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Title

The effect of deinstitutionalisation on quality of life for adults with intellectual disabilities: a systematic review

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Data sharing

There are no unpublished data from this study.

Competing interest statement

All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work.

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Statement of independence

All authors are independent of the study sponsors.

Statement of access

All authors had full access to all of the data in the study and can take responsibility for the integrity of the data and the accuracy of the analysis.

Transparency declaration

The lead author affirms that the manuscript is an honest, accurate and transparent account of the study being reported; that no important aspects of the study have been omitted; and that there are no discrepancies from the study as planned.

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Strengths and limitations of this study

- We conducted an extensive systematic search of academic databases, using two reviewers to assess eligibility independently.
- Eligible studies were required to meet a minimum quality threshold.
- We included studies using both quantitative and qualitative methods.
- We excluded studies not reporting ethical approval, which minimises bias and quality standards but potentially excludes earlier studies conducted without reporting guidelines.
- We did not include static cross-sectional studies, requiring that studies evaluated a move in residence for a person with intellectual disability.

Abstract (<=300 words)

Objective: To review systematically the evidence on how deinstitutionalisation affects quality of life for adults with intellectual disabilities.

Design: Systematic review.

Population: adults (aged 18 years and over) with intellectual disabilities.

Interventions: a move in residential setting.

Primary and secondary outcome measures: studies were eligible if evaluating effect on quality of life or life quality, as defined by study authors.

Search: We searched MEDLINE, PsycINFO, CENTRAL, CINAHL, EconLit, Embase and Scopus to September 2017 and supplemented this with grey literature searches. We assessed study quality using the Critical Appraisals Skills Programme (CASP) suite of tools, excluding those judged to be of poor methodological quality.

Results: Thirteen studies were included; eight quantitative studies, two qualitative, two mixed methods studies, and one case study. There was substantial agreement across quantitative and qualitative studies that a move to community living was associated with improved quality of life. Quality of life for people with any level of intellectual disabilities who move from any type of institutional setting to any type of community setting was increased at up to one year post-move (SMD 2.03; 95% CI [1.21, 2.85], 5 studies, 246 participants) and beyond one year post-move (SMD 2.34. 95% CI [0.49, 4.20], 3 studies, 160 participants), with total QoL change scores higher at 24 months comparative to 12 months.

Conclusion: Our systematic review demonstrated a consistent pattern that moving to the community was associated with improved quality of life compared to the institution. However, significant gaps in the evidence base are observable,

particularly with regard to growing populations of older people with intellectual disability and complex needs.

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Introduction

Background/rationale

The right to live independently in a place of one's own choosing reflects the guiding principles of the 2006 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).[1] A process of 'deinstitutionalisation' - that is, moving people with disabilities and mental health problems from institutions to community-living arrangements that support autonomous decision-making and full participation in society - has occurred at different times and different speeds since the 1960s in Scandinavia, the United Kingdom, United States, Canada and Australia.[2]

We undertook a systematic review of the evidence on deinstitutionalisation for people with intellectual disabilities. We examined specifically the effect of deinstitutionalisation on economic outcomes and on quality of life (QoL). In this paper we report the results for the QoL studies. The economics results, as well as further details on our search strategy, are available in a companion paper.[3]

QoL is a priority outcome measure for policymakers but measurement is challenging due to the fluidity of definitions and variability in applications of the concept in practice.[4 5] The Schalock framework of QoL is the most widely accepted within the field, with its eight core components of emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights.[6] Research to date highlights that people with intellectual disabilities persistently score lower on QoL measures than the general population,[7] and that level of intellectual disability, environmental factors and the level and nature of supports received can impact QoL for people with intellectual disabilities.[7-9] Tracking outcomes, including QoL outcomes, for people with intellectual disabilities following deinstitutionalisation encounters measurement challenges both in the gathering of self-report, proxy and family data and in the value placed on each type of report.[6 10-15] These issues are particularly challenging when engaging people with severe/profound intellectual disability yet inclusion of these subgroups is essential.[16]

The impetus for deinstitutionalisation arises from, *inter alia*, concerns about standards of care, poor outcomes and the recognition that people with intellectual disabilities were being unnecessarily deprived of ordinary lives.[17 18] Research alludes to positive benefits of smaller community-based settings[19 20] but also attests that gains in health and other outcome measures are not inevitable.[19] In addition, improvements recorded shortly after a move may plateau after one year.[21] Lack of community readiness to support people to live in the new setting has been mooted as a reason when there are poor outcomes given a primary policy focus on the closure of the institutions rather than preparing the community to meet the needs of people with disability now living in the community.[22] A change in the size of setting also cannot be assumed to result automatically in better outcomes in terms of health, well-being and overall QoL, particularly if the new community setting continues to mirror the culture and practices of the larger institutions with real change in how people live, as well as how, when and what type of supports received, being minimal or not materialising.[23 24]

Given the lack of consensus on QoL outcomes as a consequence of deinstitutionalisation there is a need to consolidate the available evidence. This is particularly important in the context of countries that have recently begun or plan to begin implementing a policy of deinstitutionalisation. It is also important for countries that may be challenged by the sustainability and maintenance of the community models put in place in the context of coming demographic change.

Objectives

To review systematically the evidence on how deinstitutionalisation affects quality of life for adults with intellectual disabilities.

Methods

Eligibility criteria

Studies reporting on the following PICOS (Participants, Interventions, Comparators, Outcomes and Study types) or PEOS (Participants, Exposure, Outcomes and Study types), were eligible for this review.

Types of participants

Adults (aged 18 years and over) with intellectual disabilities.

Types of intervention/exposure/comparators

Our intervention of interest was deinstitutionalisation – that is, a residential move from an institutional to a community setting.

We did not define institutional and community settings *ex ante*, since no widely accepted definitions (e.g. according to the number of residents per unit) exist and we did not want to exclude arbitrarily studies of relevance. Additionally we were conscious that processes of deinstitutionalisation have happened and are happening at different speeds in different countries, sometimes now involving reinstitutionalisation (moving back from the community to an institution) and transinstitutionalisation (moving between institutions).[25]

Consequently we assessed the characteristics of institutions and community-living arrangements on the information provided in each paper.

Types of outcomes

Our pre-specified primary outcome of interest was "quality of life" or "life quality", as defined by study authors. There were no *a priori* restrictions on the operationalisation of QoL. To be eligible as a primary outcome, we required QoL to be measured both prior to and following a move. While cross-sectional quantitative studies were generally excluded, as they lacked comparative data on a move, it was not by rule. For example, if a study cross-sectionally asked study participants after a move about changes in QoL arising from that move, this would be included. However, studies that cross-sectionally compared QoL for groups living in institutional and community settings without either group having moved were excluded.

Types of studies/reports

Study designs eligible for inclusion were: prospective/retrospective before and after studies, randomised trials, economic evaluations, qualitative/descriptive and exploratory studies.

Search strategy

Database search

To ensure a search strategy that was both sensitive and specific, a comprehensive search methodology to identify both published and grey (e.g. policy reports, national/international guideline documents, etc.) literature was developed and executed through routine scientific database searches and grey literature retrieval. 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 not initially included and assess whether this may have presented a source of possible language bias.

The following electronic databases were searched from date of inception to September 2017: MEDLINE, PsycINFO, CENTRAL, CINAHL, EconLit, Embase and Scopus. Search terms used to guide the review were developed and subsequently finalised by an information specialist (GS) in collaboration with the review team topic experts, and by executing 'scoping' and pilot searches to cross-reference search terms with prior studies and reviews. A combination of title/abstract keywords and related controlled vocabulary terms were incorporated into the search to ensure comprehensiveness. See Appendix 1 for details.

Other sources

The search of grey literature was concerned with non-academic publications, readily available online and included a range of different types of documents such as government, statutory organisation, non-statutory organisation (with particular focus on national disability organisations and university based centres of disability studies) policy, guidance, standards or clinical audit documents which included analytical data – either primary or secondary data analysis. See Appendix 2 for details.

Study selection and quality assessment

Screening of titles and abstracts

Two reviewers (RLV and EM) screened the titles and abstracts of retrieved citations, independently, based on the eligibility criteria. Subsequently, approximately 600 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 process.

Screening of full text reports

Two independent reviewers (RLV and EM) screened the full texts papers independently, with any conflicts or uncertainties resolved in discussion between the two reviewers.

Assessment of methodological quality/risk of bias

Each included study was assessed for methodological quality using one of a group of standardised instruments developed by the Critical Appraisal Skills Programme (CASP, http://www.casp-uk.net/casp-tools-checklists). A pair of reviewers conducted the quality assessment process whereby one reviewer (RLV or EM) assessed the studies' methodological quality and a second reviewer (RLV or EM) performed their own rapid assessment to corroborate quality assessments. Any conflicts were resolved through discussion and consensus. Given that studies of low (or poor) methodological quality can lead to overestimates of the effects of interventions or variables under investigation, and can increase the potential for bias in the results, usually in a positive direction, an a priori decision was made to exclude studies assessed as being of low methodological quality (see Appendix 3).

Guided by the CASP quality assessment tool, studies involving primary data collection that did not demonstrate evidence of informed consent were excluded.

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

Data analyses

Data extraction

Comprehensive data extraction forms were pre-designed and piloted to extract relevant data. One reviewer (RLV or EM) extracted the data from the included papers, and a second reviewer (RLV or EM) 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 study design features (randomised trial, prospective or retrospective, etc.), study setting (country of origin), participant details (characteristics, numbers, etc.), recruitment and sampling, exposure/intervention details, ethical issues (e.g. consent), QoL data before and after a move (including summary measures and their standard deviations as well as qualitative themes), and author-identified implications.

Data syntheses

Quantitative studies

We aimed, *a priori*, to perform a meta-analysis of individual studies' data to achieve an overall (higher level) effect estimate following a move from an institutional setting to a different/community-based setting on QoL. Inclusion in a meta-analysis required sufficient similarity in design (i.e. include prospectively collected pre-move and post-move data) and had to provide overall QoL measures. Specifically they had to have measured QoL prospectively as a pre-test (before the move) and post-test (at least one follow-up time point post-move) measure(s). For studies that used repeated post-test measures, we selected QoL measures at one time point for inclusion in the meta-analysis, to avoid over-counting, and described all other time point results narratively. To further reduce characteristic variances in the meta-analyses, we sub-grouped the data according to follow-up at either up to and including one year post-move and at more than one year following a move from any type of institutional setting to any type of community setting. In addition, while sub-scales of QoL might be chosen as a proxy measure of overall QoL, to be included in the meta-analyses, an overall QoL scale score had to be provided; where sub-scale results only were provided, we present the results for these narratively. High levels of statistical heterogeneity in the analyses were likely due to elements of clinical variation across the included studies (e.g. participants with varying levels of intellectual disability across studies, and differing age profiles), rather than study design issues. To counterbalance 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.[26] Lastly, because the instruments used to measure QoL across the included studies differed, we calculated the standardised mean difference (SMD) as per recommended meta-analytical methods.[26] We interpreted the results as an average of the effect of a move from an institutional setting to a community setting, rather than a 'best-estimate' of the effect, as provided by a fixed-effect model. Studies not meeting these similarity criteria, are reported narratively.

Studies not meeting these similarity criteria, are reported narratively.

Qualitative studies

We employed a thematic narrative synthesis for identified qualitative studies and the qualitative elements of mixed methods studies.[27]

Patient and Public Involvement

The National Disability Authority of Ireland,[28] an independent state body that advises government and the public sector on policy and practice, contributed to the search strategy.

Results

Search and selection results

Database search

The database search for both cost and QoL studies identified 25,853 citations for consideration against the eligibility criteria for the review. Following removal of duplicates (*n* = 6,568), 19,000 citations were excluded on title and abstract, as they clearly did not meet the review's pre-specified eligibility criteria (Figure 1). A full-text review of the remaining 285 citations was performed, following which a further 217 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 QoL as an outcome (46), opinion or commentaries and reviews (18), not in English language (12), not an adult population with intellectual disability (8) and miscellaneous (6).

Thirty-six articles were therefore identified as meeting the eligibility criteria, of which 21 were subsequently excluded following an assessment of their methodological quality using the CASP tool. Reasons for exclusion at quality assessment included no report of establishing consent of study participants, and insufficient and negligible data on participants and/or outcomes (Appendix 4). Of the 15 studies remaining, two addressed economic outcomes only and are included in a separate paper.[3] No eligible study looked at both economics and QoL.

Thirteen QoL studies were therefore identified from the database search.

Grey literature search

A total of 74 specific reports were identified from the grey literature search. Following detailed review, 30 reports were identified as relevant to deinstitutionalisation from a cost and/or QoL perspective. Of these, six include 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 pre/post-move, none of the reports were included in the final analysis. See Appendix 2 for details.

Main results

Description of included studies

Of the 13 included QoL studies, eight were quantitative,[29-36] two were qualitative,[37 38] two were mixed methods studies,[39 40] and one was a case study.[41]

Characteristics of included studies are summarised in Table 1. Sample size ranged from one to 76 persons and publication year was from 1994 to 2015. Six studies originated in Australia, four in the UK, two in Ireland and one in New Zealand. Of the six from Australia, two report different analyses of the same sample and these were dealt with in unison where it was more meaningful to do so.

Table 1: Summary characteristics of included studies on quality of life

Study	**Location**	**Aim**	**Study design**	**Participants**	**Pre-move setting**		**Post-move setting**		**Quality of life tool or proxies**
					Description	No. in institution	Description	No. moving to community	
Ager *et al.* (2001)[29]	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 influential on such integration	Prospective cohort. Pre-post. Pre-move: baseline. Post-move: 6-9 months.	Total sample=76 Age: mean = 53 (range: 21 - 92). Gender: not reported. Intellectual disability (ID) level: not reported. Time in institution: 1-66 years. Health status: not reported.	1 hospital	76	19 community-based homes (18 voluntary funding, 1 private), OR one of two nursing homes (private), OR one of five older people's homes (local authority)	76	LEC
Barber *et al.* (1994)[30]	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.	Total sample =15 Age: mean =42.4 years (standard deviation 8.51, range 30-57). Gender: 8 female, 7 male ID Level: mild=8, moderate=6, severe=1	1 institution	15	Community-based group homes	15	QoL-Q
Bigby (2008)[40]	Australia	To examine changes in the nature of the informal relationships of residents 5 years after leaving an institution.	Mixed methods. Pre-move: baseline. Post-move: 1, 3, and 5	Total sample =24 Mean age=51.5, range 39-68. ID level: Mild=0, moderate=15, severe or	1 large institution	24	Small group home houses in the community.	24	Analysis of social networks (quantitative), and structure interviews

			years.	profound=6, unknown = 3. Identified health issues =17, psychiatric diagnosis =7, mobility impairment =6. Some residents had more than 1 health issue. Time in institution prior to move: mean =38 years, range 10-54 years					(qualitative)
Cooper & Picton (2000)[31]	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 post-move.	Total sample = 45 Group moving to community = 26: age: mean = 52 (standard deviation = 15.3); gender: 52% male/48% female; ID level: mild = 24%, moderate = 52%, severe/profound = 24%. Group moving to refurbished institution = 19: age: mean = 55.2 (standard deviation =12); gender: 53% male/47% female; ID level: mild = 5%, moderate = 47%,	1 institution - closure order	45	Community group homes housing not more than 6 people (=26) Refurbished institution (=19)	26	QoL-Q

				severe/profound = 47%. The authors report no significant difference between groups in terms of ID level, though no statistics were reported. Health status: not reported.					
Di Terlizzi (1994)[41]	UK	To describe "the life history of a woman with severe learning disabilities and communicative impairment".	Case study	Total sample =1. Aged 36 when moved to community house. Severe learning disability and challenging behaviour.	Residential hospital institution	1	Small community staffed house. Shared with 3 other highly independent co-tenants with mild learning disabilities. Service provided 1:1 staff ratio throughout the day	1	Qualitative case study
Golding *et al.* (2005)[32]	UK	To evaluate the effects of relocation from institutional to specialised community-based provision for people with severe challenging behaviour.	Prospective cohort (+ additional comparison group that already in community - irrelevant here). Pre-move: baseline. Post-move: 3 months, 9	Total sample = 6 males with mild to moderate ID and challenging behaviour. An additional six participants who were already in the community were also included in this study but are not reported on for the	Institution operated by the NHS	6	Two separate houses managed by a specialist challenging behaviour residential service with an on-duty staffing ratio of four staff to every six residents between 07:00	6	LEC

			months	purposes of this review.			and 22:00		
Howard & Spencer (1997)[33]	UK	To provide local management and staff with some insight into the effect of service changes [move from group home to smaller community settings] on the lives of the residents.	Prospective cohort. Pre-move: baseline. Post-move: 1 year	Total sample = 10 participants (7 females and 3 males, mean age=61) who had a preference to remain in a rural setting post-move	Large rural group home with institutional features	10	One of two rural community houses	10	LEC
Kilroy *et al.* (2015)[37]	Ireland	To explore "key workers' perceptions of the impact of a move to community living on the QoL of individuals with an ID".	Qualitative. Proxy participants.	8 people with severe intellectual disability who had had moved from a residential campus to the community over the past 4 years. Age: range 26 - 44, mean = 37.4. Gender: 6 male and 2 female.	1 institution	8	Two community houses that are owned by two housing associations set up by family of the individuals and staff of the disability organisation but are run as independent entities.	8	Qualitative interviews

O'Brien *et al.* (2001)[39]	New Zealand	To investigate the outcomes of the move into community homes 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.	Mixed methods. Retrospective cohort.	Total sample =54 (31 females, 23 males). Mean age=48 years (No standard deviation reported, age range 36-65). High support needs =41, medium -=3, low =10	1 long stay hospital	54	Group homes located in the community 1:1 on duty staff ratio to assist with integration	54	Family ratings of quality of changes in quality of life, and qualitative interviews
Sheerin *et al.* (2015)[38]	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.	7 included (3 females, 2 males) Age: not reported 5 people with ID 2 relatives of other tenants Health status: not reported	1 institution	7	New residence The new living unit is located within the commuter belt of Dublin and incorporates a number of self-contained living spaces with shared living areas within staffed houses.	7	Qualitative interviews

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, 24 months.	Total sample = 60 (38 males, 22 females). Age range: 27 to 81. ID Level: mostly moderate or severe/profound. Two groups of 30 matched post-hoc: demographic, health, impairment, adaptive behaviour variables.	1 institution	60	Cluster centres: accommodating 20-25. 7-8 houses and an admin centre. Outer suburb. Resemble surroundings. Modified as required. Community: pre-existing outer-suburban houses, 2-3 residents. Good description in paper.	30	LCQ
Young & Ashman (2004a & 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 retardation in the community."	Prospective cohort. Pre-move: baseline 6 months pre-move. 1, 6, 12, 18, and 24 months post-move.	Total sample =104 (57 males, 47 females). Mean age=47 (range 21 to 84). ID level: 61% severe, 25% moderate, 14% mild. Majority: challenging behaviour, specific health needs or impairments (50 with visual, hearing or mobility impairment), long-term institutionalisation (in many cases most of their lives;	1 institution	104	Modern, brick, freestanding, public housing, which was typical of the surrounding neighbourhood in outer suburban areas and had more favourable staff-to-resident ratios. Additional info. In paper.	104	LCQ

				2 to 70 years, mean length of stay=26)					

QoL was operationalised 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 QoL, and for which validity and reliability data are available. Three studies used the Life Circumstances Questionnaire, a non-standardised tool to assess objective QoL developed by the authors of the studies in which it is used (LCQ).[35] Two studies used the QoL Questionnaire (QoL-Q), a validated tool providing information on subjective and objective QoL.[43] Other ways of measuring QoL included aspects of informal social relationships (one study) and family ratings of QoL (one study).

