster group had 6–10 hours of community recreation available per week, while the community group had 10–15 hours of community recreation per week. A post-move assessment was undertaken when each participant had been living in the community for 12 months, and again at 24 months. Analyses of variances, both between and within groups, showed that for both groups there was a significant ($p < 0.001$) improvement in total and in all LCQ domain scores at the 24-month follow-up compared to baseline scores in the institution. Analysis of the 12-month follow-up was not reported. Compared to the group that moved to clustered accommodation, the community group had significantly better quality of life in the following areas: total, physical well-being, community access, routines, self-determination, residential well-being, and general factors. The groups did not differ in material well-being or in social-emotional well-being.

Another study from the UK undertook research with a small sample of six males with ID and challenging behaviour.³¹ The authors examined changes in LEC total scores and in domain-specific scores from three months pre-move (T1) to three months (T2) and nine months (T3) post-move. The post-move community living arrangement consisted of two separate houses managed by a specialist challenging behaviour residential service with an on-duty staffing ratio of four staff per six residents. Mean total LEC scores were 24.3 (standard deviation=3.1) at three months pre-move (T1). Statistically significant ($p < 0.05$) increases in total LEC scores were recorded between T1 and T2 (demonstrating a 49% increase) and were maintained at T3. Four of the five LEC domain-specific scores also increased significantly ($p < 0.05$) between T1 and T2 and were maintained at T3 ($p < 0.05$): home (51% increase), freedom (46% increase), opportunities (48% increase), and relationships (53% increase). The leisure domain showed a significant increase only from T1 to T2 (51%) and this increase was not maintained at T3.

Di Terlizzi's (1994) study presented an in-depth case study of the life of one woman with severe intellectual disability and challenging behaviour who had experienced several residential settings before her eventual move to a community setting in closer proximity to her family.³⁹ This individual

had no verbal abilities nor any other means of communication. Evidence indicates that she showed significant progress only when trained staff supported her to experience a range of opportunities and to access meaningful daily activities and social interaction, in particular with her family.

3.2.3.3 Summary and conclusion

Overall, the results indicate that people with intellectual disability and high support needs benefit from quality of life improvements related to deinstitutionalisation. Nevertheless, there is evidence that this group may not benefit to the same degree as those with less complex needs. There may be a lack of improvement in physical well-being following relocation to the community for older people with severe or profound intellectual disability, although this may reflect lower capacity among older people to improve physically due to ageing rather than due to any issue specific to intellectual disability or place of residence. For people with challenging behaviour, there is evidence of improved quality of life following a move to the community. There is also evidence of improved quality of life following a move to a clustered setting, but the included studies indicate that community living arrangements generally afford greater improvement in overall quality of life and across most domains, except for material well-being and social-emotional well-being. No studies included in this review explicitly examined any of the following subpopulations of interest: people with very complex medical needs (e.g. ventilation requirement), people with dementia, or people who present a forensic risk or who are ex-prisoners.

4 Discussion

4.1 Main findings

4.1.1 Quality of life literature

4.1.1.1 Quantitative quality of life outcomes

A range of positive changes for individuals' quality of life are reported following a move to the community. These changes are evident both in overall quality of life and across a wide range of quality-of-life domains. Meta-analyses showed statistically significant improvements in overall quality of life across all comparisons for community living arrangements post-relocation. This held for shorter- (one year or less) and longer-term (more than one year) outcomes, with an increased difference (albeit slight) between overall pre-move quality of life and longer-term quality of life than shorter-term quality of life. The included studies have limitations, but the authors of this review employed quality appraisal to limit the risk of associated biases.

Prior to moving, participating individuals were reportedly living in inappropriate accommodation.^{33 40}⁴¹ In general, a move into the community offered an improved living environment with more space and privacy where a sense of freedom and independence could be fostered.^{33 40 41} Self-help skills and social skills reportedly improved in the new environment.³³ Factoring in compatibility with housemates when planning an individual's move to the community resulted in fewer occurrences of noise disturbances and self-injurious behaviour, which in turn positively impacted on individuals' quality of life.^{33 40} Social contact in the form of increased family integration was also associated with improved quality of life in some studies, where increased access and engagement with family was facilitated due to the move into the community.^{29 39 41} It is unclear whether this outcome was due to residents' closer proximity to their families, to the family perceiving the group home as a more welcoming environment to visit, or to other factors. These are all issues for further research.

4.1.1.2 Ongoing quality of life challenges

While overall positive quality of life changes due to better family contact were reported in some studies, evidence of a decrease in family contact and network size was also recorded. Bigby (2008) noted that residents' individual programme plans did not reflect a consideration of support for maintaining family contact following the participants' move to the community.²⁹

Becoming part of the community is considered to be one of the main advantages associated with living in the community.^{4 29} Some studies discussed social integration as an outcome of better quality of life; however, these studies reported mixed findings in terms of the impact of moving on individuals' social integration into the wider community, indicating that progress on authentic community participation still eluded many individuals.^{40 41} Some individuals were reportedly feeling lonelier since their move due to differing expectations of staff support roles causing a loss of security,^{40 41} and most of the seven participants in Sheerin *et al.*'s⁴⁰ study indicated that they did not feel integrated into the local community, as they stated that they did not know anyone. Lack of adequate funding also meant reduced night staffing and no overnight trips.

In one of the only quantitative analyses of factors aside from relocation which might influence quality of life outcomes, there was a lack of significant improvement in physical well-being following a move for the youngest age group with mild or moderate intellectual disability and for the oldest age group with severe or profound intellectual disability and challenging behaviour.³⁶ This may have reflected lower health needs in general for the youngest age group and more intractable health challenges for the older age group with severe or profound intellectual disability and challenging behaviour.

