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Title

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

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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.

Data sharing

There are no unpublished data from this study.

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Abstract

Objective: To review systematically the economic evidence on deinstitutionalisation for adults with intellectual disabilities.

Design: Systematic review.

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

Intervention: a move in residential setting.

Primary and secondary outcome measures: studies were eligible if evaluating effect on costs or related economic outcomes (including cost-effectiveness analyses).

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: Two studies were included; both were cohort studies from the payer perspective of people leaving long-stay NHS hospitals in the United Kingdom in the 1980s. One study found that deinstitutionalisation reduced costs, one study found an increase in costs.

Conclusion: A wide-ranging literature review found limited evidence on costs associated with deinstitutionalisation for people with intellectual disabilities. From two studies included in the review, the results were conflicting. Significant gaps in the evidence base were observable.

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Strengths and limitations of this study

- We systematically searched seven databases of peer-reviewed literature without time limitation.
- Two researchers independently reviewed returned studies for eligibility.
- Included studies were additionally subject to quality assessment to minimise bias.
- We did not search books or monographs.
- We did not include static cross-sectional studies, which potentially excludes a larger literature with tangential relevance.

Introduction

Background/rationale

The 2006 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) emphasises the right to live independently in a place of one's own choosing.[1] The promotion of autonomous decision-making and full participation in society for people with disabilities and mental health problems through deinstitutionalisation - movement from living in institutional settings to community settings - has variously occurred in Scandinavia, the United Kingdom, United States, Canada and Australia since the 1960s.[2] Substantial groups of people with disabilities, including intellectual disabilities, are still prevented from living in a place of their own choosing, instead being restricted to institutions or inadequate community-based services.[3]

We undertook a systematic review of the evidence on the effect of deinstitutionalisation on economic outcomes and on quality of life (QoL) for people with intellectual disabilities (ID). In this paper we report the search strategy for the whole systematic review, and the results for the economics studies. QoL results are presented separately (see supplementary file).[4]

Economic evaluations comparing the costs and outcomes of different options may inform decisions on which of the available choices represents best use of the resources available.[5] The accurate estimation of resource use in providing services can inform budgeting, workforce planning and organisation of services in the short and long term when groups of interest, in this case people with ID are growing in number and complexity of need, and account disproportionately for overall expenditures.[6]

The population of people with intellectual disabilities is changing in important ways that must be accounted for in planning and provision of services.[7] Life expectancy for children born with high levels of disability has increased markedly, meaning that supports must be provided to a growing number of people with very high needs, and increased life expectancy among the population of people with intellectual disabilities means rising prevalence of old age, multimorbidity and dementia.[7-10] Taken together, these trends mean that in the 21st century societies worldwide face never-before-seen populations of people with intellectual disabilities and high support needs, and a limited evidence base on which to base funding decisions and budget projections. An historic reliance on informal care from unpaid family and friends may not be sustainable as age and mobility burdens increase among the carers themselves.[11]

Objectives

To review systematically the economic evidence on deinstitutionalisation for adults with intellectual disabilities.

Methods

Eligibility criteria

We used the PICOS (Participants, Interventions, Comparators, Outcomes and Study types)/PEOS (Participants, Exposure, Outcomes and Study types) acronyms to define review eligibility as follows:

Types of participants

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

Types of intervention/exposure/comparators

The intervention of interest in this review was deinstitutionalisation, i.e. the move from institutional to community settings. We chose not define these *ex ante*, e.g. according to the number of residents per unit, since no widely accepted cut-offs exist and any such cut-offs risked arbitrarily excluding studies of relevance. Moreover, deinstitutionalisation has occurred at different speeds in different countries over the last half century, in some cases incorporating phases of reinstitutionalisation (the residential move back from the community to an institution) and transinstitutionalisation (a residential move between institutions).[12]

We therefore defined our intervention/ exposure variable broadly so as to avoid arbitrary exclusion of relevant studies, and we assessed the characteristics of settings on a study by study basis on the information provided.