Five research studies were included which attempted to assess QoL longitudinally, i.e. with multiple post-move assessments. Details on follow-up across studies are presented in Table 2.

Table 2 Timings of post-move assessments in studies with quantitative quality of life data

Study	Timing of post-move assessment								
	1 Mth	3 Mth	6 Mth	9 Mth	1 Year	1.5 Years	2 Years	3 Years	5-9 Years
Ager *et al.* (2001)[29]			Yes *						
Barber *et al.* (1994)[30]	Yes								
Bigby (2008)[40]					Yes			Yes	Yes
Cooper & Picton (2000)[31]			Yes					Yes	
Golding *et al.* (2005)[32]		Yes		Yes					
Howard & Spencer (1997)[33]					Yes				
O'Brien *et al.* (2001)[39]									Yes
Young (2006)[34]					Yes		Yes		
Young & Ashman (2004a & b)[35 36]	Yes		Yes		Yes	Yes	Yes		
Total	2	1	3	1	4	1	2	2	2

* Between six and nine months

Note. Young & Ashman (2004a and 2004b) are combined in summary tables, as both papers analyse outcomes for the same cohort at the same time points.

Key findings

Quantitative studies

The key findings of the ten studies with quantitative elements are summarised in Table 3.

Of these, five were deemed suitable for inclusion in a meta-analysis to examine QoL outcomes for people with any level of intellectual disabilities who move from any type of institutional setting to any type of community setting.[29 31 33-35] In secondary meta-analyses we performed subgroup analysis by QoL subscale, age and level of intellectual disabilities. In addition, outcomes following a move from one institutional setting to another institutional setting were analysed (two studies).[31 34]

Overall QoL

Meta-analysis of QoL outcomes for people with any level of intellectual disabilities who move from any type of institutional setting to any type of community setting are presented in Figure 2. QoL was significantly increased at up to one year post-move (SMD 2.03; 95% CI [1.21, 2.85], 5 studies, 246 participants, GRADE level of evidence: moderate) and beyond one year post-move (SMD 2.34. 95% CI [0.49, 4.20], 3 studies, 160 participants, GRADE level of evidence: moderate), with total QoL change scores higher at 24 months comparative to 12 months.

Table 3 Quantitative QoL research

Author/Year	Key findings on quality of life
Ager *et al.* (2001)[29]	Significant pre-move/post-move improvements in overall quality of life and on all five of the LEC subscales (all p<0.005). LEC change scores stratified by dependency level: post-move changes greater as dependency level increased, but not statistically significant.
Barber *et al.* (1994)[30]	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)[40]	Slight, but not statistically significant downward trend from pre- to five years post-move in the number of residents in contact with family members annually or more frequently (85% [20 individuals] to 75% [18]). Significant drop in the mean number of family members in contact with residents between one and five years post-move (p<.05). Mean informal network size increased from pre-move to one year post-move, but then decreased at three years and again at five years; the overall decrease was not statistically significant (p >.05). Reasons cited by family members for changes in/low 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 (most frequently cited), being unknown by staff, 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 lack of implementation of same, as a reason for contact with family and friends not being maintained.
Cooper & Picton (2000)[31]	Significant improvement in quality of life (QoL-Q) at both six months and at three years following move to the community from a decommissioned institution. A sub-group of 19 individuals who moved to refurbished units in a different institution at also showed significant improvement in overall quality of life at both six months and at three years following the move.
Golding, Emerson, & Thornton (2005)[32]	Improvements in overall LEC scores, for a small sample of six with mild to moderate intellectual disability and severe challenging behaviour, at both three and nine months post-move; 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, Leisure, Freedom, Opportunities, Relationships), and all increases, other than Leisure, were maintained at nine months post-baseline (p<0.05).
Howard & Spencer (1997)[33]	Improvement in quality of life overall (LEC) for a small sample of ten moving to rural settings (as was movers' preference). All domain areas (Home, Leisure, Freedom, and Opportunities) except Relationships increased significantly at one-year post-move compared to pre-move scores (p<0.01 or p<0.001).
O'Brien *et al.* (2001)[39]	Quantitative data was provided for a small subsample in this study (11 to 14). 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 at follow-up (Material Possessions, Health, Productivity, Safety, Place in Community, and Wellbeing).
Young (2006)[34]	Individuals (with mostly moderate to severe/profound ID) who moved to either small group homes or cluster housing had significantly higher QoL scores at both 12 and 24 months compared to pre-move in an institution. Those who move to the

	community also had significantly better outcomes than those who moved to clustered settings at 12 (MD 26.9, 95% CI 1.27 to 52.53) and at 24 months (MD 39.2, 95% CI 14.31 to 64.09) post-move. All QoL sub-domains (material wellbeing, physical wellbeing, community access, routines, self-determination, social-emotional wellbeing, residential wellbeing, and general wellbeing) improved significantly with a linear trend from pre-move to 12 and 24 months for both groups (all p<0.001). Community settings afforded significantly better physical wellbeing (p<0.005), community access (p=0.001), routines (p<0.01), self-determination (p<0.01), residential wellbeing (p<0.01) and general life improvements (p<0.001) compared to clustered settings. The groups did not differ on material wellbeing and social/emotional wellbeing.
Young & Ashman (2004a, 2004b)[35 36]	Improved quality of life, for a sample of 104 people described as having generally higher support needs, at both 12 and 24 months post-move. There was a significant linear increase in QoL scores, but also a significant quadratic trend suggesting a plateauing of QoL scores at 24 months post-move. Overall quality of life experienced by people with mild/moderate intellectual disability did not significantly improve following a move to a community setting for 20-39 or 40-59-year-olds, and showed a nonsignificant reduction for the 60+ age group. There was a significant increase in overall QoL scores at 24 months post-move for those with severe/profound intellectual disability for all three age categories (p<0.01 or p<0.001). Participants with severe/profound intellectual disability had lower total QoL scores at both pre-move and at follow-up, than those with mild/moderate intellectual disability. Participants in all three age groups and 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 lack of significant improvement in physical wellbeing for the youngest mild/moderate intellectual disability group and the oldest severe/profound group.

Level of intellectual disability

Some studies were not disaggregated by level of intellectual disability while others provided exact numbers for those with mild, moderate or severe/profound intellectual disability. To explore QoL specific to levels of intellectual disability, we were able to extrapolate data explicitly on people with mild to moderate intellectual disability from four studies, [29 32 33 35] of which two were suitable for including in a sensitivity analysis (Figure 3).[33 36] Overall QoL experienced by people with mild/moderate intellectual disability did not significantly improve following a move from an institution to any community setting (mean difference (MD) 0.99, 95% CI [-0.41, 0.46], 2 studies, 51 participants).

One study provided data explicitly on a group of people with severe/profound intellectual disability.[36] These data are also stratified by age (20-39, 40-59, 60+), but using the average mean and standard deviation scores across the three age groups, results demonstrated significantly increased QoL scores at 24 months post-move in this cohort with severe/profound intellectual disability (MD 170.1, 95% CI [158.4, 181.8]; $p<0.0001$).

One study assessed QoL in a hospital group (n=6) with mild/moderate intellectual disability and severe challenging behaviour (baseline data) prior to a move to community houses and again three and nine months post-move.[32] The authors narratively described significant improvements in overall LEC scores (baseline to three months, 49% increase; three to nine months, additional 24% increase increase), and in all five LEC domains (between 46% and 53%) were described. Domain increases, except Leisure, were maintained nine months post-baseline ($p<0.05$).

One study provided mean LEC change scores stratified by dependency level.[29] These change scores increased (i.e. representing improved QoL) as levels of dependency increased by 11.0 to 13.5 to 17.0 for low, medium and high dependency, respectively, but increases were not statistically significant.

Level of intellectual disability and age

One included study stratified intellectual disability by age (20-39, 40-59 and 60+) and by level of intellectual disability together (mild/moderate and severe/profound).[36] As precise numbers in each age category were not provided, results are narratively presented. Following a move to the community at 24 months follow-up, people with mild/moderate intellectual disability had nonsignificant ($p>0.05$) increases in QoL scores in both the 20-39 and 40-59 age categories, whilst there were nonsignificant decreases for those aged 60+. For people with severe/profound intellectual disability, there were statistically significant QoL improvements across all age categories (age 20-39 $p<0.001$; age 40-59 $p<0.001$, age 60+ $p<0.01$). Furthermore, participants with severe/profound intellectual disability had significantly ($p<0.01$) lower total QoL scores than those with mild/moderate intellectual disability at both baseline and at follow-up. Participants in all age groups and both levels of intellectual disability had significantly increased scores across domains, with the exception of nonsignificant improvement in physical wellbeing for the youngest mild/moderate intellectual disability group and the oldest severe/profound group.

QoL when moving from institutional setting to institutional setting

Two studies evaluated QoL following a move from an institution to either another institution or to a clustered setting (Figure 4).[31 34] Cluster or campus living refers to specialised housing in an institutional setting or specialised housing for people with disabilities clustered together in an estate/street. This is in contrast to dispersed housing which is non-specialised accommodation spread across a neighbourhood amongst general population.[44] Considerable differences in the type of settings the participants moved to precluded combination in a meta-analysis.

Overall QoL-Q scores, at both six months and three years post-move, improved significantly for a sub-group of 19 who moved to refurbished units in a different institution.[31] A sub-group of individuals (with challenging behaviour), who moved from institutions to cluster centres (accommodating between 20-25 residents in each centre) had significantly higher QoL scores at 12 (MD 97.8, 95% CI [68.16, 127.44]) and 24 months (MD 103.5 95% CI [75.77, 131.23], post-move.[34] All QoL sub-domains improved significantly with a linear trend from pre-move to 12 and 24 months post-move to cluster centres (all $p<0.001$). [34]

Direct comparison of two alternative settings demonstrated that individuals who moved from institutions to dispersed small group community homes had significantly higher QoL scores at 12 (MD 26.9, 95% CI [1.27, 52.53] and 24 months (MD 39.2, 95% CI [14.31, 64.09], post-move compared to clustered settings (Figure 5).[34] When subdomain outcomes were compared between dispersed community and clustered settings over time, dispersed settings afforded significantly better physical wellbeing ($p<0.005$), community access ($p=0.001$), routines ($p<0.01$), self-determination ($p<0.01$), residential wellbeing ($p<0.01$) and general life improvements ($p<0.001$). Groups did not differ on material wellbeing and social/emotional wellbeing.

Qualitative studies

The main themes identified in the five qualitative or mixed methods studies were: 1) positive changes experienced following the move to the community and a sense of ‘freedom’ and independence living in the community increased QoL; 2) compatibility amongst housemates; 3) perceived staff’s role in supporting community living; 4) social integration and family contact; 5) ongoing challenges for individuals' QoL. Key qualitative findings are presented in Table 4.

A sense of 'freedom' and independence living in the community increased QoL

Positive outcomes for individuals' wellbeing following a move to the community were reported in all five studies. In contrast to the experience of living in an institutional setting, individuals' new living arrangement in the community was perceived as a more suitable environment as it was more private, less noisy with more space including a garden area and wheelchair access.[37 38] Increased independence regarding money management gave participants the freedom to make every day personal choices that positively impacted their QoL.[38] Compared with their previous experience living in a more restricted residential environment, moving to the community for all participants in three studies was perceived as giving them a sense of 'freedom'.[37-39] Moving to the community was also connected with increased personal space and privacy resulting in improved QoL.

Considering compatibility amongst housemates increased QoL

More careful consideration of the impact of individuals' compatibility with housemates when placing individuals in the community houses is reported as positively impacting individuals' QoL.[37 39] In one study, individuals were perceived by proxies to have been previously affected by housemates making noise or engaging in self-injurious behaviour and indicated the importance of housemate compatibility to QoL.[37]

Perceived staff roles in supporting community living

Staff's support roles were perceived as contributing to individuals' QoL.[37 38] Permanent staff familiar with individuals' interests and choices helped improve individuals' participation in the community and alleviated some individuals' stress related to staff turnover.[37 38] However, some other participants had higher expectations of staff support and involvement, which subsequently negatively impacted their perceived QoL.[38]

Social integration and family contact

The impact of the move on the individuals' social integration and family contact as it related to their QoL was a common theme in all five studies. The case study presents the life history of a woman with learning disabilities and severe challenging behaviour who after 30 years in UK institutions, experienced increases in QoL following her eventual move to a small community staffed house.[41] In particular, access to individualised day programs increased perceived positive social integration. Additionally, increased contact with her family due to the community home's significantly closer proximity to her family meant she ultimately could get to know her siblings after years of separation, and visit her family more regularly. This increased integration into her family's life had a perceived positive impact on her QoL, as noted especially by her mother.

An Australian mixed methods study specifically focused on the significance of the role of informal social networks on QoL. Four types of informal networks for residents were identified: i) non-existent (n = 4 participants); ii) special occasion family (n = 6); iii) engaged family (n = 9); iv) friendship-based (n = 5). Although one of the community house staff's key responsibilities was to support residents maintain contact with family and friends following relocation, this was not substantiated in residents' individual plans.[40]

Table 4 Qualitative data results

Theme	Qualitative data	Study reference
Positive outcome following move to the community	*"She is happier since the move, more responsive and willing, now that she trusts other people."*	O'Brien et al., 2001: 75, Community staff member
	"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: 72, Person with an intellectual disability's Key worker
	"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: 271, Tenant 6
A sense of 'freedom' and independence living in the community improved quality of life	*"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: 79, Person with an intellectual disability
	"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: 74, Person with an intellectual disability's Key worker
Increased personal space and privacy in the community improved quality of life	*"There is more space to move around in. Life has changed."*	O'Brien et al., 2001: 79, Person with an intellectual disability
	"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
	"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

Considering compatibility between housemates critical to quality of life	*"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 (community) 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: 72, Person with an intellectual disability
	"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: 80, Person with an intellectual disability
Perception of staff role in the community	*"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: 73, Person with an intellectual disability's Key worker
	"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: 276, Tenant 2
Improved family contact	*"They . . . are involved more now that I'm up [here]."*	Sheerin et al. 2015: 277, Tenant 5
	"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: 277, Relative of Tenant 4
Social integration outcomes	*"Yeah I do more things . . . Going to the library . . . getting to know the people up here in. Sometimes I say hello to them and . . . They can be*	Sheerin et al., 2015, 276, Tenant 5

	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."	
Ongoing challenges	*"I'm afraid I might fall and there's nobody there and I might get a pain in my heart."*	Sheerin et al., 2015: 275, Tenant 6
	"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"	Sheerin et al., 2015: 275, Tenant 6

In another study, it was perceived that all participants were accessing more services within the community and also "getting out into the community" more as a result of the move.[37] However, the individuals with intellectual disabilities 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 (from the community house). In another study, relatives' experiences differed on how socially integrated into the community their relatives with intellectual disabilities were, ranging from those who felt their relative was welcomed to others who perceived they were not.[38] Overall, most of the participants in this study indicated that they did not feel integrated into the local community and stated that they did not know anyone there. Indeed, some participants appeared to be even more isolated than they were when living in their previous residential setting.

Ongoing challenges for individuals' QoL

Although all five studies with a qualitative component reported positive outcomes for individuals with intellectual disabilities moving into the community, ongoing challenges to individuals' QoL were also reported. Adjustment to the move could reportedly take months, depending on the individuals' transition circumstances. Ongoing difficulties included day programmes being too cramped, with poor consideration of the individuals' needs in particular in relation to challenging behaviours; unavailability of speech and language therapy or communication aids; [37] family contact was infrequent and accessing amenities was inconvenient due to a post-move rural location; [37] lack of adequate funding meant reduced night time community staffing and no overnight trips;[37] and some participants experienced a loss of security following the move related to change in staffing routines, leading to loneliness and insecurity.[38]

Discussion

Key findings

Our systematic review yielded quantitative and qualitative findings that deinstitutionalisation is associated with QoL improvements for people with intellectual disabilities. These findings are broadly consistent with prior reviews.[23 45-47]

There was substantial agreement across quantitative analysis regarding improved QoL which held for shorter (up to one year) and longer (more than one year) term QoL measures, with a slightly increased difference between pre-move and longer term QoL (overall) than shorter-term QoL. This challenges to some extent previous findings which indicated modest gains which occurred soon after the move and plateaued at one year.[48]

When institutional settings close, it tends to happen in a phased approach with evidence showing the younger less complex needs cohort moving first.[19 49] The present analysis highlighted the positive gains in QoL that can be experienced by people with severe/profound ID and higher support needs. This finding also held for most aspects or sub-domains of QoL where these were studied.

Qualitative studies found that movement to community residences facilitated an improved sense of wellbeing, freedom and independent decision-making. When housemate compatibility was more carefully considered prior to their move, individuals had higher quality daily living experiences. There remain, however, challenges for aspects of QoL, including social integration and relationships, and physical wellbeing for certain subgroups.

Becoming part of the community is considered one of the main advantages associated with living in the community.[40 44] In our review, mixed findings are reported on the impact of the move on individuals' social integration into the wider community. Authentic community participation eluded many individuals and some individuals reported feeling lonelier since the move due to differing expectations of staff supports. This concurs with previous work with regard to the importance of the quality of supports provided and further highlights that an improvement in QoL is not inevitable but must be managed and supported.[40] Prior to the move, individuals living in institutional settings had relied more heavily upon staff to care for their basic living needs. Following the move to the community with an increased emphasis on nurturing independence, some individuals may experience a loss of security. Without the support from staff to maintain family contact and retain friendships from previous residential setting, individuals' sense of disconnectedness could be compounded. It would be interesting in future research to see if this disconnect is better bridged over time.

This review indicates that support from staff to facilitate integration into the community whilst maintaining family and other social contacts is vital to the individuals' QoL. Individual transition-planning requires thoughtful consideration to address the issue of housemate compatibility, and service user expectations about the level of support provided by staff. Increased contact with family could create new opportunities for family to participate more in supporting social activities (e.g. overnight trips and excursions) that could otherwise be restricted due to limited funding. Yet, despite the ostensible QoL benefits of family contact and relationships, and that community living might facilitate same, there is evidence in the findings that social network sizes may not increase significantly in the longer term following a move, and that family contact in fact shows a downwards trend.