Taken together, these findings suggest the need for caution in statements made about improvements (i.e. relative change) in quality of life. There is a need to establish whether the quantified change in quality of life represents a real and qualitative change in the life of the individual.

4.1.1.3 Comparison of post-relocation settings

The included literature allowed for a limited comparison of post-relocation destinations. Results from one study suggest that both community and clustered accommodations offer advantages over institutions in both overall objective quality of life and in all of its domains.³⁴ However, community housing afforded more favourable quality of life than clustered (i.e. congregated) settings, both overall and across a range of domains: community access, routines, self-determination, residential well-being, and general factors. While neither material well-being nor social-emotional well-being as quality of life subdomain outcomes differed between settings, non-significant differences in terms of social contact (represented by the construct of social-emotional well-being) contradicted the idea that clustered accommodation affords increased social connectedness.³⁴

With a measure incorporating subjective ratings of quality of life using the Quality of Life Questionnaire (QOL-Q), Cooper and Picton (2000) reported improvements for both those who moved to the community and for those who moved to refurbished institutions, with no difference between these two groups at up to three years post-move.³⁰ It is understandable that a move to a refurbished institution might result in an improvement in quality of life outcomes by virtue of a presumably more homely environment; however, this must be interpreted in the context of near-universal findings of quality-of-life outcome improvements upon moving to the community, and demonstration elsewhere of more favourable outcomes for matched samples moving to the community versus moving to clustered settings.³⁴ These results accord with cross-sectional research by Emerson *et al.* (1996) showing better outcomes in dispersed community housing compared with residential campuses (which are often equivalent to refurbished institutions).²³

The data here are influenced by approaches to moving and choices among settings that would not necessarily meet criteria for community living in 2018. Nevertheless, they raise a critical question about the underlying drivers of observed improvements: To what extent are these short-term increases reflecting the novelty of having moved as opposed to representing contributors to meaningful long-term improvements in people's quality of life?

4.1.1.4 Quality of life and groups with specific needs

While the studies included in this review addressed some issues, such as challenging behaviour and higher support needs, there were limitations in the literature in terms of how groups with specific needs were addressed and the depth in which issues were investigated. There was an overall scarcity of consideration of those with high support needs in the included literature.

Individuals with challenging behaviour were highlighted as a group that may not have been given the opportunity to move, giving rise to ethical concerns about the way the decision-making process was executed.⁴⁰

No study in this review included people with intellectual disability who either had dementia or who may have been in the early stages of dementia. There is an elevated dementia incidence in people with intellectual disability, which is generally associated with extended life expectancy for people with disabilities.^{51,52} No study included in this review considered the quality of life outcomes of people who were described as being a forensic risk or who were ex-prisoners. Specific needs therefore remain an issue where there is not good evidence for the quality-of-life value of particular living arrangements.

4.1.1.5 Reporting weaknesses in the extant quality of life literature

The quality of data reporting could stand to improve in future literature. Across the board, there was a general insufficiency of information about ethical procedures, sampling methods and procedures, efforts to reduce bias, or statistical analyses. There was also often a lack of consideration for the generalisability of findings.

In this review, a range of issues related to ethical considerations were present. The absence of reporting whether informed consent was obtained, or whether there was a procedure for obtaining

informed consent, was a particularly prevalent issue. This is a serious problem considering the impact that a lack of an informed consent procedure would have on the autonomy and choices available to an individual. In situations where people with intellectual disability are deemed unable to provide meaningfully informed consent themselves, this should be sought from and provided by a person known to the individual. Standard consent procedures should also be followed. Where informed consent is not reported, concerns for anonymity and privacy may be raised. Further areas of concern include a lack of reporting on potential conflicts of interest and funding; as potential sources of bias, each should be detailed in any published manuscript.

The authors of this review identified a need for further longitudinal studies over longer periods of time, along with the need to account for confounding variables such as service types; location of residence; proximity to services, transport, and established contacts; and family and friendship maintenance strategies. Furthermore, future study designs would benefit from the inclusion of additional baseline measurements and independent or blinded data collection. The limited length of longitudinal follow-up in the studies included in this review is a barrier to understanding long-term outcomes and their trajectory.

The included studies did not detail their sampling methods or procedures with sufficient frequency. Reporting guidelines would suggest that eligibility criteria, sampling sources, and sampling methods should be well detailed, as should any methods of follow-up.⁵³ A number of studies did not report the results of their statistical analyses as fully as they could have. For example, although Golding *et al.* (2005) reported a percentage increase in quality-of-life scores and inferential tests of same, actual mean quality-of-life scores were only reported for the pre-move baseline.³¹

Again, based on this systematic review, it appears that a gap exists in knowledge about outcomes for particular populations of people with intellectual disability, including people with challenging behaviour, people with high support needs (e.g. people with physical or sensory disability or who require ventilators), and people who are a forensic risk or who are ex-prisoners. Given the increased potential for people with intellectual disability to live longer than they have in previous generations, more attention is required in order to capture quality of life and cost outcomes for older people with intellectual disability who are ageing in the community. Indeed, in order to better understand the differential effects of these population characteristics, new studies such as prospective cohort studies of high methodological quality (for example, with longitudinal measurements of outcomes and matched pre- and post-move comparison groups) are required.