Types of outcomes

Our pre-specified primary outcome of interest was economic effects. For purposes of the review, economic effects were defined broadly as any cost-consequence framework (e.g. cost-effectiveness analysis, cost-utility analysis) or resource use typically considered to fall within the societal viewpoint (e.g. cost to payers, service-users, families, informal care costs). We did not require that resource use reflect the literal cost of provision for the study to be included, but also considered eligibility based on non-cost measurements of resource use, such as insurance programme charges, frequency utilisation combined with unit cost data.

Types of studies/reports

Prospective/retrospective before and after studies, randomised trials, qualitative/descriptive and exploratory studies that reported on economic evaluations were eligible for inclusion. We excluded studies that did not evaluate economic effects following a move, and cross-sectional studies comparing community-living and institutional arrangements for two different groups at a single point in time.

Search strategy

Database search

Our search methodology encompassed both published and grey (e.g. policy reports, national/international guideline documents, etc.) literature using multiple sources. We restricted inclusion of studies to English language publications, but noted potentially eligible non-English language papers to determine whether this might present as a possible source of language bias.

Electronic databases were searched from their date of inception to September 2017. Using search terms and Medical Subject Headings, developed by an information specialist (GS) following 'scoping' and pilot searches, and confirmed with the review team, the databases of MEDLINE, PsycINFO, CENTRAL, CINAHL, EconLit, Embase and Scopus were searched (see Appendix 1 for full details).

Other sources

Grey literature searching focused on non-academic publications, readily available online. Documents of interest included government, statutory organisation, non-statutory organisation (e.g. national disability organisations and university based centres of disability studies), guideline or policy documents or reports of clinical audit with available primary or secondary analytical data (see Appendix 2 for details).

Study selection and quality assessment

Screening citations

Titles and abstracts of retrieved citations were assessed independently by two reviewers (RLV and EM); full-text papers forwarded from title and abstract screening were assessed independently by two reviewers (RLV and PM;. Any differences of opinion on inclusion/exclusion at both stages were resolved between the reviewers based on discussion and consensus. A review manager software package, COVIDENCE (https://www.covidence.org/) supported screening and selecting relevant studies.

Assessment of methodological quality/risk of bias

The methodological quality of each included studies was assessed using the Critical Appraisal Skills Programme (CASP, http://www.casp-uk.net/casp-tools-checklists) standardised assessment tool appropriate to the included study's design, that is, CASP Case Control Checklist, CASP Economic Evaluation Checklist, or CASP Qualitative Checklist.

One reviewer (PM) assessed the studies' methodological quality and a second reviewer (CN) performed a rapid assessment to confirm judgements on quality. Conflicts were resolved through discussion and consensus. To limit bias and/or overestimates of effects that may arise from poorly designed, conducted and reported studies, studies were determined to meet a minimum of moderate to high quality of rigour to be included in the review (see Appendix 3).

Data analyses

Data extraction

Predesigned and piloted data extraction forms captured year of study, study setting, type of study design, descriptions of the population/participants, interventions and comparator, ethical issues (e.g. consent), cost outcome data (results) and authors' conclusions. One reviewer (PM) extracted the data from the included papers, and a second reviewer (CN) performed a rapid assessment to confirm accuracy and comprehensiveness of the extracted data. As before, any differences were resolved by discussion and consensus.

Data syntheses

Summary measures

The principal summary measure was the mean estimated effect of move in residential setting on costs or cost-effectiveness (from whatever perspective the study specified). Mean estimated effects on sub-categories of costs, as well as drivers of costs, were secondary measures of interest.

Analytical measures

A priori, our aim was to perform a meta-analysis of individual studies' data so as to achieve an overall (higher level) effect estimate of cost outcomes following a move from an institutional setting to a different/community-based setting. Statistical pooling of data across studies proved neither feasible nor appropriate due to inadequate information on post-discharge residences and associated costs. We therefore present a narrative synthesis of the data using descriptive statistics and thematic analyses.

Patient and Public Involvement

A representative from the National Disability Authority of Ireland,[13] an independent state body providing expert advice on disability policy and practice to the government and the public sector, participated in the design of the systematic search strategy.