Strengths and limitations

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

Nevertheless, there are a number of important limitations to our work. We were unable to define *ex ante* definitions of 'congregated/institutional' and 'community' settings. In practice, institutions were clearly institutions – places with a number of institutional features, and described as such. Community definitions were more nebulous and we made the best judgements we could as well as providing all available information on the precise conditions in each study, to allow for third party evaluation. We are satisfied retrospectively with this approach. Applying a hard definition would have been very problematic, due to reporting insufficiencies of the extant research. In devising our search strategy we were faced with profound challenges in defining our intervention. 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.

Similarly, QoL is a multi-faceted concept with many potential definitions. We considered different approaches to capturing QoL, for example including all identified sub-domains in the Schalock framework,[6] but we did not consider it feasible to identify reliably all named domains and their synonyms. We therefore chose author-defined QoL as our outcome of interest.

In reviewing returned studies from the database search, we used two independent reviewers for title/abstract and full texts, but one reviewer at quality assessment and data extraction with a second reviewer providing a corroborating review. While corroboration by a second reviewer can be acceptable in the review process, the lack of independent second reviewer assessments does introduce the potential for bias in the quality assessment and data extraction phases of the review. Thirty-two (17%) of the studies that we identified as suitable for full text review proved unobtainable and so are not included in our final analyses, thus, potentially introducing selection bias. These studies, however, are on average older than those we were able to access and are listed in Appendix 5.

The decision to require documentation of consent obtained from participants with intellectual disabilities and ethical considerations did mean that a number of older studies were excluded as well as all of the grey literature. We considered that categorically requiring reporting of a consent process helped to safeguard against: a) bias derived from inappropriately conducted research (e.g. acquiescence), and b) inclusion of research with inadequate ethical protocols in meta-analyses and consequent publication of new and original research findings based partly on such research. In consideration of the importance of choice and subjective evaluation, and the potential for conflict of interest, we viewed this as an unacceptable risk of bias. However, we are not implying that good or appropriate ethical practice was not adhered to in excluded studies, merely that we could not necessarily ascertain this. A surface appraisal of our decisions for exclusion (Appendix) attests to the fact that the clear majority of research excluded for reasons of ethical considerations also had other methodological shortcomings that would have been sufficient to exclude the study from our review, either in concert with the ethical considerations, or in and of themselves.

Included studies were all observational and had a sample size range of 1 to 76. It is not surprising that observational designs dominate in this field and to maximise confidence in our results we ensured that all included studies met a minimum threshold for methodological quality using the CASP quality assessment tool (that is ‘good/high’ quality). Additionally to assess the level and quality of the evidence for QoL, we performed a GRADE (Grading of Recommendations Assessment, Development, and Evaluation) assessment of the summary results. 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 QoL measures, that is up to one year post-move, and more than one year post-move, the quality of evidence is moderate (downgraded 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 (Table 5).

Table 5 Summary of findings: Pre-move compared to post-move for quality of life in persons with any level of ID, and any setting

Patient or population: Quality of life; **Setting**: Institutional and Community

Intervention: Post-move; **Comparison**: Pre-move

Outcomes	**№ of participants (studies)**	**Certainty of the evidence (GRADE)**	**Comments**
Quality of Life: less than/= 1 year post-move	492 (5 observational studies)	⊕⊕⊕◯ MODERATE [a,b]	a. Observational (pre/post) studies b. Statistical heterogeneity
Quality of Life: greater than 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 effect

We also included only English language studies in our review, excluding 12 studies on this basis, which is another potential source of bias. These studies are listed in Appendix 6 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 with 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 topic experts on the websites of research centres active in this field and those of governments in countries at the forefront of deinstitutionalisation in intellectual disability. This may have biased reviewed studies against other nations and research groups. While much grey literature was excluded from the review for considerations including lack of comprehensive reporting on ethics, there may be findings of import within that literature that may warrant separate review or discussion.

Future research

Subpopulations with additional needs or who require high-levels of support have received insufficient attention in the literature, and research of high methodological quality is required to better understand the needs of a range of groups. It could be reasonably concluded from the available evidence that a move to the community provides similar benefits for people with more severe levels of intellectual disability and that people with high-support needs or challenging behaviour experience similar benefits to their counterparts who have fewer additional needs. This conclusion is based on a few studies and is subject to limitations similar to the wider literature.

With people with intellectual disabilities now living much longer into old age than previous generations, how older age interacts with residential moves also needs comprehensive investigation. Physical well-being has emerged as an aspect of QoL which may not improve as much for groups encompassing younger people with mild intellectual disability and older people with severe intellectual disability. Whilst it is possible that younger groups reach a relative ceiling of functioning and well-being, with little room for additional improvement *per se*, older adults with intellectual disabilities may require additional and different supports. Special attention must be paid to the population with dementia, a population which likely faces additional and growing challenges and may require specific supports for optimal QoL. Research is also lacking on people with other specific health needs or impairments (e.g. those using ventilators), those who present a forensic risk and ex-prisoners. We have limited information about whether and how these particular groups' QoL might be affected by where they live, and furthermore how such clients might ultimately be best supported to experience the benefits of community living and optimal QoL.

There is a scarcity of comprehensive data on outcomes more than two years post-relocation to the community. Existing evidence indicates that while QoL may increase following a move to a non-institutional setting, it begins to plateau between one and two years after the move. Longitudinal studies with longer follow-up periods are warranted to monitor whether the improvement of outcomes is maintained at least in the longer term. Again, serious attention must be paid to the different populations outlined above and to understanding the mechanisms by which changes or improvements in QoL occur, including the impact of changes in services available, proximity to important services and opportunities.

Conclusion

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 QoL compared to the institution. Qualitative studies in particular suggest that observed improvements occur through improved wellbeing, freedom and independent decision making, more careful consideration of housemate compatibility, increased family contact and social integration opportunities.

While it is tempting to suggest sufficient evidence exists, there remain a number of unanswered questions. There is not yet enough knowledge about the long-term course of QoL outcomes, which is of particular interest considering the ageing nature of this population, or for specific aspects of QoL, including social integration and relationships. Subpopulations with additional needs or who require high-levels of support have received insufficient attention in the literature, and research of high methodological quality is required to better understand heterogeneity of need and outcome. Moreover, qualitative studies highlighted a number of negative QoL outcomes including insecurity, fear and loneliness that emphasise that gains do not come without a cost. These concerns also need further investigation.

Future research must address these issues to ensure that, as deinstitutionalisation continues around the world in the context of profound demographic change, people with intellectual disabilities are supported to live healthy, independent lives of their own choosing.

Figure Legends

Figure 1 PRISMA for QoL search

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

Figure 3 Quality of life in people with mild/moderate intellectual disability only post-move

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

Figure 5 Quality of life in community versus cluster settings following a move from an institution

Author statement

MMC, PMC co-designed the original review protocol, oversaw all phases of the review process and, drafted and revised the paper. MMC is guarantor. RLV and EM were lead researchers on all stages of the systematic review - title and abstract, full text, quality assessment, data analysis – and led authorship of the manuscript. MAOD co-designed the original review protocol, led the grey literature search, advised and contributed throughout the review process as a topic expert, and drafted and revised the paper. NW conducted the grey literature search, and drafted and revised the paper. GS was the information specialist, co-designing and running the database searchers, and revising the paper. RS co-designed the original review protocol, advised and contributed throughout the review process as a topic expert, and drafted and revised the paper. VS co-designed the original review protocol, advised and contributed throughout the review process as a systematic review expert, and drafted and revised the paper. CN co-designed the original review protocol, advised and contributed throughout the review process as an economics expert, and drafted and revised the paper. PM co-designed the original review protocol, project-managed the review process and, drafted and revised the paper.

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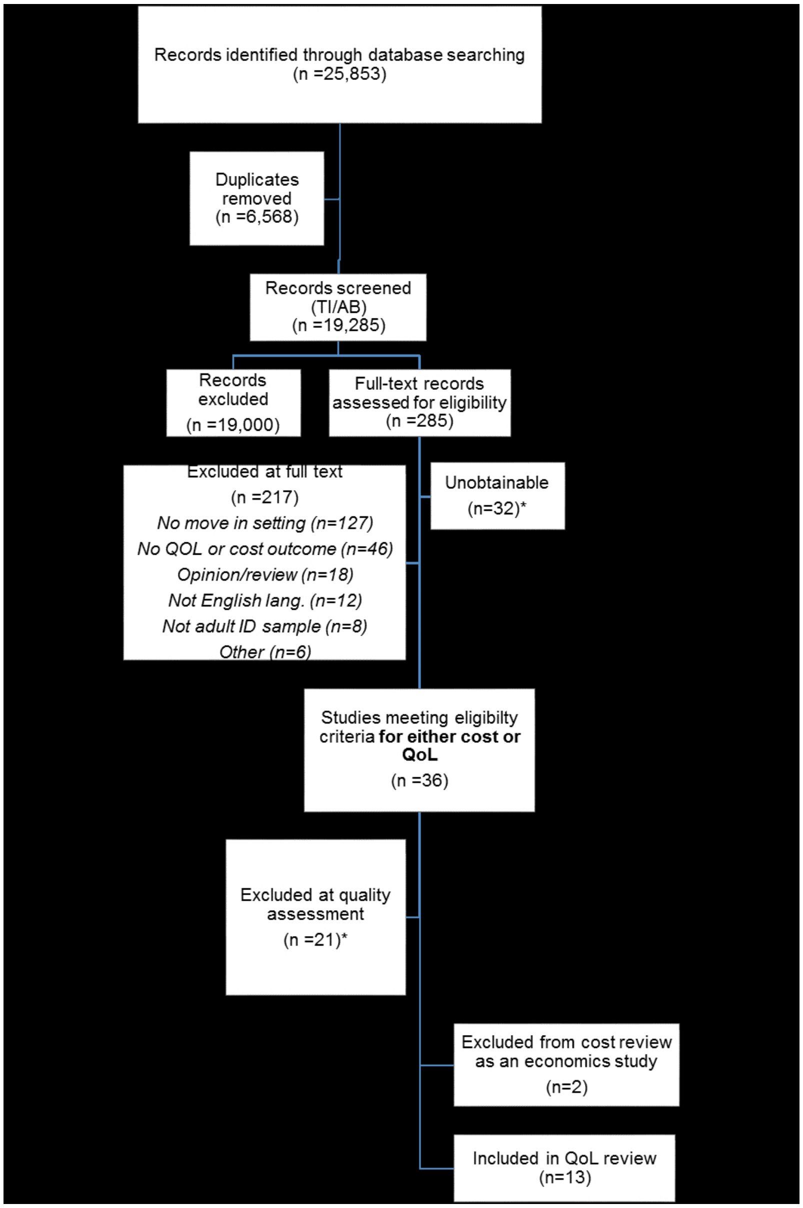
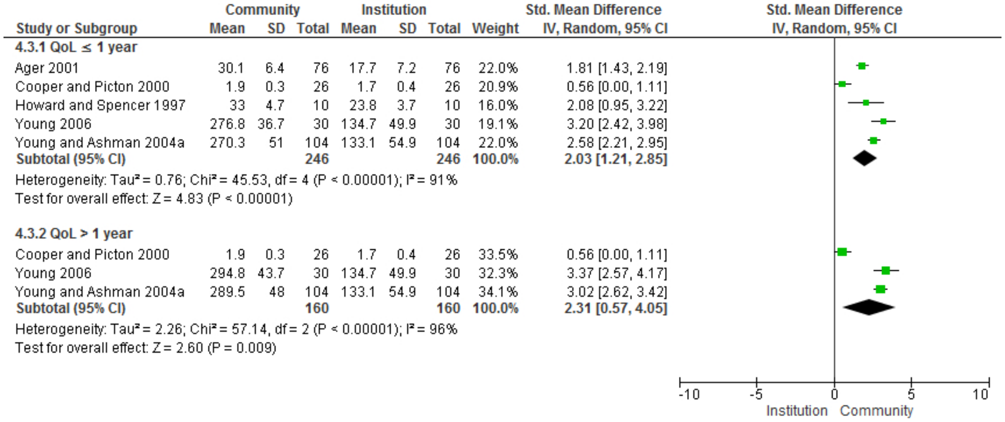


Figure 1 PRISMA for QoL search

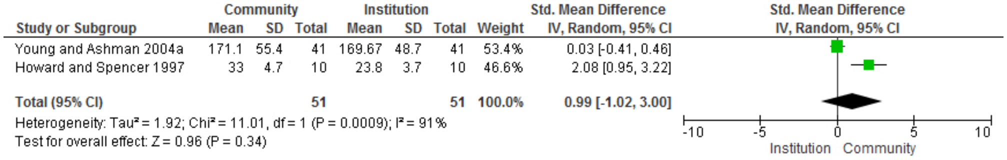
156x236mm (150 x 150 DPI)



Study or Subgroup	Community Mean	Community SD	Community Total	Institution Mean	Institution SD	Institution Total	Weight	Std. Mean Difference IV, Random, 95% CI
4.3.1 QoL ≤ 1 year								
Ager 2001	30.1	6.4	76	17.7	7.2	76	22.0%	1.81 [1.43, 2.19]
Cooper and Picton 2000	1.9	0.3	26	1.7	0.4	26	20.9%	0.56 [0.00, 1.11]
Howard and Spencer 1997	33	4.7	10	23.8	3.7	10	16.0%	2.08 [0.95, 3.22]
Young 2006	276.8	36.7	30	134.7	49.9	30	19.1%	3.20 [2.42, 3.98]
Young and Ashman 2004a	270.3	51	104	133.1	54.9	104	22.0%	2.58 [2.21, 2.95]
Subtotal (95% CI)			**246**			**246**	**100.0%**	**2.03 [1.21, 2.85]**
Heterogeneity: Tau² = 0.76; Chi² = 45.53, df = 4 (P < 0.00001); I² = 91%								
Test for overall effect: Z = 4.83 (P < 0.00001)								
4.3.2 QoL > 1 year								
Cooper and Picton 2000	1.9	0.3	26	1.7	0.4	26	33.5%	0.56 [0.00, 1.11]
Young 2006	294.8	43.7	30	134.7	49.9	30	32.3%	3.37 [2.57, 4.17]
Young and Ashman 2004a	289.5	48	104	133.1	54.9	104	34.1%	3.02 [2.62, 3.42]
Subtotal (95% CI)			**160**			**160**	**100.0%**	**2.31 [0.57, 4.05]**
Heterogeneity: Tau² = 2.26; Chi² = 57.14, df = 2 (P < 0.00001); I² = 96%								
Test for overall effect: Z = 2.60 (P = 0.009)								

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

227x97mm (96 x 96 DPI)

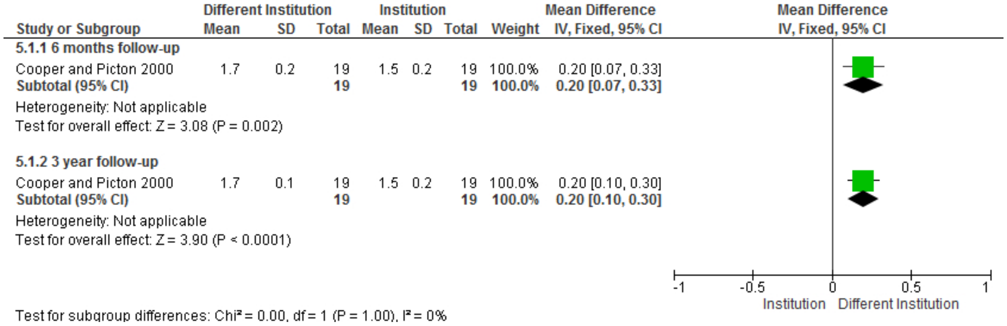


Study or Subgroup	Community Mean	SD	Total	Institution Mean	SD	Total	Weight	Std. Mean Difference IV, Random, 95% CI
Young and Ashman 2004a	171.1	55.4	41	169.67	48.7	41	53.4%	0.03 [-0.41, 0.46]
Howard and Spencer 1997	33	4.7	10	23.8	3.7	10	46.6%	2.08 [0.95, 3.22]
Total (95% CI)			**51**			**51**	**100.0%**	**0.99 [-1.02, 3.00]**

Heterogeneity: Tau² = 1.92; Chi² = 11.01, df = 1 (P = 0.0009); I² = 91%
Test for overall effect: Z = 0.96 (P = 0.34)

Figure 3 Quality of life in people with mild/moderate intellectual disability only post-move

228x38mm (96 x 96 DPI)

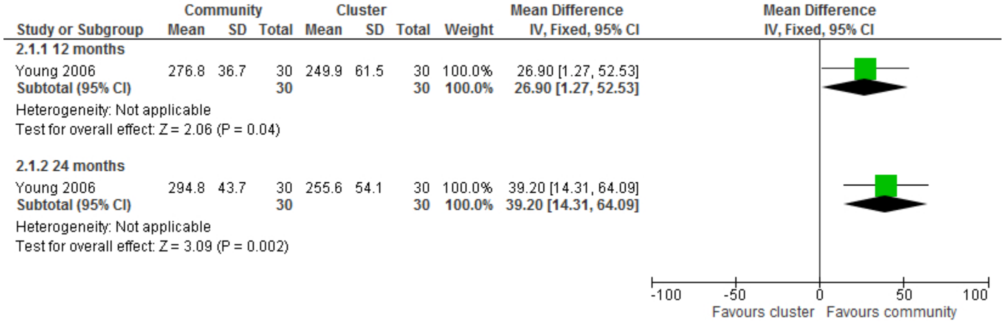


Study or Subgroup	Different Institution Mean	SD	Total	Institution Mean	SD	Total	Weight	Mean Difference IV, Fixed, 95% CI
5.1.1 6 months follow-up								
Cooper and Picton 2000	1.7	0.2	19	1.5	0.2	19	100.0%	0.20 [0.07, 0.33]
Subtotal (95% CI)			**19**			**19**	**100.0%**	**0.20 [0.07, 0.33]**
Heterogeneity: Not applicable								
Test for overall effect: Z = 3.08 (P = 0.002)								
5.1.2 3 year follow-up								
Cooper and Picton 2000	1.7	0.1	19	1.5	0.2	19	100.0%	0.20 [0.10, 0.30]
Subtotal (95% CI)			**19**			**19**	**100.0%**	**0.20 [0.10, 0.30]**
Heterogeneity: Not applicable								
Test for overall effect: Z = 3.90 (P < 0.0001)								

Test for subgroup differences: Chi² = 0.00, df = 1 (P = 1.00), I² = 0%

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

222x71mm (96 x 96 DPI)



Study or Subgroup	Community Mean	Community SD	Community Total	Cluster Mean	Cluster SD	Cluster Total	Weight	Mean Difference IV, Fixed, 95% CI
2.1.1 12 months								
Young 2006	276.8	36.7	30	249.9	61.5	30	100.0%	26.90 [1.27, 52.53]
Subtotal (95% CI)			**30**			**30**	**100.0%**	**26.90 [1.27, 52.53]**
Heterogeneity: Not applicable								
Test for overall effect: Z = 2.06 (P = 0.04)								
2.1.2 24 months								
Young 2006	294.8	43.7	30	255.6	54.1	30	100.0%	39.20 [14.31, 64.09]
Subtotal (95% CI)			**30**			**30**	**100.0%**	**39.20 [14.31, 64.09]**
Heterogeneity: Not applicable								
Test for overall effect: Z = 3.09 (P = 0.002)								

Figure 5 Quality of life in community versus cluster settings following a move from an institution

217x71mm (96 x 96 DPI)

Appendix 1 Search strategy

We searched seven databases for studies of deinstitutionalisation for people with intellectual disabilities, specifically evaluating effects on economic outcomes and quality of life (see main article).