4.1.1.6 Conclusion on quality of life

There was a substantial level of agreement between quantitative meta-analytic (i.e. standardised mean differences for all movers) and other results, supported by the qualitative findings, that a move to the community was associated with improved quality of life versus the quality of life for those living in an institution. However, while it is tempting to suggest that the matter is settled, a number of serious questions have yet to be answered. There remain challenges in certain aspects of quality of life – social integration and relationships, for example, as well as physical well-being for certain subgroups. There is not yet enough knowledge about the long-term course of quality of life outcomes, which is of particular interest considering the ageing nature of this population. Subpopulations with additional needs or who require high levels of support have received insufficient attention in the literature, and more research of high methodological quality is required in order to better understand the needs of a range of groups. While it might be reasonable to say that those with higher levels of intellectual disability and high support needs or challenging behaviour can have improved quality of life in the community, this is based on a small number of studies that are subject to limitations similar to those in the wider literature. The following groups or issues would certainly benefit from additional investigation: people with varying levels of intellectual disability, people of different ages (especially older people), people with specific health needs or impairments (e.g. people who use a ventilator), people with dementia, and people who are a forensic risk or who are ex-prisoners. Arguably, sufficient rigour has not yet been applied to understanding the mechanisms by which changes or improvements in quality of life occur – for example, changes in services available to

residents and proximity to important services and opportunities. Lastly, there have not yet been any studies which consider both quality of life and costs together.

The qualitative studies in our review conveyed an overall positive impact on individuals' quality of life, i.e. improved well-being, freedom, and independent decision-making; more careful consideration of housemate compatibility; and increased family contact and social integration opportunities. Studies specifically examining quality of life have also found freedom and self-determination to be meaningful aspects of community living for individuals.^{54 55} Following a move into the community, expectations of staff involvement could lead to negative quality of life outcomes. In particular, changing staff roles and an unfamiliar setting could contribute to a sense of insecurity and fear of having an accident (e.g. a fall) in isolation. Differing expectations of staff roles could also contribute to both poor participation in the new community and limited support in returning to the institution to maintain friendships. Consequently, there is the potential for an increased sense of loneliness among individuals with intellectual disability following moving to a community setting. An ongoing challenge to individuals' quality of life that was reported was ensuring that family contact was maintained.

4.1.2 Cost literature

The two economic studies (Beecham *et al.*, 1997 and Hallam *et al.*, 2006) identified in our review report opposing headline findings: one concludes that community care is less costly per individual than long-stay hospital care,³⁷ whereas the other finds the reverse.³⁸ Lack of detail regarding the type of community care that participants moved to, as well as limitations in reporting of cost data and their characteristics, preclude meta-analysis. Thus, our cost analysis does not support the claim that community living is typically or always less costly than institutional living, but it does bear out the well-established concerns about limitations in the literature that has been published to date.

The greatest strength of the two included cost-effects studies is the seriousness and detail with which costs were calculated for formal care services received by each individual participant.^{37 38} Each study assessed a comparable basket of health and community care services both pre- and post-move. One of the two studies also examined patterns over a 12-year time frame – an approach with growing value, as populations of those with intellectual disability are ageing and so an understanding of the changing needs of these populations as they age becomes more important.³⁸ Secondary analysis suggests significant associations between post-move costs and the characteristics of both the participants and the residences.

However, other reservations about the strength of the available evidence were justified. The studies' perspectives were restricted to the formal cost of care provided to individuals without measuring the cost of informal care. Neither of the included studies examined the costs associated with deinstitutionalisation process itself or the costs associated with the institution itself after people had left.²⁰

In considering how the results of this cost literature can inform contemporary healthcare policy, the most important limitations were not specific to economic evaluation but were more general to the use of observational data. Both studies report substantial variation in costs according to residence type, but neither study describes the destinations nor presents their cost-effects in such a way as to facilitate an understanding of the impact of moving people from hospital to a specific type of residence. One study (Beecham *et al.*, 1997) categorised post-move residences by private, public, and voluntary sector, but not by any other characteristic (e.g. environment, number of residents per unit). The other study (Hallam *et al.*, 2006) did provide basic descriptive details of post-move settings, but hospital costs were only compared statistically with all types of community care – nursing homes and hospices with high numbers of residents per unit; group homes with two to five residents; and established homes – pooled together. The number of people living independently following a move were negligible in both studies.

Details on the participants were similarly scant in both studies, but participants from both studies moved from long-stay hospitals at some point between 1983 and 1992 and were older than 40 years of age on average at the time of the move, so it is fair to assume that neither study sample is

representative of the growing populations for whom there is a particular lack of evidence on the cost- and quality of life effects of moving into the community: older people with intellectual disability and serious medical illness, and younger people with very complex needs and challenging behaviours.

4.2 Strengths and limitations

This review has followed best-practice guidelines for systematic evidence reviews wherever possible. A search strategy was devised following pilot searches and multiple meetings among a large team that included subject experts in intellectual disability and quality of life, an information specialist, a systematic review specialist, and two health economists. The breadth and thoroughness of the search strategy was illustrated by the very large number (>25,000) of returned titles and abstracts from databases, and each of these was independently reviewed by two team members. Likewise, all full texts that we accessed were independently reviewed by two team members. For studies included in the review, quality assessment and data extraction were performed by one reviewer with a corroborating rapid review by a second reviewer.