Results

Search and selection results

Database search

The database search, which was a combined search of studies reporting on both cost and QoL, returned 25,853 citations for consideration against the review's eligibility criteria of which 6,568 were duplicate citations across databases, and were excluded. A further 19,000 citations were excluded during title and abstract screening as they clearly did not meet the review's pre-specified eligibility criteria (Figure 1). This left 285 papers for full text review; of these 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 data (46), opinion or commentaries and reviews (18), not in English language (12), not an adult population with intellectual disability (8) and miscellaneous (6).

Of the remaining 36 included studies, 21 of these were subsequently excluded based on methodological quality assessments using the CASP tool. Reasons for exclusion at this stage were failure to establish consent of study participants, and insufficient and negligible data on participants and/or outcomes (see Appendix 4). Of the 15 studies remaining, 13 addressed QoL outcomes only (reported separately[4]) and two reported on costs. None of the included studies evaluated both cost data and QoL.

Grey literature search

The grey literature search resulted in retrieval of 74 reports, of which 30 appeared relevant to deinstitutionalisation from a cost and/or QoL perspective, but on further review, only six provided pre- and post-move measures. Following a quality assessment of these six reports, none met the minimum standards, and all 6 were excluded from the review.(see Appendix 2 for details).

Main results

Description of included studies

Two studies evaluated the impact on economic outcomes for people with intellectual disabilities who experienced a move in residential setting. Both studies follow a single cohort of people moving from long-stay hospitals in the UK National Health Service (NHS) and are summarised in Table 1. Beecham *et al.* examine costs at 12 months for adults moving from what were then called 'mental handicap' and psychiatric hospitals in Northern Ireland between 1990 and 1992;[14] Hallam *et al.* examine longitudinally costs after one, five and 12 years for adults moving from 12 different sites in England between 1984 and 1987.[15] Risk of bias within studies is considered low: both follows a single cohort of participants with each person effectively acting as their own control.

Table 1 Summary characteristics of included studies

Lead author& year	Location (country); dates of study	Aim	Study design	Description of study sample	Description of congregated setting	Description of community setting
Beecham *et al.* (1997)[14]	Northern Ireland, 1990-1993	To evaluate the effect on costs of discharging people with ID from long-stay hospitals to "community care"	One cohort assessed prior to leaving hospital and 12 months after doing so	Adults with learning disabilities. Of 214 adults moving during study period, 22 were lost to follow-up leaving a sample of 192. 57% male[§] Median age 47 years[§] Median hospital stay prior to move 20 years[§] 7% low mental handicap (IQ<20), 52% Medium (20-49), 33% high (50-69), and 8% not recorded[§]	Three mental handicap hospitals and four psychiatric hospitals	Residential facilities provided by statutory bodies (=30) Residential facilities provided by voluntary bodies (=20) Residential and nursing homes from private bodies (=141) Independent living arrangements (=1).
Hallam *et al.* (2006)[15]	England, 1984-1999	Evaluation of "community care" for people moving from mental handicap hospitals	One cohort assessed prior to leaving hospital and at 1, 5 and 12 years post-move	Adults moving from mental handicap hospitals. Of 397 recruited in hospital, 103 have cost data at all three outcome points. 47% Male Mean age at move 44 Mean hospital length of	12 long-stay hospitals across different regions	Residential/nursing home or hospice (=45)[#] Group home (=42)[#] Adult foster care or sheltered housing (=15)[#] Hospital (=1) Independent living (=0)

				stay pre-move 27 years		

§Data presented for 497 people moving 1987-1992; analytic cost sample of 192 are a subset of these for whom no specific data on characteristics are provided. # All sample sizes for 12-year time point, some small divergence from these at one and five years. Categories grouped for this review according to number of residents: Residential/nursing home or hospice had six or more residents; Group homes had two to five residents; Adult foster care and sheltered housing don't specify sample size but are clients moving into established homes.