We executed a search with four categories of terms and controlled vocabulary:

- Category 1: Intervention
- Category 2: Intellectual disability
- Category 3: Quality of life
- Category 4: Economic outcomes

With respect to the intervention, no standardised terminology exists for the concept of deinstitutionalisation/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 in our search strategy (Appendix Table 1) therefore includes not only vocabulary related to transitions but also different categories of residence (e.g. hospital, home).

Similarly with respect to population, the language used in describing people with intellectual disability has changed profoundly over the last 50 years. Category 2 choices are therefore intended to capture current and historic terminology. In specifying language for Category 3 (quality of life) in our search strategy we considered multiple approaches, including 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. 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. In Category 4 (economics) we selected both terms for resource use and terms for economic evaluation.

Appendix 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).

Appendix 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(“” 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 behaviour”) 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 behaviour”)
4	**Economic outcomes**	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)

Appendix 2 Grey literature search strategy

Methodology

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

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

The countries searched are those outlined in the IASSIDD Policy and Practice SIRG position paper on deinstitutionalisation - UK, USA/Canada, Australia, Scandinavian. These countries have been at the forefront in implementing policies on 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 key words set out for the systematic review (see chapter 2.2).

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

- countries not listed above
- documents that are purely descriptive with no data on quality of life measurement or cost measurement
- documents that do not deal with movement but which assess cross sectional data of people within a particular setting and comparisons across settings but not movement
- PhD/masters and books

Steps in the search for grey literature:

1. Generate 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) search within the agency/centre website for key words 'deinstitutionalisation', 'housing', 'home', 'decongregation', 'transition' as per broad search terms. If not an intellectual disability specific organisation, then the search terms of 'intellectual disability', 'developmental disability' or 'learning disability' will need to be include 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 each report on this list was then reviewed by the two researchers (MA and NW) and categorised as 1: included (data), 2: included (background information), 3. Exclude, 4. Unclear.

Any queries were then discussed and agreed between the two researchers and the report assign to the appropriate category.

RelevantGrey Literature
Conroy *et al.* (1985) The Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis. Retrieved from https://aspe.hhs.gov/pdf-report/pennhurst-longitudinal-study-combined-report-five-years-research-and-analysis
Conroy, J. and Seiders, J. (1994) 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. PA: Conroy and Feinstein Associates, Wynnewood. Retrieved from https://mn.gov/mnddc/parallels2/pdf/90s/93/93-CJN-UNJ.pdf
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Dixon, R. M., Marsh, H. W. & Craven, R. G. (2004). Moving out: the impact of deinstitutionalisation on salient affective variables for people with mild intellectual disabilities. Proceedings of the Third International Biennial SELF Research Conference: Self-concept, Motivation and Identity: Where to from here? 4-7 July, 2004 (pp. 1-12). Sydney, Australia: SELF Research Centre, University of Sydney. Retrieved from http://ro.uow.edu.au/cgi/viewcontent.cgi?article=1172&context=edupapers
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Conroy, J. W., Lemanowicz, J. A., Feinstein, C. S., & Bernotsky, J. M. (1991). The Connecticut Applied Research Project: 1990 results of the CARC v. Thorne longitudinal study. Retrieved from http://static1.squarespace.com/static/53dfdc3be4b0a86a2dbf76ae/t/5671ccbdcbced6829d5f191b/1450298557957/1990+Results+of+the+CARC+Vs+Thorne+Longitudinal+Study.pdf

Appendix 3 Studies excluded at quality assessment (both cost and QOL studies)

Appendix Table 2 Quality-assessed excluded studies

Study	Exclusion Reasons
Bhaumik *et al.* (2011)	• CASP screening question 2 E.g. no information on ethics, recruitment
Bratt & Johnston (1988)	• CASP [1]screening questions 1 & 2 • Aggregated adolescent and adult populations
Conneally *et al.* (1992)	• CASP screening question 2. • Aggregated child and adult populations
Conroy *et al.* (2003)	• CASP screening question 1 & 2 • E.g. PICO difficulties
Cullen (1995)	• CASP screening questions 1 & 2 • E.g. No aim, ethics, consent or sampling stated. • Difficulties at confirming exact ID population in terms of need.
Dagnan *et al.* (1995)	• CASP screening question 2 • E.g. No ethics or recruitment procedure detailed
Dagnan *et al.* (1996)	• CASP screening question 2
Dagnan *et al.* (1998)	• CASP screening question 2 • E.g. No ethics details provided
Donnelly (1996)	• CASP screening question 2

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[1] CASP Reference

Donnelly (1997)	• CASP screening question 2 • E.g. no consent
Fish & Lobley (2001)	• CASP screening question 1 • E.g. PICO not met
Fleming & Stenfert-Kroese (1990)	• CASP screening question 1 & 2
Forrester - Jones (2002)	• CASP screening question 2 • E.g. no ethics, consent, sampling details provided
Hemming *et al.* (1981)	• CASP screening question 1 & 2
Mansell (1994)	• CASP screening question 1. • Children in the cohort
Marlow & Walker (2015)	• CASP screening question 1 and 2
Perry *et al.* (2011)	• CASP screening question 2. • E.g. not representative of defined population
Roy *et al.* (1994)	• Did not meet CASP screening question 2 • No ethics, statement of sampling, or generalizability, no mention of bias
Sines *et al.* (2012)	• CASP screening question 1 • E.g. no ethical considerations
Spreat & Conroy (2002)	• CASP screening question 1 & 2
Srivastava & Cooke (1999)	• No reporting of findings interim report; PICO not detailed precisely
Walker *et al.* (1995)	• CASP screening question 1.
Young (2003)	• CASP screening question 1.

Appendix 4 Excluded at quality assessment

Appendix Table 3 Quality-assessed excluded studies

Study	Exclusion Reasons
Bhaumik *et al.* (2011)	• CASP screening question 2 E.g. no information on ethics, recruitment
Bratt & Johnston (1988)	• CASP [2]screening questions 1 & 2 • Aggregated adolescent and adult populations
Conneally *et al.* (1992)	• CASP screening question 2. • Aggregated child and adult populations
Conroy *et al.* (2003)	• CASP screening question 1 & 2 • E.g. PICO difficulties
Cullen (1995)	• CASP screening questions 1 & 2 • E.g. No aim, ethics, consent or sampling stated. • Difficulties at confirming exact ID population in terms of need.
Dagnan *et al.* (1995)	• CASP screening question 2 • E.g. No ethics or recruitment procedure detailed
Dagnan *et al.* (1996)	• CASP screening question 2
Dagnan *et al.* (1998)	• CASP screening question 2 • E.g. No ethics details provided
Donnelly (1996)	• CASP screening question 2

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[2] CASP Reference

Donnelly (1997)	• CASP screening question 2 • E.g. no consent
Fish & Lobley (2001)	• CASP screening question 1 • E.g. PICO not met
Fleming & Stenfert-Kroese (1990)	• CASP screening question 1 & 2
Forrester - Jones (2002)	• CASP screening question 2 • E.g. no ethics, consent, sampling details provided
Hemming *et al.* (1981)	• CASP screening question 1 & 2
Mansell (1994)	• CASP screening question 1. • Children in the cohort
Marlow & Walker (2015)	• CASP screening question 1 and 2
Perry *et al.* (2011)	• CASP screening question 2. • E.g. not representative of defined population
Roy *et al.* (1994)	• Did not meet CASP screening question 2 • No ethics, statement of sampling, or generalizability, no mention of bias
Sines *et al.* (2012)	• CASP screening question 1 • E.g. no ethical considerations
Spreat & Conroy (2002)	• CASP screening question 1 & 2
Srivastava & Cooke (1999)	• No reporting of findings interim report; PICO not detailed precisely
Walker *et al.* (1995)	• CASP screening question 1.
Young (2003)	• CASP screening question 1.

Appendix 5 Unobtainable studies

Appendix Table 4 Studies that met eligibility criteria but could not be accessed

Authors	Year	Title	Journal	Vol.	Issue	Pages
Y. Don; Y. Amir	1969	Institutions for mentally retarded in Israel: Cost structure and budget analysis	Mental Retardation	7	3	36-39
I. N. Wolfson	1970	Adjustment of institutionalized mildly retarded patients twenty years after return to the community	Mental Retardation	8	4	20-23
A. T. Bjaanes; E. W. Butler	1974	Environmental variation in community care facilities for mentally retarded persons	American Journal of Mental Deficiency	78	4	429-439
M. Aninger; K. Bolinsky	1977	Levels of independent functioning of retarded adults in apartments	Mental Retardation	15	4	Dec-13
S. C. McDevitt; P. M. Smith; D. W. Schmidt; M. Rosen	1978	The deinstitutionalized citizen: Adjustment and quality of life	Mental Retardation	16	1	22-24
A. L. Carsrud; K. B. Carsrud; D. P. Henderson; C. J. Alisch; A. V. Fowler	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
J. C. Intagliata; B. S. Wilder; F. B. Cooley	1979	Cost comparison of institutional and community based alternatives for mentally retarded persons	Mental Retardation	17	3	154-156
R. H. Bruininks; F. A. Hauber; M. J. Kudla	1980	National survey of community residential facilities: A profile of facilities and residents in 1977	American Journal of Mental Deficiency	84	5	470-478
R. L. Schalock; R. S. Harper; G. Carver	1981	Independent living placement: Five years later	American Journal of Mental Deficiency	86	2	170-177
J. Intagliata; B. Willer	1982	Reinstitutionalization of mentally retarded persons successfully placed into family-care and group homes	American Journal of Mental Deficiency	87	1	34-39

T. Heller	1982	Social disruption and residential relocation of mentally retarded children	American Journal of Mental Deficiency	87	1	48-55
W. R. Cook	1983	Economics of providing services to the mentally retarded	Mental Retardation & Learning Disability Bulletin	11	1	13-21
L.W. Heal; J. 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
J. O'Neill; M. Brown; W. Gordon; R. Schonhorn	1985	The impact of deinstitutionalization on activities and skills of severely/profoundly mentally retarded multiply-handicapped adults	Applied Research in Mental Retardation	6	3	361-371
R. L. Schalock; M. A. 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
D. 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
J. Lalonde; A. Marchand; N. Marineau	1986	La réinsertion sociale de déficientes intellectuelles résidant en milieu psychiatrique. =The social reintegration of institutionalized mentally retarded women	Revue de Modification du Comportement	16	2	84-93
N. S. Springer	1987	From institution to foster care: Impact on nutritional status	American Journal of Mental Deficiency	91	4	321-327
E. A. Eastwood; G. A. Fisher	1988	Skills acquisition among matched samples of institutionalized and community-based persons with mental retardation	American Journal Of Mental Retardation: AJMR	93	1	75-83
R. B. Edgerton	1988	Aging in the community: A matter of choice	American Journal on Mental Retardation	92	4	331-335
J. O'Neill; M. Brown; W. A. Gordon; J. P. Orazem; C. Hoffman; R. Schonhorn	1990	Medicaid versus state funding of community residences: Impact on daily life of people with mental retardation	Mental Retardation	28	3	183-188

J. W. Ashbaugh; T. Nerney	1990	Costs of providing residential and related support services to individuals with mental retardation	Mental Retardation	28	5	269-273
C. Jourdan-Ionescu; S. Ionescu; L. Corbeil; C. Rivest	1990	Evaluation de la désinstitutionnalisation: I. La qualité de vie. =Evaluation of deinstitutionalization: I. Quality of life	Revue francophone de la déficience intellectuelle	1	1	49-58
P. J. Cunningham; C. D. Mueller	1991	Individuals with mental retardation in residential facilities: Findings from the 1987 National Medical Expenditure Survey	American Journal on Mental Retardation	96	2	109-117
J. Lord; A. Pedlar	1991	Life in the community: Four years after the closure of an institution	Mental Retardation	29	4	213-221
J. Barlow; N. Kirby	1991	Residential satisfaction of persons with an intellectual disability living in an institution or in the community	Australia & New Zealand Journal of Developmental Disabilities	17	1	Jul-23
B. E. McGuire; G. Choon; E. Akuffo	1991	Community living for elderly people with an intellectual disability: A pilot study	Australia & New Zealand Journal of Developmental Disabilities	17	1	25-33
R. L. Schalock; L. T. Genung	1993	Placement from a community-based mental retardation program: A 15-year follow-up	American Journal on Mental Retardation	98	3	400-407
C. A. Knobbe; S. P. Carey; L. Rhodes; R. H. Horner	1995	Benefit-cost analysis of community residential versus institutional services for adults with severe mental retardation and challenging behaviors	American Journal on Mental Retardation	99	5	533-541
J. Tossebro	1995	Impact of size revisited: Relation of number of residents to self-determination and deprivatization	American Journal on Mental Retardation	100	1	59-67
B. R. Wagner; D. F. Long; M. L. Reynolds; J. R. Taylor	1995	Voluntary transformation from an institutionally based to a community-based service system	Mental Retardation	33	5	317-321
A. G. Philaretou; S. 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 6 Studies in a language other than English

Appendix Table 5 Studies in a language other than English

Title	Authors	Published Year	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?] [French]	Beckers, J.	1984	International Journal of Rehabilitation Research	7	4	409-418
La désinstitutionnalisation des personnes déficientes intellectuelles et leur appréciation de la qualité de vie. = Deinstitutionalization of individuals with mental disabilities and their perception of the quality of life [French]	Boudreault, Paul	1990	Revue Francophone de la Déficience Intellectuelle	1	2	147-158
Evaluation de la désinstitutionnalisation: 2. Modifications du niveau intellectuel et des comportements adaptatifs. = Evaluation of deinstitutionalization: II. Changes in intelligence level and adaptive behaviors [French]	Jourdan-Ionescu, Colette; Ionescu, Serban; Rivest, Christine; Corbeil, Luc	1990	Revue Francophone de la Déficience Intellectuelle	1	2	137-146
L'effet de l'integration sociale sur le comportement adaptatif et sur la diversité des activités. = The effects of social integration on adaptive behavior and on diversification of activities [French]	Michaud, Danielle; Horth, Raynald; Roy, Sarto	1992	Revue Francophone de la Déficience Intellectuelle	3	1	39-48
L'évaluation des besoins et de la qualité de vie d'adultes ayant une déficience intellectuelle. = Assessment of the needs and the quality of life of adults with mental retardation [French]	Lachapelle, Yves; Cadieux, Alain	1993	Comportement Humain	7	2	117-127
De l'Hôpital Louis-H. Lafontaine Ã la rue Lafontaine. = From Lafontaine Hospital to Lafontaine Street: Deinstitutionalization of persons with mental disabilities [French]	Lalonde, Francine; Lamarche, Constance	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] [German]	Meins, W.	1993	Psychiatrische Praxis	20	3	106-108
Normalisierte Wohnformen für Menschen mit geistiger [illegible] auf die Bewohnerinnen und Bewohner. = Normalized	Kief, Michael	1994	Vierteljahresschrift für Heilpädagogik und ihre Nachbargebiete	63	1	33-45

accommodation for people with intellectual disabilities and the effects on the residents [German]						
L'influence du processus de désinstitutionnalisation sur l'intégration sociale de personnes présentant une déficience intellectuelle sévère et profonde. = The influence of the deinstitutionalization process on the social integration of people with severe and profound intellectual deficiency [French]	Paré, Charles; Parent, Ghyslain; Pilon, Wilfrid; Côté, Richard	1994	Revue Francophone de la Déficience Intellectuelle	5	2	137-154
The Possibilities for Mentally Retarded Persons to Make their Own Choices in Everyday Life [Croatian]	⊠ ⊠ ⊠ ⊠ ⊠ Daniela; ⊠ ⊠ O ⊠ ⊠ Marija; 1 ⊠ ⊠ ⊠ O Branko	2003	Hrvatska Revija za Rehabilitacijska ⊠⊠ ⊠ ⊠ ⊠ ⊠ ⊠ ⊠	39	2	117-127
A study on the life satisfaction of mentally handicapped persons visiting a day care [Japanese]	Handa, M.; Kusaka, K.; Kanoya, Y.; Sato, C.	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 [Croatian]	. ⊠ ⊠ P ⊠ M.; 6 ⊠ ⊠ ⊠ ⊠ ⊠ ⊠ O ⊠ ⊠ S.; ⊠ ⊠ ⊠ ⊠ ⊠ D.	2013	Hrvatska Revija za Rehabilitacijska ⊠⊠ ⊠ ⊠ ⊠ ⊠ ⊠ ⊠	49	SUPPL.	50-63

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	5
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	7-8
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	8
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	6
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	9-10
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	10-11
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Appendix 1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	11-12
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	12-13
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	12-13
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	13
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	13
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	13

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	13
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	13
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	14-15
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	15
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	15
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	15
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	16-19
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	16-19
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	18-19
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	22-24
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	24-26
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	29
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	6

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: **www.prisma-statement.org**.

BMJ Open

The effect of deinstitutionalisation on quality of life for adults with intellectual disabilities: a systematic review

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Primary Subject Heading:	Health services research
Secondary Subject Heading:	Health policy
Keywords:	quality of life, intellectual disabilities, deinstitutionalisation

Title

The effect of deinstitutionalisation on quality of life for adults with intellectual disabilities: a systematic review

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Data sharing

There are no unpublished data from this study. This is a systematic review that generates no new data. We make our results available in full in the manuscript. Further questions should be directed to the corresponding author.

Competing interest statement

All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work.

Ethical approval

N/A.

Funding

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Statement of independence

All authors are independent of the study sponsors.

Statement of access

All authors had full access to all of the data in the study and can take responsibility for the integrity of the data and the accuracy of the analysis.

Transparency declaration

The lead author affirms that the manuscript is an honest, accurate and transparent account of the study being reported; that no important aspects of the study have been omitted; and that there are no discrepancies from the study as planned.

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Abstract (<=300 words)

Objective: To review systematically the evidence on how deinstitutionalisation affects quality of life for adults with intellectual disabilities.

Design: Systematic review.

Population: adults (aged 18 years and over) with intellectual disabilities.

Interventions: a move from residential to community setting

Primary and secondary outcome measures: studies were eligible if evaluating effect on quality of life or life quality, as defined by study authors.