Nevertheless, there are a number of important limitations to our work. In devising our search strategy, we were faced with profound challenges in defining our intervention, our population, and our outcomes of interest (see Section 2.2). While every effort was made to include all potentially relevant terms (as the high number of reviewed titles and abstracts testifies), it is possible that we overlooked some terms that would have captured other relevant material. In reviewing returned studies from the database search, we used two independent reviewers for title and abstract reviews and for full-text reviews, but one reviewer for quality assessment and data extraction with a second reviewer providing a corroborating review. This means that there was a higher risk of bias and error in the quality assessment and data extraction phases than in earlier phases of the review. We also experienced a relatively high proportion of unobtainable studies (32/285; 11%). Failure to obtain studies reflects those journals that are not available in any university library of any participating author and whose publication websites do not provide soft copies of articles back to the article's date of publication. Since excluded studies were published much earlier and are predominantly from the United States of America, we are satisfied that the risk of missing evidence with major implications for Ireland in the 21st century is low.

We were unable to define 'congregated/institutional' and 'community' settings before beginning our review. The most recent Irish healthcare policy documents typically consider best-practice community settings to have no more than 4 residents per unit and institutions to have 10 or more residents. We considered applying these cut-offs to our search but believed that they might arbitrarily exclude potentially relevant studies (e.g. evaluating movement from a nine-resident hospital to a five-resident house). We therefore decided instead not to define congregated/institutional or community settings prior to our search, but rather to assess each study on its own merits and the information provided. In practice, institutions were clearly institutions – places with a number of institutional features – and were referred to as institutions in the literature. Community definitions were more nebulous, and so we made the best judgements we could and provided all available information on the precise conditions in each study in order to allow for third-party evaluation. In retrospect, we are satisfied with this approach; applying a strict definition would have been very problematic due to reporting insufficiencies in the extant research.

The funding bodies, the Department of Health and Health Research Board (HRB), set three research questions, which could not all be addressed comprehensively in a single systematic review (see Section 1.2). We therefore agreed with the HRB to address Questions 1 and 2 with one search of comparative evaluative studies, and to assess all included studies as they potentially pertained to Question 3. It is therefore possible that other study designs, and/or comparative studies with outcomes of interest other than quality of life and cost-effectiveness, examined effects of deinstitutionalisation in ways that were excluded from our review. Additionally, Question 2 specified three phases of deinstitutionalisation: before, during, and after. No eligible study addressed costs during deinstitutionalisation, but the transition costs of any move are clearly important and must be accounted for.

The decision to require documentation of consent and ethical considerations, a standard practice in systematic reviews, did mean that a number of older studies were excluded, along with most of the grey literature. Further appraisal of our decisions for exclusion established that the clear majority of research excluded due to ethical considerations also had other methodological shortcomings that would have been sufficient to exclude the studies from our review (see Appendix 4 Studies excluded at quality assessment).

Future studies may wish to revisit this issue; older studies did not have to meet the same expectations in documenting these requirements, and grey literature reports – particularly governmental evaluations – are not always bound by such requirements but may have other criteria that support the independence of the review. In future, the potential to access large-scale administrative and anonymised datasets of total populations may also reduce the concerns that these requirements were intended to address.

We also included only English-language studies in our review, excluding 12 studies on this basis, which is another potential source of bias. The studies excluded based on language are listed in Appendix 3 Studies in a language other than English and were variously published in French (7), Croatian (2), German (2), and Japanese (1). It was therefore notable that no studies either included in the review or excluded due to language considerations originated in the Nordic countries, which have the longest history of deinstitutionalisation. It is possible that researchers and/or government agencies in these countries evaluated the impact of deinstitutionalisation prior to the mass uptake of online publishing, and that these evaluations exist somewhere purely offline.

The grey literature search was conducted by subject experts on the websites of research centres that are active in this field, as well as on the websites of governments in countries that are at the forefront of deinstitutionalisation in populations with intellectual disability. This may have biased the reviewed studies against other nations and research groups.

4.3 Implications for practice and research

The research highlights that a move from a large institution to a smaller residence is insufficient for achieving unambiguous quality of life improvements. Beyond the scope of this review, but hinted at in the results chapter above, is the importance of increasing choice and community integration for individuals.

The reports that stratified results by age do highlight that age should not be a barrier to deinstitutionalisation, albeit improvements in quality of life might be lower for people who are older.

The included cost studies provide insufficient detail on both the service users and their post-move residences to inform who benefits from moving to which residential settings – which in this case is ultimately the fundamental policy-making question. The age of both datasets, and the unknown extent to which the samples represented the demographics and needs of all long-stay residents in the time period during which the studies were conducted, compound concerns about extrapolating from the reported results to the population level in Ireland today.

Indications that highly heterogeneous community residences are more costly than long-stay hospitals in some cases and less costly in others gives a clearer indication of where a future research agenda must move: towards a detailed understanding of which residential settings and wider care packages are appropriate for specific subgroups within an intellectual disability population that currently has wide-ranging needs, and whose needs will change further and become more complex over time.

Also critical from these findings is a growing awareness that improvements in community housing relative to former institutional residences are not sufficient for good quality of life outcomes, and that a lifestyle as close as possible to that experienced by other citizens should be the aspiration.

Perhaps most of all, there is a need for studies conducted over longer time frames and for agreed standardised variables for examining representative samples of people with intellectual disability where there is the potential to gather baseline (pre-move) data; follow individuals over time; examine

health-related, community participation, and life satisfaction variables; and control for the effects of changing health and independence needs. Comparison of cost-effects requires measurement from the broadest possible perspective, incorporating both formal (residential, health, and social care; out-of-pocket costs) and informal (unpaid carer) cost domains in ways that illuminate the relationships between specific types of residential settings and their associated utilisation. Within Ireland, such a study could be embedded within the pre-existing Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA),² where the baseline is already established. Efforts should also be made to link with longitudinal studies in other countries, such as the National Core Indicators Study and Medicaid studies in the United States of America⁵⁶ and the efforts currently underway in Australia⁵⁷ and the Netherlands.⁵⁸

Over time, cross-sectional studies are becoming more sophisticated in their statistical analyses and ability to consider participants' appraisals of past periods in their lives. Although the quality of recollections will always be an issue, they may be an additional and less time-intensive way to gather data.