Both studies were parts of larger studies published in book form: Donnelly *et al.* (1994)[16] is the companion to Beecham; Knapp *et al.* (1992)[17] and Cambridge *et al.* (1994)[18] present the main study for Hallam *et al*. Review of both papers and books revealed limited information on the characteristics of the samples studied in the cost papers. Beecham *et al.* do not report any sample characteristics although cost analyses are performed on a subset of the overall study's analytic sample of 497 and indicative age, IQ level and time in hospital pre-move are provided for this larger group.[16] Hallam *et al.* report age and time in hospital pre-move, but no baseline information on level of disability or disease burden.[15]

An additional shared limitation was the use of the term "community care". In the Beecham *et al.* study, only one person (total sample =192; 0.5%) is reported as moving to an independent living arrangement.[14] Of the other settings, Beecham and colleagues differentiate other categories according to provider (statutory, voluntary, private) but not setting characteristics such as specifying how many people lived in a single unit. A large majority of study participants (141; 73%) moved from hospital to "residential and nursing homes by private bodies". It is therefore possible that a significant number of people ended up in community living with four or fewer people per unit,[2 3] but it is not reported as such. In the Hallam *et al.,* study settings are delineated more clearly by characteristics but independent living is again highly unusual: two (2%) after one year; four (4%) after five years; 0 after 12 years[15]. At each time point post-move approximately half were living in established homes via foster care or sheltered housing, or group homes with two to five residents per unit; 30-40% of people were living in either nursing homes or hostels with six or more residents.

From the information provided in the Beecham *et al.* study only the one person living independently can be said certainly to have moved to community-living arrangements as understood in the 21st century.[14] In the Hallam *et al.* study over half of people moved to an established home or small group home while most others moved to larger institutional settings such as a nursing home and hospice.[15] Risk of bias across studies is consequently difficult to ascertain: too little is known on both the populations and the interventions for strong conclusions to be drawn on services for people outside of the study samples.

Key findings

Mean costs for hospital and "community" care for each study are presented in Table 2. In the Beecham *et al.* study, mean costs are reported as lower for "community" settings than hospital but this difference is not tested for statistical significance (and none is possible *ex post* using the reported data). Differences within types of post-move residence are large and found to be statistically significant but comparisons of specific types of residence are not reported. Per Table 1, "community" settings are characterised by the sector of the provider but no other descriptive data, making it impossible to infer the characteristics of services that offer cost-savings compared to hospital, beyond the fact that public facilities are more expensive and voluntary and private facilities are cheaper. These differences may reflect different levels of need among individuals and/or different levels and characteristics across provider (e.g. number of residents, environment) or they may reflect true differences in effect of provider type on cost of residential care for this population.

Table 2 Key results from included studies

Author/ Year	Mean (standard deviation) weekly costs in pounds sterling*, by residential location						Evidence
Beecham *et al.* (1997)[14] #	Pre-move (No.)	Post-move “community” settings (No.)					Mean costs are lower in “community” settings than long-stay hospital, although considerable variation is observable between different “community” settings. Secondary analysis finds that post-move costs are associated with both client and residence characteristics.
	Hospital (192)	**Public (30)**	**Voluntary (20)**	**Private (141)**	**Ind. living (=1)**	**All (192)**	
	574 (-)	517 (165)	351 (72)	323 (45)	133	356 (106)	
Hallam *et al.* (2006)[15] §	Pre-move (No.=103)	Post-move all “community” settings (No.=103)					Mean costs are higher in “community” settings than long-stay hospital at 1, 5 and 12 years; statistically significant in each case. No presentation or analysis of post-discharge costs by type of residence. Secondary analysis shows that accommodation accounts for 81-86% of “community” costs post-move.
	Hospital	**1 Year**	**5 Years**	**12 Years**			
	736 (136)	899 (260)	871 (301)	765 (324)			

*In both cases, studies assessed formal costs per client (payer perspective) for hospital, community and accommodation services. # Costs in GBP, 1994/5 levels. § Costs in GBP, 2002/3 levels.