Search: We searched MEDLINE, PsycINFO, CENTRAL, CINAHL, EconLit, Embase and Scopus to September 2017 and supplemented this with grey literature searches. We assessed study quality using the Critical Appraisals Skills Programme (CASP) suite of tools, excluding those judged to be of poor methodological quality.

Results: Thirteen studies were included; eight quantitative studies, two qualitative, two mixed methods studies, and one case study. There was substantial agreement across quantitative and qualitative studies that a move to community living was associated with improved quality of life. Quality of life for people with any level of intellectual disabilities who move from any type of institutional setting to any type of community setting was increased at up to one year post-move (SMD 2.03; 95% CI [1.21, 2.85], 5 studies, 246 participants) and beyond one year post-move (SMD 2.34. 95% CI [0.49, 4.20], 3 studies, 160 participants), with total QoL change scores higher at 24 months comparative to 12 months, regardless of QoL measure used.

Conclusion: Our systematic review demonstrated a consistent pattern that moving to the community was associated with improved quality of life compared to the institution. It is recommended that gaps in the evidence base, for example, with

regard to growing populations of older people with intellectual disability and complex needs are addressed.

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Registration: PROSPERO (CRD42018077406)

Article summary

Strengths and limitations of this study

- We conducted an extensive systematic search of academic databases, using two reviewers to assess eligibility independently.
- Eligible quantitative and qualitative studies were required to meet a minimum quality threshold.
- We excluded studies not reporting ethical approval, which minimises bias and improves quality standards but potentially excludes earlier studies conducted without reporting guidelines.
- We did not include static cross-sectional studies, requiring that studies evaluated a move in residence for a person with intellectual disability.
- The search strategy is greater than a year old, and further research might be available that would contribute to the review.

Introduction

Background/rationale

The right to live independently in a place of one's own choosing reflects the guiding principles of the 2006 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).[1] A process of 'deinstitutionalisation' - that is, moving people with disabilities and mental health problems from institutions to community-living arrangements that support autonomous decision-making and full participation in society - has occurred at different times and different speeds since the 1960s in Scandinavia, the United Kingdom, United States, Canada and Australia.[2]

We undertook a systematic review of the evidence on deinstitutionalisation for people with intellectual disabilities. We examined specifically the effect of deinstitutionalisation on economic outcomes and on quality of life (QoL). In this paper we report the results for the QoL studies. The economics results, as well as further details on our search strategy, are available in a companion paper.[3]

QoL is a priority outcome measure for policymakers but measurement is challenging due to the fluidity of definitions and variability in applications of the concept in practice.[4 5] The Schalock framework of QoL is the most widely accepted within the field, with its eight core components of emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights.[6] Research to date highlights that people with intellectual disabilities persistently score lower on QoL measures than the general population,[7] and that level of intellectual disability, environmental factors and the level and nature of supports received can impact QoL for people with intellectual disabilities. [7-9] Tracking outcomes, including QoL outcomes, for people with intellectual disabilities following deinstitutionalisation encounters measurement challenges both in the gathering of self-report, proxy and family data and in the value placed on each type of report.[6 10-15] These issues are particularly challenging when engaging people with severe/profound intellectual disability yet inclusion of these subgroups is essential.[16]

The impetus for deinstitutionalisation arises from, *inter alia*, concerns about standards of care, poor outcomes and the recognition that people with intellectual disabilities were being unnecessarily deprived of ordinary lives.[17 18] Research alludes to positive benefits of smaller community-based settings[19 20] but also attests that gains in health and other outcome measures are not inevitable.[19] In addition, improvements recorded shortly after a move may plateau after one year.[21] The lack of community readiness to support people to live in the new setting has been proposed as a reason for poor outcomes. The primary focus of policy is on the closure of institutions rather than preparing the community to meet the needs of people with disability now living in the community.[22] A reduction in the size of setting that the individual moves to cannot be assumed to result automatically in better outcomes in terms of health, well-being and overall QoL. This is particularly the case if the new community setting mirrors the culture and practices of the larger institutions with change in how people live, as well as how, when and what type of supports received, being minimal or not materialising.[23 24]

Given the lack of consensus on QoL outcomes as a consequence of deinstitutionalisation there is a need to consolidate the available evidence. This is particularly important in the context of countries that have recently begun or plan to begin implementing a policy of deinstitutionalisation. It is also important for countries that may be challenged by the sustainability and maintenance of the community models put in place in the context of coming demographic change. This is both in terms of the growing older cohort of the general population, which includes the ageing parents and siblings of people with intellectual disability, and the increased longevity of people with ID themselves.

Objectives

To review systematically the evidence on how deinstitutionalisation affects quality of life for adults with intellectual disabilities.

Methods

Eligibility criteria

Studies reporting on the following PICOS (Participants, Interventions, Comparators, Outcomes and Study types) or PEOS (Participants, Exposure, Outcomes and Study types), were eligible for this review. While cross-sectional quantitative studies were generally excluded, as they lacked comparative data on a move, it was not by rule. For example, if a study cross-sectionally asked study participants after a move about changes in QoL arising from that move, this would be included. However, studies that cross-sectionally compared QoL for groups living in institutional and community settings without either group having moved were excluded. Only papers published in English language were eligible.

Types of participants

Adults (aged 18 years and over) with intellectual disabilities.

Types of intervention/exposure/comparators

Our intervention of interest was deinstitutionalisation – that is, a residential move from an institutional to a community setting.

We did not define institutional and community settings *ex ante*, since no widely accepted definitions (e.g. according to the number of residents per unit) exist and we did not want to exclude arbitrarily studies of relevance. Additionally we were conscious that processes of deinstitutionalisation have happened and are happening at different speeds in different countries, sometimes now involving reinstitutionalisation (moving back from the community to an institution) and transinstitutionalisation (moving between institutions).[25]

Consequently we assessed the characteristics of institutions and community-living arrangements on the information provided in each paper.

Types of outcomes

Our pre-specified primary outcome of interest was "quality of life" or "life quality", as defined by study authors. There were no *a priori* restrictions on the operationalisation of QoL. To be eligible as a primary outcome, we required QoL to be measured both prior to and following a move.

Types of studies/reports

Study designs eligible for inclusion were: prospective/retrospective before and after studies, randomised trials, economic evaluations, qualitative/descriptive and exploratory studies.

Search strategy

Database search

To ensure a search strategy that was both sensitive and specific, a comprehensive search methodology to identify both published and grey (e.g. policy reports, national/international guideline documents, etc.) literature was developed and executed through routine scientific database searches and grey literature retrieval. Though eligibility was restricted to English language publications, by searching all languages, we were able to identify the extent of potentially eligible additional papers not initially included and assess whether this may have presented a source of possible language bias.

The following electronic databases were searched from date of inception to 11th September 2017: MEDLINE, PsycINFO, CENTRAL, CINAHL, EconLit, Embase and Scopus. Search terms used to guide the review were developed and subsequently finalised by an information specialist (GS) in collaboration with the review team topic experts, and by executing 'scoping' and pilot searches to cross-reference search terms with prior studies and reviews. A combination of title/abstract keywords and related controlled vocabulary terms were incorporated into the search to ensure comprehensiveness. See Appendix 1 for details. No eligible study looked at both economics and QoL. We reviewed references of included studies and did not identify further eligible studies for inclusion.

Other sources

The search of grey literature was concerned with non-academic publications, readily available online and included a range of different types of documents such as government, statutory organisation, non-statutory organisation (with particular focus on national disability organisations and university based centres of disability studies) policy, guidance, standards or clinical audit documents which included analytical data - either primary or secondary data analysis. See Appendix 2 for details.

Study selection and quality assessment

Screening of titles and abstracts

Two reviewers (RLV and EM) screened the titles and abstracts of retrieved citations, independently, based on the eligibility criteria. Subsequently, approximately 600 conflicts were resolved between these two reviewers on the basis of consensus. Discussions were driven by closely referring to inclusion/exclusion criteria to reach consensus. A key discussion point was verifying that a move had taken place and it was not solely a cross sectional study. In the initial screening stage a particular feature was the inclusion of the concept of adaptation which was viewed through consultation with one of the SR's topic experts not to warrant inclusion as an aspect for QoL. The online reviewer tool COVIDENCE (https://www.covidence.org/) was used to manage the screening process.

Screening of full text reports

Two independent reviewers (RLV and EM) screened the full texts papers independently, with any conflicts or uncertainties resolved in discussion between the two reviewers.

Assessment of methodological quality/risk of bias

Each included study was assessed for methodological quality using one of a group of standardised instruments developed by the Critical Appraisal Skills Programme (CASP, http://www.casp-uk.net/casp-tools-checklists). The CASP tool because it has been used previously in reviews, and tools have been developed for the varying study designs. Furthermore all CASP checklists cover the three main areas of validity, results and clinical relevance. A pair of reviewers conducted the quality assessment process whereby one reviewer (RLV or EM) assessed the studies' methodological quality and a second reviewer (RLV or EM) performed their own rapid assessment to corroborate quality assessments. Any conflicts were resolved through discussion and consensus. Given that studies of low (or poor) methodological quality can lead to overestimates of the effects of interventions or variables under investigation, and can increase the potential for bias in the results, usually in a positive direction, an a priori decision was made to exclude studies assessed as being of low methodological quality (see Appendix 3).

Guided by the CASP quality assessment tool, studies involving primary data collection that did not demonstrate evidence of informed consent were excluded.

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

Data analyses

Data extraction

Comprehensive data extraction forms were pre-designed and piloted to extract relevant data. One reviewer (RLV or EM) extracted the data from the included papers, and a second reviewer (RLV or EM) 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 study design features (randomised trial, prospective or retrospective, etc.), study setting (country of origin), participant details (characteristics, numbers, etc.), recruitment and sampling, exposure/intervention details, ethical issues (e.g. consent), QoL data before and after a move (including summary measures and their standard deviations as well as qualitative themes), and author-identified implications.

Data syntheses

Quantitative studies

We aimed, *a priori*, to perform a meta-analysis of individual studies' data to achieve an overall (higher level) effect estimate following a move from an institutional setting to a different/community-based setting on QoL. Inclusion in a meta-analysis required sufficient similarity in design (i.e. include prospectively collected pre-move and post-move data) and had to provide overall QoL measures. Specifically they had to have measured QoL prospectively as a pre-test (before the move) and post-test (at least one follow-up time point post-move) measure(s). For studies that used repeated post-test measures, we selected QoL measures at one time point for inclusion in the meta-analysis, to avoid over-counting, and described all other time point results narratively. To further reduce characteristic variances in the meta-analyses, we sub-grouped the data according to follow-up at either up to and including one year post-move and at more than one year following a move from any type of institutional setting to any type of community setting. In addition, while sub-scales of QoL might be chosen as a proxy measure of overall QoL, to be included in the meta-analyses, an overall QoL scale score had to be provided; where sub-scale results only were provided, we present the results for these narratively. High levels of statistical heterogeneity in the analyses were likely due to elements of clinical variation across the included studies (e.g. participants with varying levels of intellectual disability across studies, and differing age profiles), rather than study design issues. To counterbalance 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.[26] Lastly, because the instruments used to measure QoL across the included studies differed, we calculated the standardised mean difference (SMD) as per recommended meta-analytical methods.[26] We interpreted the results as an average of the effect of a move from an institutional setting to a community setting, rather than a 'best-estimate' of the effect, as provided by a fixed-effect model. Studies not meeting these similarity criteria, are reported narratively.

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Qualitative studies

We employed a thematic narrative synthesis for identified qualitative studies and the qualitative elements of mixed methods studies.[27]

Patient and Public Involvement

The National Disability Authority of Ireland,[28] an independent state body that advises government and the public sector on policy and practice, contributed to the search strategy.

Results

Search and selection results

Database search

The database search for both cost and QoL studies identified 25,853 citations for consideration against the eligibility criteria for the review. Following removal of duplicates (*n* = 6,568), 19,000 citations were excluded on title and abstract, as they clearly did not meet the review's pre-specified eligibility criteria (Figure 1). A full-text review of the remaining 285 citations was performed, following which a further 217 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 QoL as an outcome (46), opinion or commentaries and reviews (18), not in English language (12), not an adult population with intellectual disability (8) and miscellaneous (6).

Thirty-six articles were therefore identified as meeting the eligibility criteria, of which 21 were subsequently excluded following an assessment of their methodological quality using the CASP tool. Reasons for exclusion at quality assessment included no report of establishing consent of study participants, and insufficient and negligible data on participants and/or outcomes. Of the 15 studies remaining, two addressed economic outcomes only and are included in a separate paper.[3] No eligible study looked at both economics and QoL. Thirteen quality-of-life studies passed quality assessment; eight quantitative studies, two qualitative, two mixed methods studies, and one case study (Appendix 4).

Grey literature search

A total of 74 specific reports were identified from the grey literature search. Following detailed review, 30 reports were identified as relevant to deinstitutionalisation from a cost and/or QoL perspective. Of these, six include 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 pre/post-move, none of the reports were included in the final analysis. See Appendix 2 for details.

Main results

Description of included studies

Of the 13 included QoL studies, eight were quantitative,[29-36] two were qualitative,[37 38] two were mixed methods studies,[39 40] and one was a case study.[41]

Characteristics of included studies are summarised in Table 1. Sample size ranged from one to 76 persons and publication year was from 1994 to 2015. All studies originated from high income countries, where deinstitutionalisation has been well established in policy and implemented, with six studies originated in Australia, four in the UK, two in Ireland and one in New Zealand. Of the six from Australia, two report different analyses of the same sample and these were dealt with in unison where it was more meaningful to do so.

Table 1: Summary characteristics of included studies on quality of life

Study	Location	Aim	Study design	Participants	Pre-move setting		Post-move setting		Quality of life tool or proxies
					Description	No. in institution	Description	No. moving to community	
Ager *et al.* (2001)[29]	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 influential on such integration	Prospective cohort. Pre-post. Pre-move: baseline. Post-move: 6-9 months.	Total sample=76 Age: mean = 53 years (range: 21 - 92). Gender: not reported. Intellectual disability (ID) level: not reported. Time in institution: 1-66 years. Health status: not reported.	1 hospital	76	19 community-based homes (18 voluntary funding, 1 private), OR one of two nursing homes (private), OR one of five older people's homes (local authority)	76	LEC
Barber *et al.* (1994)[30]	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.	Total sample =15 Age: mean =42.4 years (range 30-57, standard deviation 8.51). Gender: 8 female, 7 male ID Level: mild=8, moderate=6, severe=1	1 institution	15	Community-based group homes	15	QoL-Q
Bigby (2008)[40]	Australia	To examine changes in the nature of the informal relationships of residents 5 years after leaving an	Mixed methods. Pre-move: baseline. Post-move: 1,	Total sample =24 Age: Mean =51.5 years (range 39-68). ID level: Mild=0,	1 large institution	24	Small group home houses in the community.	24	Analysis of social networks (quantitative), and structure

		institution.	3, and 5 years.	moderate=15, severe or profound=6, unknown = 3. Identified health issues =17, psychiatric diagnosis =7, mobility impairment =6. Some residents had more than 1 health issue. Time in institution prior to move: Age: mean =38 years, (range 10-54)					interviews (qualitative)
Cooper & Picton (2000)[31]	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 post-move.	Total sample = 45 Group moving to community = 26: Age: mean = 52 years (standard deviation = 15.3); gender: 12 female, 14 male ID level: mild = 24%, moderate = 52%, severe/profound = 24%. Group moving to refurbished institution = 19: Age: mean = 55.2 (standard deviation =12); gender: 9 female, 10 male; ID level: mild =	1 institution - closure order	45	Community group homes housing not more than 6 people (=26) Refurbished institution (=19)	26	QoL-Q

				5%, moderate = 47%, severe/profound = 47%. The authors report no significant difference between groups in terms of ID level, though no statistics were reported. Health status: not reported.					
Di Terlizzi (1994)[41]	UK	To describe "the life history of a woman with severe learning disabilities and communicative impairment".	Case study	Total sample =1. Aged 36 when moved to community house. Severe learning disability and challenging behaviour.	Residential hospital institution	1	Small community staffed house. Shared with 3 other highly independent co-tenants with mild learning disabilities. Service provided 1:1 staff ratio throughout the day	1	Qualitative case study
Golding *et al.* (2005)[32]	UK	To evaluate the effects of relocation from institutional to specialised community-based provision for people with severe challenging behaviour.	Prospective cohort (+ additional comparison group that already in community - irrelevant here). Pre-move: baseline.	Total sample = 6 males with mild to moderate ID and challenging behaviour. An additional six participants who were already in the community were also included in this	Institution operated by the National Health Service	6	Two separate houses managed by a specialist challenging behaviour residential service with an on-duty staffing ratio of four staff to every six	6	LEC

			Post-move: 3 months, 9 months	study but are not reported on for the purposes of this review.			residents between 07:00 and 22:00		
Howard & Spencer (1997)[33]	UK	To provide local management and staff with some insight into the effect of service changes [move from group home to smaller community settings] on the lives of the residents.	Prospective cohort. Pre-move: baseline. Post-move: 1 year	Total sample = 10 Age: mean =61years,; Gender: 7 female, 3 male; who had a preference to remain in a rural setting post-move	Large rural group home with institutional features	10	One of two rural community houses	10	LEC
Kilroy *et al.* (2015)[37]	Ireland	To explore "key workers' perceptions of the impact of a move to community living on the QoL of individuals with an ID".	Qualitative. Proxy participants.	8 people with severe intellectual disability who had had moved from a residential campus to the community over the past 4 years. Age: mean =37.4 years (range 26 – 44) Gender: 2 female, 6 male;	1 institution	8	Two community houses that are owned by two housing associations set up by family of the individuals and staff of the disability organisation but are run as independent entities.	8	Qualitative interviews

O'Brien *et al.* (2001)[39]	New Zealand	To investigate the outcomes of the move into community homes 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.	Mixed methods. Retrospective cohort.	Total sample =54 Age: Mean =48 years (Range= 36-65, No standard deviation reported). Gender: 31, female, 23 male; High support needs =41, medium -=3, low =10	1 long stay hospital	54	Group homes located in the community 1:1 on duty staff ratio to assist with integration	54	Family ratings of quality of changes in quality of life, and qualitative interviews
Sheerin *et al.* (2015)[38]	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.	Total sample =7 Age: not reported; Gender: 3 female, 2 male; 5 people with ID 2 relatives of other tenants Health status: not reported	1 institution	7	New residence The new living unit is located within the commuter belt of Dublin and incorporates a number of self-contained living spaces with shared living areas within staffed houses.	7	Qualitative interviews

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, 24 months.	Total sample = 60 Age: (range: 27 to 81). Gender: 22 female, 38 male; ID Level: mostly moderate or severe/profound. Two groups of 30 matched post-hoc: demographic, health, impairment, adaptive behaviour variables.	1 institution	60	Cluster centres: accommodating 20-25. 7-8 houses and an admin centre. Outer suburb. Resemble surroundings. Modified as required. Community: pre-existing outer-suburban houses, 2-3 residents. Good description in paper.	30	LCQ
Young & Ashman (2004a & 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 retardation in the community."	Prospective cohort. Pre-move: baseline 6 months pre-move. 1, 6, 12, 18, and 24 months post-move.	Total sample =104. Age: mean =47 years (range 21 to 84). Gender: 47 female, 57 male; ID level: 61% severe, 25% moderate, 14% mild. Majority: challenging behaviour, specific health needs or impairments (50 with visual, hearing or mobility impairment), long-	1 institution	104	Modern, brick, freestanding, public housing, which was typical of the surrounding neighbourhood in outer suburban areas and had more favourable staff-to-resident ratios. Additional info. In paper.	104	LCQ

				term institutionalisation (in many cases most of their lives; 2 to 70 years, mean length of stay=26)					

QoL was operationalised 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 QoL, and for which validity and reliability data are available. Three studies used the Life Circumstances Questionnaire, a non-standardised tool to assess objective QoL developed by the authors of the studies in which it is used (LCQ).[35] Two studies used the QoL Questionnaire (QoL-Q), a validated tool providing information on subjective and objective QoL.[43] Other ways of measuring QoL included aspects of informal social relationships (one study) and family ratings of QoL (one study).