Quality of life for people with intellectual disability, along with decision-making about the allocation of considerable resources for their circumstances, must require more rigorous approaches and consideration of sufficient data over longer periods of time than have been available in the past. Ongoing longitudinal cohort studies offer that opportunity to provide additional and more rigorous information. Nevertheless, the existing studies examined in this review have proved helpful in identifying questions that may now be considered more fruitfully.

² Disclosure: The principal investigator on this report is also the principal investigator on IDS-TILDA, and multiple co-authors have roles on the IDS-TILDA project.

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Appendices

Appendix 1 Grey literature

Methodology

The review of grey literature was concerned with non-academic publications that were readily available online and included a range of document types, such as government, statutory organisation, and non-statutory organisation (with a particular focus on national disability organisations and university-based centres of disability studies) policy, guidance, standards, or clinical audit documents which included either primary or secondary data analysis. Books, book chapters, and PhD and Masters theses were excluded from this review.

Although specific grey literature databases exist, such as OpenGrey, OpenSIGLE, Open University, and GreyNet, given the subject matter experts involved on the project team, it was decided to search by country and based on centres of disability studies known to the project team. There was no restriction in publication dates for grey literature.

The countries searched were those outlined in the International Association for the Scientific Study of Intellectual and Developmental Disabilities Comparative Policy and Practice Special Interest Research Group's position paper on deinstitutionalisation: the United Kingdom, the United States of America, Canada, Australia, Denmark, and Norway. These countries have been at the forefront of implementing policies and conducting research on deinstitutionalisation. Ireland was also included in this review of grey literature, as this is the country of focus for the current review.

The search terms used were the keywords set out for the systematic review (see Section 2.2).

The exclusion criteria for the review of grey literature sources were set out as follows:

- Documents that were from countries not listed above
- Documents that were purely descriptive with no data on quality of life measurement or cost measurement
- Documents that did not deal with movement but which assessed cross-sectional data of people within a particular setting and comparisons across settings but not movement
- PhD or Masters theses, and
- Books.

The steps in the search for grey literature were as follows:

1. We generated a list of policy documents and agencies (national/State disability organisations and academic centres for disability) known to the subject experts on the project team.
2. From the list of agencies, two researchers (MA and NW) searched within the agency/centre website for the keywords 'deinstitutionalisation', 'housing', 'home', 'decongregation', and 'transition' as broad search terms. If the organisation was not specifically an intellectual disability organisation, then the search terms 'intellectual disability', 'developmental disability', or 'learning disability' needed to be included using 'AND'.
3. From the list generated, the researchers proceeded to hand-search key policy documents and seminal articles/key authors to further identify grey literature of relevance.
4. A full list of reports was collated and circulated to the all subject experts on the project team at this time.
5. This list was reviewed by all subject experts and added to, as appropriate, based on their knowledge of documents in the area.

6. This list was split into two, and one of two researchers (MA and NW) reviewed each of the reports on their half of the list, categorising each report as: 1 – included (data), 2 – included (background information), 3 – excluded, or 4 – unclear.

Any queries were discussed and agreed between the two researchers before the reports were assigned to the appropriate category.

Retrieved grey literature

Conroy JW, Bradley VJ. The Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis [Internet]. Washington, DC: U.S. Department of Health and Human Services Office of Disability, Aging and Long-Term Care Policy; 1985 [cited 2018 August 31]. Available from: <https://aspe.hhs.gov/pdf-report/pennhurst-longitudinal-study-combined-report-five-years-research-and-analysis>

Conroy J, Seiders J. 1993 Report on the Well-Being of the Former Residents of Johnstone Training and Research Centre, The New Jersey Strategic Planning Project, Report Number 5 [Internet]. Pennsylvania: Conroy and Feinstein Associates, Wynnewood; 1994 [cited 2018 August 31]. Available from: <https://mn.gov/mnddc/parallels2/pdf/90s/93/93-CJN-UNJ.pdf>

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Conroy JW, Lemanowicz JA, Feinstein CS, et al. The Connecticut Applied Research Project: 1990 Results of the CARC v. Thorne Longitudinal Study [Internet]. Place not available: Publisher not available; 1991 [cited 2018 August 31]. Available from: <http://static1.squarespace.com/static/53dfdc3be4b0a86a2dbf76ae/t/5671ccbdcbced6829d5f191b/1450298557957/1990+Results+of+the+CARC+Vs+Thorne+Longitudinal+Study.pdf>