In the Hallam *et al*. study, mean costs are reported as higher for “community” care than hospital care at 12 years and this difference is statistically significant.[15] This conclusion is consistent with analyses at one and five years. In the comparison between hospital and “community” costs, all “community” costs were pooled meaning that no cost comparison of established home or small group home *versus* hospital was reported (and none is possible *ex post* using the reported data). Established home or small group home costs cannot be separated from nursing home and hostel costs. Secondary analysis shows that accommodation accounts for 81-86% of “community” costs post-move.

Lack of detail on the type of “community care” that participants moved to, as well as limitations in reporting of cost data and their characteristics, precludes meta-analysis. Both studies examine the same cost perspective: formal costs to the payer of a broad basket of hospital, community and accommodation services associated with each specific individual. This therefore implies the same limitations, and in particular an absence of informal care costs and out-of-pocket costs that may rise when people leave institutions for settings where on-site care is less comprehensive. While both overall studies to which the cost papers were attached did examine client outcomes, no cost-consequence analysis or ratio is reported in either study.

Discussion

Key findings

The two economic studies identified by our review report opposing headline findings: one concludes that “community care” is less costly per individual than long-stay hospital care, the other finds the reverse. Lack of detail on the type of “community care” that participants moved to, as well as limitations in reporting of cost data and their characteristics, precludes meta-analysis. Thus our analysis does not find consistent evidence of cost-saving from deinstitutionalisation. Additionally they do bear out well-established concerns about limitations in work to date.

The greatest strength of the two included studies is the seriousness and detail with which costs were calculated for formal care services received by each specific participant. A comparable basket of health and community care services was assessed pre- and post-move in each study. One of the two studies also examined patterns over a 12-year window, an approach with growing value as the population of people with intellectual disabilities is aging and so understanding of changing needs becomes more important. Secondary analysis suggests significant associations between post-move costs and both participant characteristics and residence characteristics.

However, other reservations about the strength of available evidence were necessary. Perspective was restricted to the formal cost of care provided to individuals without measuring informal care or taking into account the cost implications of people leaving an institution while that institution remains an active care setting for other clients. One-off costs associated with deinstitutionalisation also appeared not to be taken into account.

In considering how the results of this cost literature may inform contemporary policy, the most important limitations were not specific to economic evaluation but were more general to the use of observational data. Both studies report substantial variation in costs according to residence type but in neither study were the destinations described and their cost-effects presented in such a way to understand the impact of moving people from hospital to specific types of residence. One study categorised post-move residences by private, public and voluntary sector but no other characteristic (e.g. environment, number of residents per unit, staff-to-resident ratio). The other study did provide basic descriptive details of post-move settings but hospital costs were only compared statistically with all types of “community care” - nursing homes and hostels with high numbers of resident per unit; group homes with two to five residents; placement in an established home - pooled together. Numbers of people living independently following a move were negligible in both studies.

Details on the participants were similarly scant but all moved from long-stay hospitals between 1983 and 1992 among groups with average age over 40 years at time of move, so it is fair to assume that neither is representative of the growing populations for whom there is a particular lack of evidence on the cost-effects of moving into the community: namely older people with intellectual disabilities and serious medical illness, and younger people with very complex needs and challenging behaviours.

Our search strategy also turned up a larger body of static comparisons, e.g. of the cost of living in institutional settings versus community settings, which also contains mixed findings on the relative costs.[19] These studies were not eligible for our review since they did not evaluate the impact of a move in residential setting, and there are additional concerns about the robustness of such comparisons and unobserved confounding, particularly with routinely collected data.

Strengths and limitations

This study has followed best practice guidelines in systematic evidence reviews where possible. The search strategy was developed by a team featuring subject experts, a systematic review specialist and an information specialist. The strategy’s thoroughness resulted in a very large number (over 25,000) of returned titles and abstracts from databases. These and advanced full texts were reviewed independently by two researchers. Likewise, all full texts accessed were independently reviewed by two team members. Quality assessment for eligible studies and data extraction for included studies was performed by one reviewer with a second reviewer's corroborating review.