Our quality appraisal assessed risk of bias within studies (Appendix 4). Of the 13 studies, 12 identified and accounted for important confounding factors. No study was found to have measured exposure or outcome inaccurately, but on these studies we concluded “can’t tell” for seven and three studies respectively.

Five research studies were included which attempted to assess QoL longitudinally, i.e. with multiple post-move assessments. Details on follow-up across studies are presented in Table 2.

Table 2 Timings of post-move assessments in studies with quantitative quality of life data

Study	**Timing of post-move assessment**								
	1 Mth	3 Mth	6 Mth	9 Mth	1 Year	1.5 Years	2 Years	3 Years	5-9 Years
Ager *et al.* (2001)[29]			Yes *						
Barber *et al.* (1994)[30]	Yes								
Bigby (2008)[40]					Yes			Yes	Yes
Cooper & Picton (2000)[31]			Yes					Yes	
Golding *et al.* (2005)[32]		Yes		Yes					
Howard & Spencer (1997)[33]					Yes				
O'Brien *et al.* (2001)[39]									Yes
Young (2006)[34]					Yes		Yes		
Young & Ashman (2004a & b)[35 36]	Yes		Yes		Yes	Yes	Yes		
Total	2	1	3	1	4	1	2	2	2

* Between six and nine months
Note. Young & Ashman (2004a and 2004b) are combined in summary tables, as both papers analyse outcomes for the same cohort at the same time points.

Key findings

Quantitative studies

The key findings of the ten studies with quantitative elements are summarised in Table 3.

Of these, five were deemed suitable for inclusion in a meta-analysis to examine QoL outcomes for people with any level of intellectual disabilities who move from any type of institutional setting to any type of community setting.[29 31 33-35] In secondary meta-analyses we performed subgroup analysis by QoL subscale, age and level of intellectual disabilities. In addition, outcomes following a move from one institutional setting to another institutional setting were analysed (two studies).[31 34]

Overall QoL

Meta-analysis of QoL outcomes for people with any level of intellectual disabilities who move from any type of institutional setting to any type of community setting are presented in Figure 2. QoL was significantly increased at up to one year post-move (SMD 2.03; 95% CI [1.21, 2.85], 5 studies, 246 participants, GRADE level of evidence: moderate) and beyond one year post-move (SMD 2.34. 95% CI [0.49, 4.20], 3 studies, 160 participants, GRADE level of evidence: moderate), with total QoL change scores higher at 24 months comparative to 12 months.

Table 3 Quantitative QoL research

Author/Year	Key findings on quality of life
Ager *et al.* (2001)[29]	Significant pre-move/post-move improvements in overall quality of life and on all five of the LEC subscales (all $p<0.005$). LEC change scores stratified by dependency level: post-move changes greater as dependency level increased, but not statistically significant.
Barber *et al.* (1994)[30]	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)[40]	Slight, but not statistically significant downward trend from pre- to five years post-move in the number of residents in contact with family members annually or more frequently (85% [20 individuals] to 75% [18]). Significant drop in the mean number of family members in contact with residents between one and five years post-move ($p<.05$). Mean informal network size increased from pre-move to one year post-move, but then decreased at three years and again at five years; the overall decrease was not statistically significant ($p >.05$). Reasons cited by family members for changes in/low 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 (most frequently cited), being unknown by staff, 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 lack of implementation of same, as a reason for contact with family and friends not being maintained.
Cooper & Picton (2000)[31]	Significant improvement in quality of life (QoL-Q) at both six months and at three years following move to the community from a decommissioned institution. A sub-group of 19 individuals who moved to refurbished units in a different institution at also showed significant improvement in overall quality of life at both six months and at three years following the move.
Golding, Emerson, & Thornton (2005)[32]	Improvements in overall LEC scores, for a small sample of six with mild to moderate intellectual disability and severe challenging behaviour, at both three and nine months post-move; 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, Leisure, Freedom, Opportunities, Relationships), and all increases, other than Leisure, were maintained at nine months post-baseline ($p<0.05$).
Howard & Spencer (1997)[33]	Improvement in quality of life overall (LEC) for a small sample of ten moving to rural settings (as was movers' preference). All domain areas (Home, Leisure, Freedom, and Opportunities) except Relationships increased significantly at one-year post-move compared to pre-move scores ($p<0.01$ or $p<0.001$).
O'Brien *et al.* (2001)[39]	Quantitative data was provided for a small subsample in this study (11 to 14). 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 at follow-up (Material Possessions, Health, Productivity, Safety, Place in Community, and Wellbeing).

Young (2006)[34]	Individuals (with mostly moderate to severe/profound ID) who moved to either small group homes or cluster housing had significantly higher QoL scores at both 12 and 24 months compared to pre-move in an institution. Those who move to the community also had significantly better outcomes than those who moved to clustered settings at 12 (MD 26.9, 95% CI 1.27 to 52.53) and at 24 months (MD 39.2, 95% CI 14.31 to 64.09) post-move. All QoL sub-domains (material wellbeing, physical wellbeing, community access, routines, self-determination, social-emotional wellbeing, residential wellbeing, and general wellbeing) improved significantly with a linear trend from pre-move to 12 and 24 months for both groups (all p<0.001). Community settings afforded significantly better physical wellbeing (p<0.005), community access (p=0.001), routines (p<0.01), self-determination (p<0.01), residential wellbeing (p<0.01) and general life improvements (p<0.001) compared to clustered settings. The groups did not differ on material wellbeing and social/emotional wellbeing.
Young & Ashman (2004a, 2004b)[35 36]	Improved quality of life, for a sample of 104 people described as having generally higher support needs, at both 12 and 24 months post-move. There was a significant linear increase in QoL scores, but also a significant quadratic trend suggesting a plateauing of QoL scores at 24 months post-move. Overall quality of life experienced by people with mild/moderate intellectual disability did not significantly improve following a move to a community setting for 20-39 or 40-59-year-olds, and showed a nonsignificant reduction for the 60+ age group. There was a significant increase in overall QoL scores at 24 months post-move for those with severe/profound intellectual disability for all three age categories (p<0.01 or p<0.001). Participants with severe/profound intellectual disability had lower total QoL scores at both pre-move and at follow-up, than those with mild/moderate intellectual disability. Participants in all three age groups and 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 lack of significant improvement in physical wellbeing for the youngest mild/moderate intellectual disability group and the oldest severe/profound group.

Level of intellectual disability

Some studies were not disaggregated by level of intellectual disability while others provided exact numbers for those with mild, moderate or severe/profound intellectual disability. To explore QoL specific to levels of intellectual disability, we were able to extrapolate data explicitly on people with mild to moderate intellectual disability from four studies, [29 32 33 35] of which two were suitable for including in a sensitivity analysis (Figure 3).[33 36] Overall QoL experienced by people with mild/moderate intellectual disability did not significantly improve following a move from an institution to any community setting (mean difference (MD) 0.99, 95% CI [-0.41, 0.46], 2 studies, 51 participants).

One study provided data explicitly on a group of people with severe/profound intellectual disability.[36] These data are also stratified by age (20-39, 40-59, 60+), but using the average mean and standard deviation scores across the three age groups, results demonstrated significantly increased QoL scores at 24 months post-move in this cohort with severe/profound intellectual disability (MD 170.1, 95% CI [158.4, 181.8]; $p<0.0001$).

One study assessed QoL in a hospital group (n=6) with mild/moderate intellectual disability and severe challenging behaviour (baseline data) prior to a move to community houses and again three and nine months post-move.[32] The authors narratively described significant improvements in overall LEC scores (baseline to three months, 49% increase; three to nine months, additional 24% increase increase), and in all five LEC domains (between 46% and 53%) were described. Domain increases, except Leisure, were maintained nine months post-baseline ($p<0.05$).

One study provided mean LEC change scores stratified by dependency level.[29] These change scores increased (i.e. representing improved QoL) as levels of dependency increased by 11.0 to 13.5 to 17.0 for low, medium and high dependency, respectively, but increases were not statistically significant.

Level of intellectual disability and age

One included study stratified intellectual disability by age (20-39, 40-59 and 60+) and by level of intellectual disability together (mild/moderate and severe/profound).[36] As precise numbers in each age category were not provided, results are narratively presented. Following a move to the community at 24 months follow-up, people with mild/moderate intellectual disability had nonsignificant ($p>0.05$) increases in QoL scores in both the 20-39 and 40-59 age categories, whilst there were nonsignificant decreases for those aged 60+. For people with severe/profound intellectual disability, there were statistically significant QoL improvements across all age categories (age 20-39 $p<0.001$; age 40-59 $p<0.001$, age 60+ $p<0.01$). Furthermore, participants with severe/profound intellectual disability had significantly ($p<0.01$) lower total QoL scores than those with mild/moderate intellectual disability at both baseline and at follow-up. Participants in all age groups and both levels of intellectual disability had significantly increased scores across domains, with the exception of nonsignificant improvement in physical wellbeing for the youngest mild/moderate intellectual disability group and the oldest severe/profound group.

QoL when moving from institutional setting to institutional setting

Two studies evaluated QoL following a move from an institution to either another institution or to a clustered setting (Figure 4).[31 34] Cluster or campus living refers to specialised housing in an institutional setting or specialised housing for people with disabilities clustered together in an estate/street. This is in contrast to dispersed housing which is non-specialised accommodation spread across a neighbourhood amongst general population.[44] Considerable differences in the type of settings the participants moved to precluded combination in a meta-analysis.

Overall QoL-Q scores, at both six months and three years post-move, improved significantly for a sub-group of 19 who moved to refurbished units in a different institution.[31] A sub-group of individuals (with challenging behaviour), who moved from institutions to cluster centres (accommodating between 20-25 residents in each centre) had significantly higher QoL scores at 12 (MD 97.8, 95% CI [68.16, 127.44]) and 24 months (MD 103.5 95% CI [75.77, 131.23], post-move.[34] All QoL sub-domains improved significantly with a linear trend from pre-move to 12 and 24 months post-move to cluster centres (all $p<0.001$). [34]

Direct comparison of two alternative settings demonstrated that individuals who moved from institutions to dispersed small group community homes had significantly higher QoL scores at 12 (MD 26.9, 95% CI [1.27, 52.53] and 24 months (MD 39.2, 95% CI [14.31, 64.09], post-move compared to clustered settings (Figure 5).[34] When subdomain outcomes were compared between dispersed community and clustered settings over time, dispersed settings afforded significantly better physical wellbeing ($p<0.005$), community access ($p=0.001$), routines ($p<0.01$), self-determination ($p<0.01$), residential wellbeing ($p<0.01$) and general life improvements ($p<0.001$). Groups did not differ on material wellbeing and social/emotional wellbeing.

Qualitative studies

The main themes identified in the five qualitative or mixed methods studies were: 1) positive changes experienced following the move to the community and a sense of ‘freedom’ and independence living in the community increased QoL; 2) compatibility amongst housemates; 3) perceived staff’s role in supporting community living; 4) social integration and family contact; 5) ongoing challenges for individuals' QoL. Key qualitative findings are presented in Table 4.

A sense of 'freedom' and independence living in the community increased QoL

Positive outcomes for individuals' wellbeing following a move to the community were reported in all five studies. In contrast to the experience of living in an institutional setting, individuals' new living arrangement in the community was perceived as a more suitable environment as it was more private, less noisy with more space including a garden area and wheelchair access.[37 38] Increased independence regarding money management gave participants the freedom to make every day personal choices that positively impacted their QoL.[38] Compared with their previous experience living in a more restricted residential environment, moving to the community for all participants in three studies was perceived as giving them a sense of 'freedom'.[37-39] Moving to the community was also connected with increased personal space and privacy resulting in improved QoL.

Considering compatibility amongst housemates increased QoL

More careful consideration of the impact of individuals' compatibility with housemates when placing individuals in the community houses is reported as positively impacting individuals' QoL.[37 39] In one study, individuals were perceived by proxies to have been previously affected by housemates making noise or engaging in self-injurious behaviour and indicated the importance of housemate compatibility to QoL.[37]

Perceived staff roles in supporting community living

Staff's support roles were perceived as contributing to individuals' QoL.[37 38] Permanent staff familiar with individuals' interests and choices helped improve individuals' participation in the community and alleviated some individuals' stress related to staff turnover.[37 38] However, some other participants had higher expectations of staff support and involvement, which subsequently negatively impacted their perceived QoL.[38]

Social integration and family contact

The impact of the move on the individuals' social integration and family contact as it related to their QoL was a common theme in all five studies. The case study presents the life history of a woman with learning disabilities and severe challenging behaviour who after 30 years in UK institutions, experienced increases in QoL following her eventual move to a small community staffed house.[41] In particular, access to individualised day programs increased perceived positive social integration. Additionally, increased contact with her family due to the community home's significantly closer proximity to her family meant she ultimately could get to know her siblings after years of separation, and visit her family more regularly. This increased integration into her family's life had a perceived positive impact on her QoL, as noted especially by her mother.

An Australian mixed methods study specifically focused on the significance of the role of informal social networks on QoL. Four types of informal networks for residents were identified: i) non-existent (n = 4 participants); ii) special occasion family (n = 6); iii) engaged family (n = 9); iv) friendship-based (n = 5). Although one of the community house staff's key responsibilities was to support residents maintain contact with family and friends following relocation, this was not substantiated in residents' individual plans.[40]

Table 4 Qualitative data results

Theme	Qualitative data	Study reference
Positive outcome following move to the community	*"She is happier since the move, more responsive and willing, now that she trusts other people."*	O'Brien et al., 2001: 75, Community staff member
	"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: 72, Person with an intellectual disability's Key worker
	"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: 271, Tenant 6
A sense of 'freedom' and independence living in the community improved quality of life	*"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: 79, Person with an intellectual disability
	"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: 74, Person with an intellectual disability's Key worker
Increased personal space and privacy in the community improved quality of life	*"There is more space to move around in. Life has changed."*	O'Brien et al., 2001: 79, Person with an intellectual disability
	"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
	"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

Considering compatibility between housemates critical to quality of life	*"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 (community) 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: 72, Person with an intellectual disability
	"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: 80, Person with an intellectual disability
Perception of staff role in the community	*"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: 73, Person with an intellectual disability's Key worker
	"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: 276, Tenant 2
Improved family contact	*"They . . . are involved more now that I'm up [here]."*	Sheerin et al. 2015: 277, Tenant 5
	"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: 277, Relative of Tenant 4
Social integration outcomes	*"Yeah I do more things . . . Going to the library . . . getting to know the people up here in. Sometimes I say hello to them and . . . They can be*	Sheerin et al., 2015, 276, Tenant 5

	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."	
Ongoing challenges	*"I'm afraid I might fall and there's nobody there and I might get a pain in my heart."*	Sheerin et al., 2015: 275, Tenant 6
	"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"	Sheerin et al., 2015: 275, Tenant 6

In another study, it was perceived that all participants were accessing more services within the community and also “getting out into the community” more as a result of the move.[37] However, the individuals with intellectual disabilities 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 (from the community house). In another study, relatives’ experiences differed on how socially integrated into the community their relatives with intellectual disabilities were, ranging from those who felt their relative was welcomed to others who perceived they were not.[38] Overall, most of the participants in this study indicated that they did not feel integrated into the local community and stated that they did not know anyone there. Indeed, some participants appeared to be even more isolated than they were when living in their previous residential setting.

Ongoing challenges for individuals’ QoL

Although all five studies with a qualitative component reported positive outcomes for individuals with intellectual disabilities moving into the community, ongoing challenges to individuals’ QoL were also reported. Adjustment to the move could reportedly take months, depending on the individuals’ transition circumstances. Ongoing difficulties included day programmes being too cramped, with poor consideration of the individuals’ needs in particular in relation to challenging behaviours; unavailability of speech and language therapy or communication aids; [37] family contact was infrequent and accessing amenities was inconvenient due to a post-move rural location; [37] lack of adequate funding meant reduced night time community staffing and no overnight trips;[37] and some participants experienced a loss of security following the move related to change in staffing routines, leading to loneliness and insecurity.[38]

A summary of the main findings from this review is presented in Table 5.

Table 5 Summary of findings: Pre-move compared to post-move for quality of life in persons with any level of ID, and any setting

Patient or population: Quality of life; **Setting**: Institutional and Community

Intervention: Post-move; **Comparison**: Pre-move

Outcomes	№ of participants (studies)	Certainty of the evidence (GRADE)	Comments
Quality of Life: less than/= 1 year post-move	492 (5 observational studies)	⊕⊕⊕◯ MODERATE a,b	a. Observational (pre/post) studies b. Statistical heterogeneity
Quality of Life: greater than 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 effect

Discussion

Key findings

Our systematic review yielded quantitative and qualitative findings that deinstitutionalisation is associated with QoL improvements for people with intellectual disabilities. These findings are broadly consistent with prior reviews.[23 45-47]

There was substantial agreement across quantitative analysis regarding improved QoL which held for shorter (up to one year) and longer (more than one year) term QoL measures, with a slightly increased difference between pre-move and longer term QoL (overall) than shorter-term QoL. This challenges to some extent previous findings which indicated modest gains which occurred soon after the move and plateaued at one year, with these studies showing continued gains after one year.[48]

When institutional settings close, it tends to happen in a phased approach with evidence showing the younger less complex needs cohort moving first.[19 49] The present analysis highlighted the positive gains in QoL that can be experienced by people with severe/profound ID and higher support needs. This finding also held for most aspects or sub-domains of QoL where these were studied.

Qualitative studies found that movement to community residences facilitated an improved sense of wellbeing, freedom and independent decision-making. When housemate compatibility was more carefully considered prior to their move, individuals had higher quality daily living experiences. There remain, however, challenges for aspects of QoL, including social integration and relationships, and physical wellbeing for certain subgroups.