Appendix 2 Unobtainable studies

Author(s)	Year	Title	Journal	Vol.	Issue	Pages
Don and Amir	1969	Institutions for the mentally retarded in Israel: Cost structure and budget analysis	Mental Retardation	7	3	36–39
Wolfson	1970	Adjustment of institutionalized mildly retarded patients twenty years after return to the community	Mental Retardation	8	4	20–23
Bjaanes and Butler	1974	Environmental variation in community care facilities for mentally retarded persons	American Journal of Mental Deficiency	78	4	429–439
Aninger and Bolinsky	1977	Levels of independent functioning of retarded adults in apartments	Mental Retardation	15	4	12–13
McDevitt <i>et al.</i>	1978	The deinstitutionalized citizen: Adjustment and quality of life	Mental Retardation	16	1	22–24
Carsrud <i>et al.</i>	1979	Effects of social and environmental change on institutionalized mentally retarded persons: The relocation syndrome reconsidered	American Journal of Mental Deficiency	84	3	266–272
Intagliata <i>et al.</i>	1979	Cost comparison of institutional and community based alternatives for mentally retarded persons	Mental Retardation	17	3	154–156
Bruininks <i>et al.</i>	1980	National survey of community residential facilities: A profile of facilities and residents in 1977	American Journal of Mental Deficiency	84	5	470–478
Schalock <i>et al.</i>	1981	Independent living placement: Five years later	American Journal of Mental Deficiency	86	2	170–177
Intagliata and Willer	1982	Reinstitutionalization of mentally retarded persons successfully placed into family-care and group homes	American Journal of Mental Deficiency	87	1	34–39
Heller	1982	Social disruption and residential relocation of mentally retarded children	American Journal of Mental Deficiency	87	1	48–55
Cook	1983	Economics of providing services to the mentally retarded	Mental Retardation and Learning Disability Bulletin	11	1	13–21
Heal and Chadsey-Rusch	1985	The Lifestyle Satisfaction Scale (LSS): Assessing individuals' satisfaction with residence, community setting, and associated services	Applied Research in Mental Retardation	6	4	475–490
O'Neill <i>et al.</i>	1985	The impact of deinstitutionalization on activities and skills of severely/profoundly mentally retarded multiply-handicapped	Applied Research in Mental Retardation	6	3	361–371

Author(s)	Year	Title	Journal	Vol.	Issue	Pages
		adults				
Schalock and Lilley	1986	Placement from community-based mental retardation programs: How well do clients do after 8 to 10 years?	American Journal of Mental Deficiency	90	6	669–676
Felce	1986	Accommodating adults with severe and profound mental handicaps: Comparative revenue costs	Journal of the British Institute of Mental Handicap (APEX)	14	3	104–107
Lalonde <i>et al.</i>	1986	The social reintegration of institutionalized mentally retarded women [La réinsertion sociale de déficientes intellectuelles résidant en milieu psychiatrique]	Revue de Modification du Comportement	16	2	84–93
Springer	1987	From institution to foster care: Impact on nutritional status	American Journal of Mental Deficiency	91	4	321–327
Eastwood and Fisher	1988	Skills acquisition among matched samples of institutionalized and community-based persons with mental retardation	American Journal of Mental Retardation	93	1	75–83
Edgerton	1988	Aging in the community: A matter of choice	American Journal of Mental Retardation	92	4	331–335
O’Neill <i>et al.</i>	1990	Medicaid versus state funding of community residences: Impact on daily life of people with mental retardation	Mental Retardation	28	3	183–188
Ashbaugh and Nerney	1990	Costs of providing residential and related support services to individuals with mental retardation	Mental Retardation	28	5	269–273
Jourdan-Ionescu <i>et al.</i>	1990	Evaluation of deinstitutionalization: I. Quality of life [Evaluation de la désinstitutionnalisation: I. La qualité de vie]	Revue francophone de la déficience intellectuelle	1	1	49–58
Cunningham and Mueller	1991	Individuals with mental retardation in residential facilities: Findings from the 1987 National Medical Expenditure Survey	American Journal of Mental Retardation	96	2	109–117
Lord and Pedlar	1991	Life in the community: Four years after the closure of an institution	Mental Retardation	29	4	213–221
Barlow and Kirby	1991	Residential satisfaction of persons with an intellectual disability living in an institution or in the community	Australia and New Zealand Journal of Developmental Disabilities	17	1	7–23
McGuire <i>et al.</i>	1991	Community living for elderly people with an intellectual disability: A pilot study	Australia and New Zealand Journal of Developmental Disabilities	17	1	25–33

Author(s)	Year	Title	Journal	Vol.	Issue	Pages
Schalock and Genung	1993	Placement from a community-based mental retardation program: A 15-year follow-up	American Journal of Mental Retardation	98	3	400–407
Knobbe <i>et al.</i>	1995	Benefit-cost analysis of community residential versus institutional services for adults with severe mental retardation and challenging behaviors	American Journal of Mental Retardation	99	5	533–541
Tossebro	1995	Impact of size revisited: Relation of number of residents to self-determination and deprivatization	American Journal of Mental Retardation	100	1	59–67
Wagner <i>et al.</i>	1995	Voluntary transformation from an institutionally based to a community-based service system	Mental Retardation	33	5	317–321
Philaretou and Myrianthous	2009	An exploratory investigation of the quality of life of adults with learning disabilities living in family homes or under residential care	International Journal of Interdisciplinary Social Sciences	4	1	57–75

Appendix 3 Studies in a language other than English

Title	Author(s)	Year published	Journal	Volume	Issue	Pages
Do residential facilities for mentally retarded people exert an influence on the capacity for autonomy and social integration of their residents?}	Beckers	1984	International Journal of Rehabilitation Research	7	4	409–418
[Deinstitutionalisation of individuals with mental disabilities and their perception of the quality of life]	Boudreault	1990	Revue francophone de la déficience intellectuelle	1	2	147–158
[Evaluation of deinstitutionalisation: II. Changes in intelligence level and adaptive behaviours] [Jourdan-Ionescu <i>et al.</i>	1990	Revue francophone de la déficience intellectuelle	1	2	137–146
[The effects of social integration on adaptive behaviour and on diversification of activities]	Michaud <i>et al.</i>	1992	Revue francophone de la déficience intellectuelle	3	1	39–48
[Assessment of the needs and the quality of life of adults with mental retardation]	Lachapelle and Cadieux	1993	Comportement Humain	7	2	117–127
[From Lafontaine Hospital to Lafontaine Street: Deinstitutionalisation of persons with mental disabilities]	Lalonde and Lamarche	1993	Revue francophone de la déficience intellectuelle	4	2	103–120
[Social support of mentally handicapped adults: effects of degree of handicap and type of residential facility]	Meins	1993	Psychiatrische Praxis	20	3	106–108
[Normalized accommodation for people with intellectual disabilities and the effects on the residents]	Kief	1994	Vierteljahresschrift für Heilpädagogik und ihre Nachbargebiete	63	1	33–45
[The influence of the deinstitutionalisation process on the social integration of people with severe and profound intellectual deficiency]	Paré <i>et al.</i>	1994	Revue francophone de la déficience intellectuelle	5	2	137–154