Nevertheless, there are a number of important limitations to our work. In devising our search strategy we were faced with profound challenges in defining our intervention. While every effort was made to include all potentially studies through broad search criteria and no *ex ante* definition of institutional or community settings, it is possible that we overlooked some terms that would have captured other relevant material.

In reviewing returned studies from the database search, we used two independent reviewers for title/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, a standard practice in systematic reviews, did mean that a number of older studies were excluded as well as all of the grey literature. Future studies may wish to revisit this issue.

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.

Undoubtedly the greatest limitation was that only two studies met criteria and they were from a period when community-based options available were different from current offerings and the level of detail gathered in those studies is not fit for today's policy purposes.

Conclusion

A systematic review of the economic evidence of deinstitutionalisation for adults with intellectual disabilities identified two relevant studies, one of which found an increase in costs and one a decrease. Both were conducted on processes in the NHS in the 1980s, which limits relevance to 21st century international policy challenges. Economic studies of deinstitutionalisation for people with intellectual disabilities are therefore rare in the context of an ageing population with complex clinical and behavioural characteristics. Such research faces particular challenges in recruiting and retaining representative samples, defining and evaluating the causal effects of complex interventions often provided in multiple settings with multiple components, and maintaining study processes over long periods as people live months and years with serious illness and support needs. The growth in administrative datasets with the potential of standardised costs and shared definitions of key variables may offer an opportunity to better address these concerns. It is critical that more studies are conducted to understand both how to best support this growing population in leading independent lives of their choosing and the resources and resource allocations that will be needed to achieve this.

Figure legend

Figure 1 PRISMA for economics search

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. PM co-designed the original review protocol, project-managed title/abstract and full text review, performed the quality assessment and data extraction, and led writing of the paper. RLV and EM reviewed return studies for eligibility at title and abstract, 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. 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.

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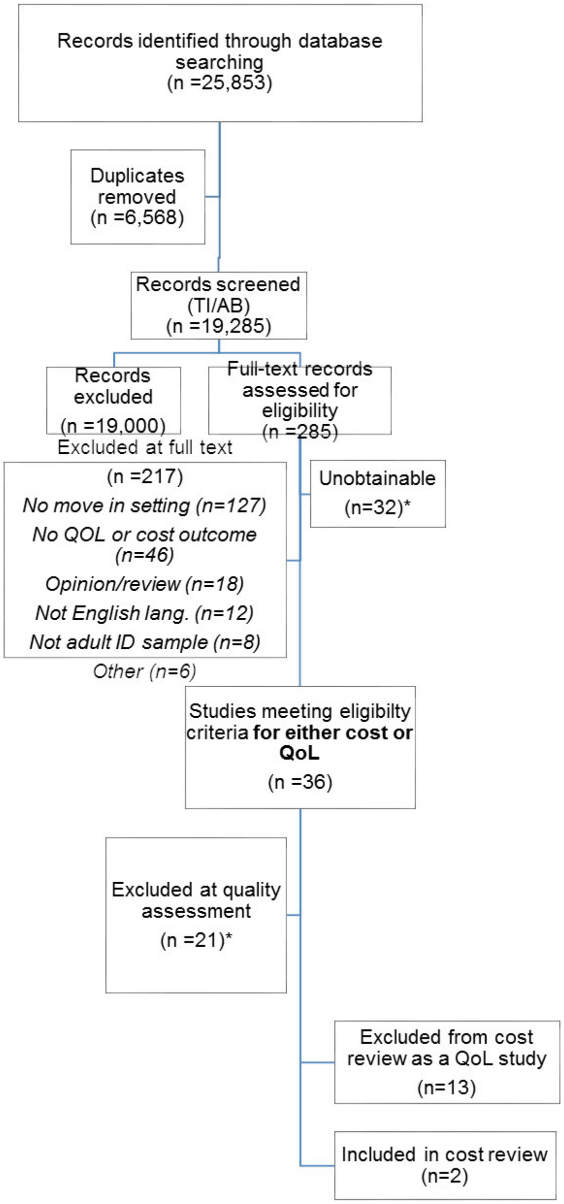