Becoming part of the community is considered one of the main advantages associated with living in the community.[40 44] In our review, mixed findings are reported on the impact of the move on individuals' social integration into the wider community. Authentic community participation eluded many individuals and some individuals reported feeling lonelier since the move due to differing expectations of staff supports. This concurs with previous work with regard to the importance of the quality of supports provided and further highlights that an improvement in QoL is not inevitable but must be managed and supported.[40] Prior to the move, individuals living in institutional settings had relied more heavily upon staff to care for their basic living needs. Following the move to the community with an increased emphasis on nurturing independence, some individuals may experience a loss of security. Without the support from staff to maintain family contact and retain friendships from previous residential setting, individuals' sense of disconnectedness could be compounded. It would be interesting in future research to see if this disconnect is better bridged over time.

This review indicates that support from staff to facilitate integration into the community whilst maintaining family and other social contacts is vital to the individuals' QoL. Individual transition-planning requires thoughtful consideration to address the issue of housemate compatibility, and service user expectations about the level of support provided by staff. Increased contact with family could create new opportunities for family to participate more in supporting social activities (e.g. overnight trips and excursions) that could otherwise be restricted due to limited funding. Yet, despite the ostensible QoL benefits of family contact and relationships, and that community living might facilitate same, there is evidence in the findings that social network sizes may not increase significantly in the longer term following a move, and that family contact in fact shows a downwards trend.

Strengths and limitations

This study has followed best practice guidelines in systematic evidence reviews where possible. A search strategy was devised following pilot searches and multiple meetings of a team that includes subject experts in intellectual disability, an information specialist and a systematic review specialist. The breadth and thoroughness of the search strategy was illustrated in a very large number (over 25,000) of returned titles and abstracts from databases, and each of these was independently reviewed by two team members. Likewise, all full texts accessed were independently reviewed by two team members. For studies included in the review, quality assessment and data extraction was performed by one reviewer with a corroborating rapid review by a second reviewer. It should be noted that all included studies originated from high income countries, where deinstitutionalisation has been well established and implemented, and thus generalisability of the findings for low to middle income countries is not clear due to local cultural challenges to implementation. However, the broad findings on enablers to de-institutionalisation in improving quality of life, particularly those garnered from the qualitative studies, should provide useful indicators for implementation.

Nevertheless, there are a number of important limitations to our work. We were unable to define *ex ante* definitions of 'congregated/institutional' and 'community' settings. In practice, institutions were clearly institutions – places with a number of institutional features, and described as such. Community definitions were more nebulous and we made the best judgements we could as well as providing all available information on the precise conditions in each study, to allow for third party evaluation. We are satisfied retrospectively with this approach. Applying a hard definition would have been very problematic, due to reporting insufficiencies of the extant research. In devising our search strategy we were faced with profound challenges in defining our intervention. 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.

Similarly, QoL is a multi-faceted concept with many potential definitions. We considered different approaches to capturing QoL, for example including all identified sub-domains in the Schalock framework,[6] but we did not consider it feasible to identify reliably all named domains and their synonyms. We therefore chose author-defined QoL as our outcome of interest.

In reviewing returned studies from the database search, we used two independent reviewers for title/abstract and full texts, but one reviewer at quality assessment and data extraction with a second reviewer providing a corroborating review. While corroboration by a second reviewer can be acceptable in the review process, the lack of independent second reviewer assessments does introduce the potential for bias in the quality assessment and data extraction phases of the review. Thirty-two (17%) of the studies that we identified as suitable for full text review proved unobtainable and so are not included in our final analyses, thus, potentially introducing selection bias. These studies, however, are on average older than those we were able to access and are listed in Appendix 5.

The decision to require documentation of consent obtained from participants with intellectual disabilities and ethical considerations did mean that a number of older studies were excluded as well as all of the grey literature. We considered that categorically requiring reporting of a consent process helped to safeguard against: a) bias derived from inappropriately conducted research (e.g. acquiescence), and b) inclusion of research with inadequate ethical protocols in meta-analyses and consequent publication of new and original research findings based partly on such research. In consideration of the importance of choice and subjective evaluation, and the potential for conflict of interest, we viewed this as an unacceptable risk of bias. However, we are not implying that good or appropriate ethical practice was not adhered to in excluded studies, merely that we could not necessarily ascertain this. The clear majority of research excluded for reasons of ethical considerations also had other methodological shortcomings that would have been sufficient to exclude the study from our review, either in concert with the ethical considerations, or in and of themselves.

Included studies were all observational and had a sample size range of 1 to 76. It is not surprising that observational designs dominate in this field and to maximise confidence in our results we ensured that all included studies met a minimum threshold for methodological quality using the CASP quality assessment tool (that is 'good/high' quality). Additionally to assess the level and quality of the evidence for QoL, we performed a GRADE (Grading of Recommendations Assessment, Development, and Evaluation) assessment of the summary results. 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 QoL measures, that is up to one year post-move, and more than one year post-move, the quality of evidence is moderate (downgraded 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 (Table 5).

Acknowledging the challenges in measurement and reporting of QoL by proxy, particularly for people with severe/profound ID, the analysis used a random effects rather than a fixed effects model, to counterbalance any potential subtle differences across studies with regard level of ID and type of reporting. Future studies could explore the differences in type and change in proxies over time and the impact on QoL measurement. We note the high levels of heterogeneity in the synthesised results for QoL. This, we believe, is likely to be explained by both clinical and methodological variation within the included studies. While we attempted to explore this further through sub-groups analyses, we highlight that it needs to be considered when interpreting the results of the review.

We also included only English language studies in our review, excluding 12 studies on this basis, which is another potential source of bias. These studies are listed in Appendix 6 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 with 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 topic experts on the websites of research centres active in this field and those of governments in countries at the forefront of deinstitutionalisation in intellectual disability. This may have biased reviewed studies against other nations and research groups. While much grey literature was excluded from the review for considerations including lack of comprehensive reporting on ethics, there may be findings of import within that literature that may warrant separate review or discussion.

Future research

Subpopulations with additional needs or who require high-levels of support have received insufficient attention in the literature, and research of high methodological quality is required to better understand the needs of a range of groups. It could be reasonably concluded from the available evidence that a move to the community provides similar benefits for people with more severe levels of intellectual disability and that people with high-support needs or challenging behaviour experience similar benefits to their counterparts who have fewer additional needs. This conclusion is based on a few studies and is subject to limitations similar to the wider literature.

With people with intellectual disabilities now living much longer into old age than previous generations, how older age interacts with residential moves also needs comprehensive investigation. Physical well-being has emerged as an aspect of QoL which may not improve as much for groups encompassing younger people with mild intellectual disability and older people with severe intellectual disability. Whilst it is possible that younger groups reach a relative ceiling of functioning and well-being, with little room for additional improvement *per se*, older adults with intellectual disabilities may require additional and different supports. Special attention must be paid to the population with dementia, a population which likely faces additional and growing challenges and may require specific supports for optimal QoL. Research is also lacking on people with other specific health needs or impairments (e.g. those using ventilators), those who present a forensic risk and ex-prisoners. We have limited information about whether and how these particular groups' QoL might be affected by where they live, and furthermore how such clients might ultimately be best supported to experience the benefits of community living and optimal QoL.

There is a scarcity of comprehensive data on outcomes more than two years post-relocation to the community. Existing evidence indicates that while QoL may increase following a move to a non-institutional setting, it begins to plateau between one and two years after the move. Longitudinal studies with longer follow-up periods are warranted to monitor whether the improvement of outcomes is maintained at least in the longer term. Again, serious attention must be paid to the different populations outlined above and to understanding the mechanisms by which changes or improvements in QoL occur, including the impact of changes in services available, proximity to important services and opportunities.

Conclusion

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 QoL compared to the institution. Qualitative studies in particular suggest that observed improvements occur through improved wellbeing, freedom and independent decision making, more careful consideration of housemate compatibility, increased family contact and social integration opportunities.

While it is tempting to suggest sufficient evidence exists, there remain a number of unanswered questions. There is not yet enough knowledge about the long-term course of QoL outcomes, which is of particular interest considering the ageing nature of this population, or for specific aspects of QoL, including social integration and relationships. Subpopulations with additional needs or who require high-levels of support have received insufficient attention in the literature, and research of high methodological quality is required to better understand heterogeneity of need and outcome. Moreover, qualitative studies highlighted a number of negative QoL outcomes including insecurity, fear and loneliness that emphasise that gains do not come without a cost. These concerns also need further investigation.

Future research must address these issues to ensure that, as deinstitutionalisation continues around the world in the context of profound demographic change, people with intellectual disabilities are supported to live healthy, independent lives of their own choosing.

Figure Legends

Figure 1 PRISMA for QoL search

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

Figure 3 Quality of life in people with mild/moderate intellectual disability only post-move

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

Figure 5 Quality of life in community versus cluster settings following a move from an institution

Author statement

MMC, PMC co-designed the original review protocol, oversaw all phases of the review process and, drafted and revised the paper. MMC is guarantor. RLV and EM were lead researchers on all stages of the systematic review - title and abstract, full text, quality assessment, data analysis - and led authorship of the manuscript. PM co-designed the original review protocol, project-managed the review process and, drafted and revised the paper. NW conducted the grey literature search, and drafted and revised the paper. GS was the information specialist, co-designing and running the database searchers, and revising the paper. RS co-designed the original review protocol, advised and contributed throughout the review process as a topic expert, and drafted and revised the paper. VS co-designed the original review protocol, advised and contributed throughout the review process as a systematic review expert, and drafted and revised the paper. CN co-designed the original review protocol, advised and contributed throughout the review process as an economics expert, and drafted and revised the paper. MAOD co-designed the original review protocol, led the grey literature search, advised and contributed throughout the review process as a topic expert, and drafted and revised the paper.

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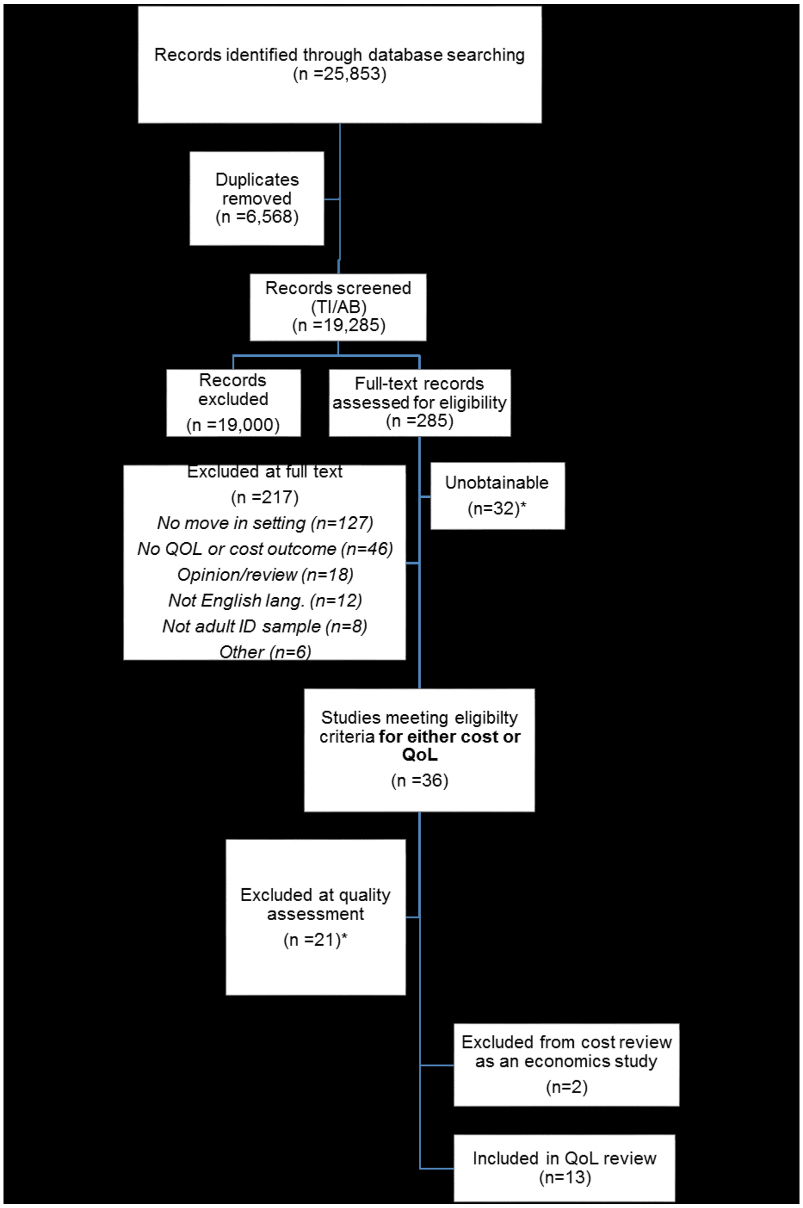
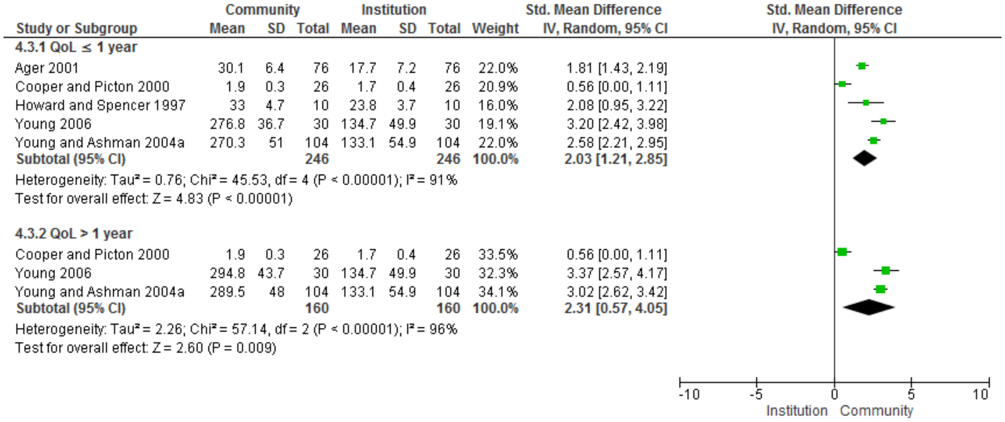


Figure 1 PRISMA for QoL search

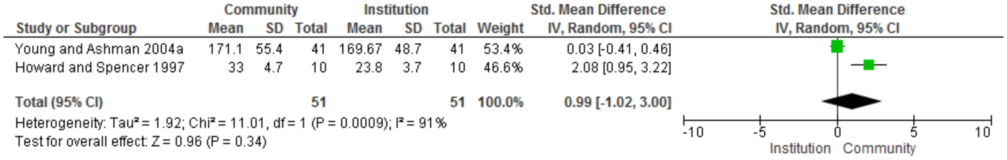
156x236mm (150 x 150 DPI)



	Community			Institution				Std. Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
4.3.1 QoL ≤ 1 year								
Ager 2001	30.1	6.4	76	17.7	7.2	76	22.0%	1.81 [1.43, 2.19]
Cooper and Picton 2000	1.9	0.3	26	1.7	0.4	26	20.9%	0.56 [0.00, 1.11]
Howard and Spencer 1997	33	4.7	10	23.8	3.7	10	16.0%	2.08 [0.95, 3.22]
Young 2006	276.8	36.7	30	134.7	49.9	30	19.1%	3.20 [2.42, 3.98]
Young and Ashman 2004a	270.3	51	104	133.1	54.9	104	22.0%	2.58 [2.21, 2.95]
Subtotal (95% CI)			**246**			**246**	**100.0%**	**2.03 [1.21, 2.85]**
Heterogeneity: $Tau^2 = 0.76$; $Chi^2 = 45.53$, df = 4 ($P < 0.00001$); $I^2 = 91\%$								
Test for overall effect: $Z = 4.83$ ($P < 0.00001$)								
4.3.2 QoL > 1 year								
Cooper and Picton 2000	1.9	0.3	26	1.7	0.4	26	33.5%	0.56 [0.00, 1.11]
Young 2006	294.8	43.7	30	134.7	49.9	30	32.3%	3.37 [2.57, 4.17]
Young and Ashman 2004a	289.5	48	104	133.1	54.9	104	34.1%	3.02 [2.62, 3.42]
Subtotal (95% CI)			**160**			**160**	**100.0%**	**2.31 [0.57, 4.05]**
Heterogeneity: $Tau^2 = 2.26$; $Chi^2 = 57.14$, df = 2 ($P < 0.00001$); $I^2 = 96\%$								
Test for overall effect: $Z = 2.60$ ($P = 0.009$)								

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

227x97mm (96 x 96 DPI)

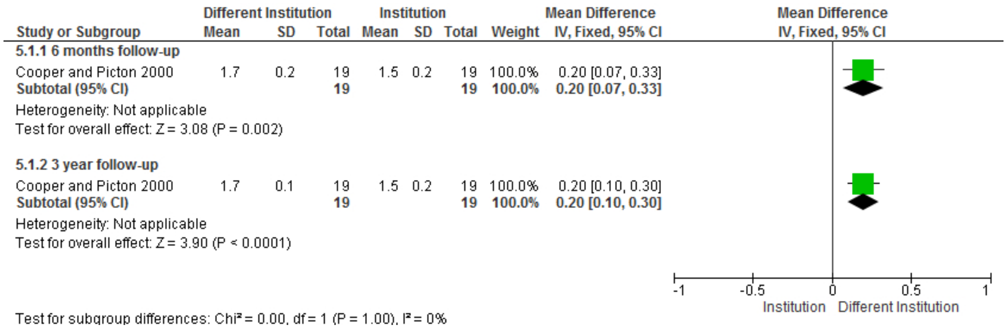


	Community			Institution				Std. Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
Young and Ashman 2004a	171.1	55.4	41	169.67	48.7	41	53.4%	0.03 [-0.41, 0.46]
Howard and Spencer 1997	33	4.7	10	23.8	3.7	10	46.6%	2.08 [0.95, 3.22]
Total (95% CI)			**51**			**51**	**100.0%**	**0.99 [-1.02, 3.00]**

Heterogeneity: Tau² = 1.92; Chi² = 11.01, df = 1 (P = 0.0009); I² = 91%
Test for overall effect: Z = 0.96 (P = 0.34)

Figure 3 Quality of life in people with mild/moderate intellectual disability only post-move

228x38mm (96 x 96 DPI)

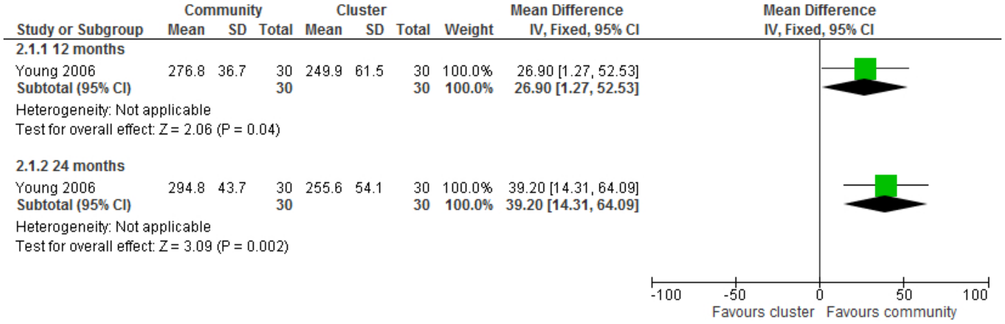


Study or Subgroup	Different Institution Mean	SD	Total	Institution Mean	SD	Total	Weight	Mean Difference IV, Fixed, 95% CI
5.1.1 6 months follow-up								
Cooper and Picton 2000	1.7	0.2	19	1.5	0.2	19	100.0%	0.20 [0.07, 0.33]
Subtotal (95% CI)			**19**			**19**	**100.0%**	**0.20 [0.07, 0.33]**
Heterogeneity: Not applicable								
Test for overall effect: Z = 3.08 (P = 0.002)								
5.1.2 3 year follow-up								
Cooper and Picton 2000	1.7	0.1	19	1.5	0.2	19	100.0%	0.20 [0.10, 0.30]
Subtotal (95% CI)			**19**			**19**	**100.0%**	**0.20 [0.10, 0.30]**
Heterogeneity: Not applicable								
Test for overall effect: Z = 3.90 (P < 0.0001)								

Test for subgroup differences: Chi² = 0.00, df = 1 (P = 1.00), I² = 0%

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

222x71mm (96 x 96 DPI)



Study or Subgroup	Community Mean	Community SD	Community Total	Cluster Mean	Cluster SD	Cluster Total	Weight	Mean Difference IV, Fixed, 95% CI
2.1.1 12 months								
Young 2006	276.8	36.7	30	249.9	61.5	30	100.0%	26.90 [1.27, 52.53]
Subtotal (95% CI)			**30**			**30**	**100.0%**	**26.90 [1.27, 52.53]**
Heterogeneity: Not applicable								
Test for overall effect: Z = 2.06 (P = 0.04)								
2.1.2 24 months								
Young 2006	294.8	43.7	30	255.6	54.1	30	100.0%	39.20 [14.31, 64.09]
Subtotal (95% CI)			**30**			**30**	**100.0%**	**39.20 [14.31, 64.09]**
Heterogeneity: Not applicable								
Test for overall effect: Z = 3.09 (P = 0.002)								

Figure 5 Quality of life in community versus cluster settings following a move from an institution

217x71mm (96 x 96 DPI)

Appendix 1 Search strategy

We searched seven databases for studies of deinstitutionalisation for people with intellectual disabilities, specifically evaluating effects on economic outcomes and quality of life (see main article).