Title	Author(s)	Year published	Journal	Volume	Issue	Pages
[The possibilities for mentally retarded persons to make their own choices in everyday life]	Bratković <i>et al.</i>	2003	Hrvatska Revija za Rehabilitacijska Istraživanja	39	2	117–127
[A study on the life satisfaction of mentally handicapped persons visiting a day care]	Handa <i>et al.</i>	2004	Journal of Japan Academy of Nursing Science	23	4	20–30
[Mental health problems and objective indicators of quality of life of adults with intellectual disabilities]	Kramarić <i>et al.</i>	2013	Hrvatska Revija za Rehabilitacijska Istraživanja	49	SUPPL.	50–63

Appendix 4 Studies excluded at quality assessment

Study author(s) and date	Reason(s) for exclusion
Bhaumik <i>et al.</i> 2011	Critical Appraisal Skills Programme (CASP) screening question 2 No information on ethics, recruitment
Bratt and Johnston 1988	CASP ³ screening questions 1 and 2 Aggregated adolescent and adult populations
Conneally <i>et al.</i> 1992	CASP screening question 2 Aggregated child and adult populations
Conroy <i>et al.</i> 2003	CASP screening questions 1 and 2 Participants, Intervention, Comparator, and Outcome(s), Study Types PICO requirements not met
Cullen 1995	CASP screening questions 1 and 2 No aim, ethics, consent, or sampling stated Difficulties confirming exact intellectual disability population in terms of need
Dagnan <i>et al.</i> 1995	CASP screening question 2 Consent not reported, recruitment procedure not detailed
Dagnan <i>et al.</i> 1996	CASP screening question 2 Consent process not reported
Dagnan <i>et al.</i> 1998	CASP screening question 2 No ethics details provided
Donnelly 1996	CASP screening question 2 Consent process not reported
Donnelly 1997	CASP screening question 2 Consent process not reported
Fish and Lobley 2001	CASP screening question 1 e.g. PICO requirements not met
Fleming and Stenfert-Kroese 1990	CASP screening questions 1 and 2 PICO requirements not met
Forrester-Jones 2002	CASP screening question 2 No ethics, consent, or sampling details provided

Study author(s) and date	Reason(s) for exclusion
Mansell 1994	CASP screening question 1 Children in the cohort
Marlow and Walker 2015	CASP screening questions 1 and 2 PICO requirements not met Consent process not reported
Perry <i>et al.</i> 2011	CASP screening question 2 Sample not representative of defined population
Roy <i>et al.</i> 1994	CASP screening question 2 No ethics details, statement of sampling, or generalisability No mention of bias
Sines <i>et al.</i> 2012	CASP screening question 1 No ethics details provided
Spreat and Conroy 2002	CASP screening questions 1 and 2 PICO requirements not met
Srivastava and Cooke 1999	CASP screening question 1 No findings reported in interim report PICO requirements not met
Walker <i>et al.</i> 1995	CASP screening question 1 PICO requirements not met
Young 2003	CASP screening question 1 PICO requirements not met No detail on how case study was undertaken

Appendix 5 Data extraction forms

Data extraction form

Quality of life outcomes and costs changes associated with providing supports to people with an intellectual disability who moved living arrangements

Date data extracted:
Name of reviewer completing this form:
Study reference:

Study characteristics

Dates study was conducted	
Geographic location (<i>country, city, state, etc.</i>)	
Aim of study	
Description of study design: (<i>RCT, before-after, prospective/retrospective cohort, qualitative, etc.</i>)	
Evidence of ethical (institutional review board) approval (yes/no)	
Evidence of informed consent	
Confidentiality and anonymity	
Conflict of interest statement(s)	
Declaration of funding source(s)	
Method of recruitment to study (<i>e.g. by whom, how, etc.</i>), including details of how consent was obtained	
Description of population (<i>e.g. principle ID health condition(s), age (mean, SD), gender, comorbidities, current living arrangement, etc.</i>)	
Specific analysis of a DOH population of interest: severely physically disabled with complex medical needs (such as people on ventilators); people who are a forensic risk or ex-prisoners	
Description of original or default setting	

Description of new or 'intervention' setting <i>(N/A for Question 3)</i>	
Outcome measure(s) reported in the study <i>(e.g. QOL, costs, views/experiences, etc.)</i>	
Additional information <i>(further information of possible relevance)</i>	

Study relevant for answering which review question(s)	
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Numbers involved

Total number recruited to study	
Number in original or default setting	
Number in intervention setting <i>(N/A for Question 3)</i>	
Withdrawals/dropouts <i>(with reasons)</i>	
Lost to follow-up <i>(for each group; with reasons)</i>	

Question 1: Data collection and analysis methods *(can delete if not relevant)*

Method/instrument used to assess the outcome	Outcome assessor/person collecting the data <i>(e.g. self-report, carer, clinician, etc.)</i>	Timing of outcome measurement <i>(time point before, during, and after the decongregation period)</i>	Method of analysis, summary statistics used, etc.

Question 2: Data collection and analysis methods *(can delete if not relevant)*

Evaluation type: <i>Cost-min CEA CUA CCA (if CEA/CUA/CCA, then state outcome)</i>	Cost perspective: Formal Informal Societal Other	Time horizon and currency Discount rates?	Method of analysis, models used; sensitivity analyses

Question 3: Views, experiences (can delete if not relevant; repeat this table if more than one relevant population featured)

Description of cohort with specific needs	
Person collecting the data (e.g. self-report, carer, clinician, etc.)	
Method of analysis (narrative, descriptive statistics, thematic, etc.)	
Rationale for the care option	
How care needs are meet	

Results

Quality-of-life (continuous data)	Congregated setting			Community setting		
	Mean	SD	Total	Mean	SD	Total
	Total in group =			Total in group =		
Quality of life (overall)						
*						
If narrative results only, provide details here						
Quality of life (dichotomous data)	Number with 'high' QOL as per study cut-off score	Total	Number with 'high' QOL as per study cut-off score	Total		
Quality of life (overall)						
*						

**add additional rows as necessary for categories/subgroups of quality-of-life outcomes*

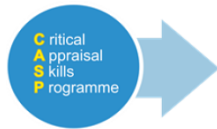
Costs (continuous data)	Congregated setting			Community setting		
	Mean	SD	Total	Mean	SD	Total
	Total in group =			Total in group =		
Formal (system/payer)						
Out of pocket						
Informal costs						
Lost productivity						
*						
If narrative results only, provide details here						

**add additional rows as necessary*

General conclusions

Very brief summary of the study authors' main conclusions and recommendations

Appendix 6 CASP risk of bias/quality appraisal tool



12 questions to help you make sense of cohort study

How to use this appraisal tool

Three broad issues need to be considered when appraising a cohort study:

- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 12 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions.

There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA ‘Users’ guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.:

Critical Appraisal Skills Programme (2017). CASP (insert name of checklist i.e. Cohort Study) Checklist. [online] Available at: *URL*. Accessed: *Date Accessed*.

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(A) Are the results of the study valid?

Screening Questions

1. Did the study address a clearly focused issue? Yes Can't tell No

HINT: A question can be 'focused' in terms of

- The population studied
- The risk factors studied
- The outcomes considered
- Is it clear whether the study tried to detect a beneficial or harmful effect?

2. Was the cohort recruited in an acceptable way? Yes Can't tell No

HINT: Look for selection bias which might compromise the generalisability of the findings:

- Was the cohort representative of a defined population?
- Was there something special about the cohort?
- Was everybody included who should have been included?

Is it worth continuing?



Detailed questions

3. Was the exposure accurately measured to minimise bias? Yes Can't tell No

HINT: Look for measurement or classification bias:

- Did they use subjective or objective measurements?
- Do the measurements truly reflect what you want them to (have they been validated)?
- Were all the subjects classified into exposure groups using the same procedure

4. Was the outcome accurately measured to Yes Can't tell No

minimise bias?

HINT: Look for measurement or classification bias:

- Did they use subjective or objective measurements?
- Do the measures truly reflect what you want them to (have they been validated)?
- Has a reliable system been established for detecting all the cases (for measuring disease occurrence)?
- Were the measurement methods similar in the different groups?
- Were the subjects and/or the outcome assessor blinded to exposure (does this matter)?

5. (a) Have the authors identified all important confounding factors? Yes Can't tell No

List the ones you think might be important, that the author missed.

(b) Have they taken account of the confounding factors in the design and/or analysis? Yes Can't tell No

HINT: Look for restriction in design, and techniques e.g. modelling, stratified-, regression-, or sensitivity analysis to correct, control or adjust for confounding factors

6. (a) Was the follow up of subjects complete enough? Yes Can't tell No

(b) Was the follow up of subjects long enough? Yes Can't tell No

HINT: Consider

- The good or bad effects should have had long enough

- to reveal themselves
- The persons that are lost to follow-up may have different outcomes than those available for assessment
- In an open or dynamic cohort, was there anything special about the outcome of the people leaving, or the exposure of the people entering the cohort?

(B) What are the results?

7. What are the results of this study?

HINT: Consider

- What are the bottom line results?
- Have they reported the rate or the proportion between the exposed/unexposed, the ratio/the rate difference?
- How strong is the association between exposure and outcome (RR,)?
- What is the absolute risk reduction (ARR)?

8. How precise are the results?

HINT: Look for the range of the confidence intervals, if given.

9. Do you believe the results?

Yes Can't tell No

HINT: Consider

- Big effect is hard to ignore!
- Can it be due to bias, chance or confounding?
- Are the design and methods of this study sufficiently flawed to make the results unreliable?
- Bradford Hills criteria (e.g. time sequence, dose-response gradient, biological plausibility, consistency)

(C) Will the results help locally?

10. Can the results be applied to the local population?

Yes

Can't tell

No

HINT: Consider whether

- A cohort study was the appropriate method to answer this question
- The subjects covered in this study could be sufficiently different from your population to cause concern
- Your local setting is likely to differ much from that of the study
- You can quantify the local benefits and harms

11. Do the results of this study fit with other

Yes

Can't tell

No

available evidence?

12. What are the implications of this study for practice?

HINT: Consider

- One observational study rarely provides sufficiently robust evidence to recommend changes to clinical practice or within health policy decision making
- For certain questions observational studies provide the only evidence
- Recommendations from observational studies are always stronger when supported by other evidence