We executed a search with four categories of terms and controlled vocabulary:

- Category 1: Intervention
- Category 2: Intellectual disability
- Category 3: Quality of life
- Category 4: Economic outcomes

With respect to the intervention, no standardised terminology exists for the concept of deinstitutionalisation/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 in our search strategy (Appendix Table 1) therefore includes not only vocabulary related to transitions but also different categories of residence (e.g. hospital, home).

Similarly with respect to population, the language used in describing people with intellectual disability has changed profoundly over the last 50 years. Category 2 choices are therefore intended to capture current and historic terminology. In specifying language for Category 3 (quality of life) in our search strategy we considered multiple approaches, including 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. 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. In Category 4 (economics) we selected both terms for resource use and terms for economic evaluation.

Appendix 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).

Appendix 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("" 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 behaviour") 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 behaviour")
4	**Economic outcomes**	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)

Appendix 2 Grey literature search strategy

Methodology

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

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

The countries searched are those outlined in the IASSIDD Policy and Practice SIRG position paper on deinstitutionalisation - UK, USA/Canada, Australia, Scandinavian. These countries have been at the forefront in implementing policies on 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 key words set out for the systematic review (see chapter 2.2).

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

- countries not listed above
- documents that are purely descriptive with no data on quality of life measurement or cost measurement
- documents that do not deal with movement but which assess cross sectional data of people within a particular setting and comparisons across settings but not movement
- PhD/masters and books

Steps in the search for grey literature:

1. Generate 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) search within the agency/centre website for key words 'deinstitutionalisation', 'housing', 'home', 'decongregation', 'transition' as per broad search terms. If not an intellectual disability specific organisation, then the search terms of 'intellectual disability', 'developmental disability' or 'learning disability' will need to be include 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 each report on this list was then reviewed by the two researchers (MA and NW) and categorised as 1: included (data), 2: included (background information), 3. Exclude, 4. Unclear.

Any queries were then discussed and agreed between the two researchers and the report assign to the appropriate category.

Relevant Grey Literature
Conroy *et al.* (1985) The Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis. Retrieved from https://aspe.hhs.gov/pdf-report/pennhurst-longitudinal-study-combined-report-five-years-research-and-analysis
Conroy, J. and Seiders, J. (1994) 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. PA: Conroy and Feinstein Associates, Wynnewood. Retrieved from https://mn.gov/mnddc/parallels2/pdf/90s/93/93-CJN-UNJ.pdf
Cooper and Harkins (2006) Going Home – Keys to Systems Success in Supporting the Return of People to Their Communities from State Facilities. Retrieved from http://www.nasddds.org/uploads/documents/Going_Home_October_06_Final_%282%29.pdf
Dixon, R. M., Marsh, H. W. & Craven, R. G. (2004). Moving out: the impact of deinstitutionalisation on salient affective variables for people with mild intellectual disabilities. Proceedings of the Third International Biennial SELF Research Conference: Self-concept, Motivation and Identity: Where to from here? 4-7 July, 2004 (pp. 1-12). Sydney, Australia: SELF Research Centre, University of Sydney. Retrieved from http://ro.uow.edu.au/cgi/viewcontent.cgi?article=1172&context=edupapers
Conroy, J. W., Garrow, J., Fullerton, A., Brown, M., & Vasile, F. (2003). Initial outcomes of community placement for the people who moved from Stockley Center. Center for Outcome Analysis, Narberth, PA. Retrieved from http://dhss.delaware.gov/dhss/ddds/files/conroyrep.pdf
Conroy, J. W., Lemanowicz, J. A., Feinstein, C. S., & Bernotsky, J. M. (1991). The Connecticut Applied Research Project: 1990 results of the CARC v. Thorne longitudinal study. Retrieved from http://static1.squarespace.com/static/53dfdc3be4b0a86a2dbf76ae/t/5671ccbdcbced6829d5f191b/1450298557957/1990+Results+of+the+CARC+Vs+Thorne+Longitudinal+Study.pdf

Appendix 3 Studies excluded at quality assessment (both cost and QOL studies)

This review used the CASP suite of tools to appraise studies meeting our eligibility criteria. Section A of the CASP tools asks reviewers two questions: (1) Did the study address a clearly focused issue?; (2) Was the cohort recruited in an acceptable way?

In each case the reviewer has three potential responses: Yes/No/Can't tell.

To merit full quality assessment in our review, studies had to receive a 'Yes' for both questions in Section A. The studies that did not pass Section A are presented below, with the relevant question on which they were excluded.

Appendix Table 3 Quality-assessed excluded studies

Study	Exclusion Reasons
Bhaumik *et al.* (2011)	• CASP screening question 2 (Was the cohort recruited in an acceptable way?)
Bratt & Johnston (1988)	• CASP screening questions 1 (Did the study address a clearly focused issue?) & 2
Conneally *et al.* (1992)	• CASP screening question 2
Conroy *et al.* (2003)	• CASP screening questions 1 & 2
Cullen (1995)	• CASP screening questions 1 & 2
Dagnan *et al.* (1995)	• CASP screening question 2
Dagnan *et al.* (1996)	• CASP screening question 2
Dagnan *et al.* (1998)	• CASP screening question 2
Donnelly (1996)	• CASP screening question 2
Donnelly (1997)	• CASP screening question 2
Fish & Lobley (2001)	• CASP screening question 1
Fleming & Stenfert-Kroese (1990)	• CASP screening questions 1 & 2
Forrester - Jones (2002)	• CASP screening question 2
Hemming *et al.* (1981)	• CASP screening question 1 & 2
Mansell (1994)	• CASP screening question 1
Marlow & Walker (2015)	• CASP screening questions 1 and 2

Perry *et al.* (2011)	• CASP screening question 2
Roy *et al.* (1994)	• CASP screening question 2
Sines *et al.* (2012)	• CASP screening question 1
Spreat & Conroy (2002)	• CASP screening questions 1 & 2
Srivastava & Cooke (1999)	• CASP screening questions 1 & 2
Walker *et al.* (1995)	• CASP screening question 1
Young (2003)	• CASP screening question 1

Appendix 4 Quality assessment tables Table *4a*: Quality assessment: Included quantitative and mixed methods studies

Appendix Table *4a*: Quality assessment: Included quantitative studies

Study	Screening Q.1: Address clearly focused issue	Screening Q. 2: Cohort acceptably recruited	Exposure accurately measured (min. bias)	Outcome accurately measured (min. 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 *Can't tell*
Ager *et al.* (2001)[26]	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	9	0	2
Barber & Cooper (1994)[27]	Yes	Yes	Can't tell	Can't tell	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9	0	2
Bigby (2008)[28]	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10	0	1
Cooper & Picton (2000)[29]	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10	0	1
Golding *et al.* (2005)[30]	Yes	Yes	Can't tell	Can't tell	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	8	0	3
Howard & Spencer (1997)[31]	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	9	0	2
O'Brien *et al.* (2001)[32]	Yes	Yes	Can't tell	Can't tell	No	No	No	Yes	Yes	Can't tell	Yes	5	3	3
Young (2006)[33]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	11	0	0
Young & Ashman (2004a)[34]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	11	0	0
Young & Ashman (2004b)[35]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	11	0	0

Study	Screening Q.1: Address clearly focused issue	Screening Q. 2: Cohort acceptably recruited	Exposure accurately measured (min. bias)	Outcome accurately measured (min. 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 *Can't tell*

Note. Bigby (2008) and O'Brien *et al.* (2001) are both mixed method studies, i.e. presenting both quantitative and qualitative data. Beecham et al. (1997) and Hallam et al. (2006) are economic studies and were appraised with the 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.

Appendix Table *4b*: 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 & participant considered	Ethical issues considered	Data analysis sufficiently rigorous	Findings clearly stated	Value of the research	Total *Yes*	Total *No*	Total Can't tell
Di Terlizzi. (1994)[38]	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	9	0	1
Kilroy *et al.* (2015)[39]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10	0	0
Sheerin *et al.* (2015)[40]	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 both present qualitative data, are presented in Table .

Appendix 5 Unobtainable studies

Appendix Table 5 Studies that met eligibility criteria but could not be accessed

Authors	Year	Title	Journal	Vol.	Issue	Pages
Y. Don; Y. Amir	1969	Institutions for mentally retarded in Israel: Cost structure and budget analysis	Mental Retardation	7	3	36-39
I. N. Wolfson	1970	Adjustment of institutionalized mildly retarded patients twenty years after return to the community	Mental Retardation	8	4	20-23
A. T. Bjaanes; E. W. Butler	1974	Environmental variation in community care facilities for mentally retarded persons	American Journal of Mental Deficiency	78	4	429-439
M. Aninger; K. Bolinsky	1977	Levels of independent functioning of retarded adults in apartments	Mental Retardation	15	4	Dec-13
S. C. McDevitt; P. M. Smith; D. W. Schmidt; M. Rosen	1978	The deinstitutionalized citizen: Adjustment and quality of life	Mental Retardation	16	1	22-24
A. L. Carsrud; K. B. Carsrud; D. P. Henderson; C. J. Alisch; A. V. Fowler	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
J. C. Intagliata; B. S. Wilder; F. B. Cooley	1979	Cost comparison of institutional and community based alternatives for mentally retarded persons	Mental Retardation	17	3	154-156
R. H. Bruininks; F. A. Hauber; M. J. Kudla	1980	National survey of community residential facilities: A profile of facilities and residents in 1977	American Journal of Mental Deficiency	84	5	470-478
R. L. Schalock; R. S. Harper; G. Carver	1981	Independent living placement: Five years later	American Journal of Mental Deficiency	86	2	170-177
J. Intagliata; B. Willer	1982	Reinstitutionalization of mentally retarded persons successfully placed into family-care and group homes	American Journal of Mental Deficiency	87	1	34-39
T. Heller	1982	Social disruption and residential relocation of mentally retarded children	American Journal of Mental Deficiency	87	1	48-55

W. R. Cook	1983	Economics of providing services to the mentally retarded	Mental Retardation & Learning Disability Bulletin	11	1	13-21
L.W. Heal; J. 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
J. O'Neill; M. Brown; W. Gordon; R. Schonhorn	1985	The impact of deinstitutionalization on activities and skills of severely/profoundly mentally retarded multiply-handicapped adults	Applied Research in Mental Retardation	6	3	361-371
R. L. Schalock; M. A. 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
D. 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
J. Lalonde; A. Marchand; N. Marineau	1986	La réinsertion sociale de déficientes intellectuelles résidant en milieu psychiatrique. =The social reintegration of institutionalized mentally retarded women	Revue de Modification du Comportement	16	2	84-93
N. S. Springer	1987	From institution to foster care: Impact on nutritional status	American Journal of Mental Deficiency	91	4	321-327
E. A. Eastwood; G. A. Fisher	1988	Skills acquisition among matched samples of institutionalized and community-based persons with mental retardation	American Journal Of Mental Retardation: AJMR	93	1	75-83
R. B. Edgerton	1988	Aging in the community: A matter of choice	American Journal on Mental Retardation	92	4	331-335
J. O'Neill; M. Brown; W. A. Gordon; J. P. Orazem; C. Hoffman; R. Schonhorn	1990	Medicaid versus state funding of community residences: Impact on daily life of people with mental retardation	Mental Retardation	28	3	183-188
J. W. Ashbaugh; T. Nerney	1990	Costs of providing residential and related support services to individuals with mental retardation	Mental Retardation	28	5	269-273

C. Jourdan-Ionescu; S. Ionescu; L. Corbeil; C. Rivest	1990	Evaluation de la désinstitutionnalisation: I. La qualité de vie. =Evaluation of deinstitutionalization: I. Quality of life	Revue francophone de la déficience intellectuelle	1	1	49-58
P. J. Cunningham; C. D. Mueller	1991	Individuals with mental retardation in residential facilities: Findings from the 1987 National Medical Expenditure Survey	American Journal on Mental Retardation	96	2	109-117
J. Lord; A. Pedlar	1991	Life in the community: Four years after the closure of an institution	Mental Retardation	29	4	213-221
J. Barlow; N. Kirby	1991	Residential satisfaction of persons with an intellectual disability living in an institution or in the community	Australia & New Zealand Journal of Developmental Disabilities	17	1	Jul-23
B. E. McGuire; G. Choon; E. Akuffo	1991	Community living for elderly people with an intellectual disability: A pilot study	Australia & New Zealand Journal of Developmental Disabilities	17	1	25-33
R. L. Schalock; L. T. Genung	1993	Placement from a community-based mental retardation program: A 15-year follow-up	American Journal on Mental Retardation	98	3	400-407
C. A. Knobbe; S. P. Carey; L. Rhodes; R. H. Horner	1995	Benefit-cost analysis of community residential versus institutional services for adults with severe mental retardation and challenging behaviors	American Journal on Mental Retardation	99	5	533-541
J. Tossebro	1995	Impact of size revisited: Relation of number of residents to self-determination and deprivatization	American Journal on Mental Retardation	100	1	59-67
B. R. Wagner; D. F. Long; M. L. Reynolds; J. R. Taylor	1995	Voluntary transformation from an institutionally based to a community-based service system	Mental Retardation	33	5	317-321
A. G. Philaretou; S. 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 6 Studies in a language other than English

Appendix Table 6 Studies in a language other than English

Title	Authors	Published Year	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?] [French]	Beckers, J.	1984	International Journal of Rehabilitation Research	7	4	409-418
La désinstitutionnalisation des personnes déficientes intellectuelles et leur appréciation de la qualité de vie. = Deinstitutionalization of individuals with mental disabilities and their perception of the quality of life [French]	Boudreault, Paul	1990	Revue Francophone de la Déficience Intellectuelle	1	2	147-158
Evaluation de la désinstitutionnalisation: 2. Modifications du niveau intellectuel et des comportements adaptatifs. = Evaluation of deinstitutionalization: II. Changes in intelligence level and adaptive behaviors [French]	Jourdan-Ionescu, Colette; Ionescu, Serban; Rivest, Christine; Corbeil, Luc	1990	Revue Francophone de la Déficience Intellectuelle	1	2	137-146
L'effet de l'integration sociale sur le comportement adaptatif et sur la diversité des activités. = The effects of social integration on adaptive behavior and on diversification of activities [French]	Michaud, Danielle; Horth, Raynald; Roy, Sarto	1992	Revue Francophone de la Déficience Intellectuelle	3	1	39-48
L'évaluation des besoins et de la qualité de vie d'adultes ayant une déficience intellectuelle. = Assessment of the needs and the quality of life of adults with mental retardation [French]	Lachapelle, Yves; Cadieux, Alain	1993	Comportement Humain	7	2	117-127
De l'Hôpital Louis-H. Lafontaine Ã la rue Lafontaine. = From Lafontaine Hospital to Lafontaine Street: Deinstitutionalization of persons with mental disabilities [French]	Lalonde, Francine; Lamarche, Constance	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] [German]	Meins, W.	1993	Psychiatrische Praxis	20	3	106-108
Normalisierte Wohnformen für Menschen mit geistiger Behinderungâ€”Auswirkungen auf die Bewohnerinnen und Bewohner. = Normalized	Kief, Michael	1994	Vierteljahresschrift für Heilpädagogik und ihre Nachbargebiete	63	1	33-45

accommodation for people with intellectual disabilities and the effects on the residents [German]						
L'influence du processus de désinstitutionnalisation sur l'intégration sociale de personnes présentant une déficience intellectuelle sévère et profonde. = The influence of the deinstitutionalization process on the social integration of people with severe and profound intellectual deficiency [French]	Paré, Charles; Parent, Ghyslain; Pilon, Wilfrid; Côté, Richard	1994	Revue Francophone de la Déficience Intellectuelle	5	2	137-154
The Possibilities for Mentally Retarded Persons to Make their Own Choices in Everyday Life [Croatian]	Bratković, Daniela; Bilić, Marija; Nikolić, Branko	2003	Hrvatska Revija za Rehabilitacijska Istraživanja	39	2	117-127
A study on the life satisfaction of mentally handicapped persons visiting a day care [Japanese]	Handa, M.; Kusaka, K.; Kanoya, Y.; Sato, C.	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 [Croatian]	Kramarić, M.; Sekušak-Galešev, S.; Bratković, D.	2013	Hrvatska Revija za Rehabilitacijska Istraživanja	49	SUPPL.	50-63