Figure 1 PRISMA for economics search

73x104mm (300 x 300 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
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)

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 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

PRISMA 2009 Checklist

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.	3
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	6
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	7
METHODS			
Protocol a#]nd 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.	4
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.	7-8
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.	8-9
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).	9-10
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.	10
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	10
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.	9-10
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	10
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.	Impossibility of meta-

PRISMA 2009 Checklist

			analysis explained pg 18

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).	9-10
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/a
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.	11-12
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.	12
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).	12
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.	17
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	n/a
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	16
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	n/a
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).	18-20
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).	20-22
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	23
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.	1-2

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

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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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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.

Data sharing

There are no unpublished data from this study.

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Abstract

Objective: To review systematically the evidence on the costs and cost-effectiveness of deinstitutionalisation for adults with intellectual disabilities.

Design: Systematic review.

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

Intervention: a move in residential setting.

Primary and secondary outcome measures: studies were eligible if evaluating within any cost-consequence framework (e.g. cost-effectiveness analysis, cost-utility analysis) or resource use typically considered to fall within the societal viewpoint (e.g. cost to payers, service-users, families, informal care costs).

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

Results: Two studies were included; both were cohort studies from the payer perspective of people leaving long-stay NHS hospitals in the United Kingdom between 1984 and 1992. One study found that deinstitutionalisation reduced costs, one study found an increase in costs.

Conclusion: A wide-ranging literature review found limited evidence on costs associated with deinstitutionalisation for people with intellectual disabilities. From two studies included in the review, the results were conflicting. Significant gaps in the evidence base were observable, particularly with respect to priority populations in

contemporary policy: older people with intellectual disabilities and serious medical illness, and younger people with very complex needs and challenging behaviours.

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Strengths and limitations of this study

- Examining a topic that was not previously the subject of a systematic review, we searched seven databases of peer-reviewed literature evaluating returned studies using two independent reviewers.
- Identified evidence therefore represents state of the science on a pressing policy question for an underserved population.
- We did not search books or monographs.
- Commissioned by policymakers to examine specifically the process of deinstitutionalisation, we did not include cross-sectional studies comparing outcomes for different populations in different settings.

Introduction

Background/rationale

The 2006 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) emphasises the right to live independently in a place of one's own choosing.[1] The promotion of autonomous decision-making and full participation in society for people with disabilities and mental health problems through deinstitutionalisation – movement from living in institutional settings to community settings - has variously occurred in Scandinavia, the United Kingdom, United States, Canada and Australia since the 1960s.[2]

While significant numbers of people have moved out of institutional settings over the last half century, substantial numbers with disabilities, including intellectual disabilities, are still prevented from living in a place of their own choosing, instead being restricted to institutions or inadequate community-based services.[3] This is the case even in those countries where the process of deinstitutionalisation is quite advanced.[4]

We undertook a systematic review of the evidence on the effect of deinstitutionalisation on economic outcomes and on quality of life (QoL) for people with intellectual disabilities. In this paper we report the search strategy for the whole systematic review, and the results for the economics studies. QoL results are presented separately.[5]

Economic evaluations comparing the costs and outcomes of different options may inform decisions on which of the available choices represents best use of the resources available.[6] The accurate estimation of resource use in providing services can inform budgeting, workforce planning and organisation of services in the short and long term when groups of interest, in this case people with intellectual disabilities, are growing in number and complexity of need, and account disproportionately for overall expenditures.[7]

The population of people with intellectual disabilities is changing in important ways that must be accounted for in planning and provision of services.[8] Life expectancy for children born with high levels of disability has increased markedly, meaning that supports must be provided to a growing number of people with very high needs, and increased life expectancy among the population of people with intellectual disabilities means rising prevalence of old age, multimorbidity and dementia.[8-11] Taken together, these trends mean that in the 21st century societies worldwide face never-before-seen populations of people with intellectual disabilities and high support needs, and a limited evidence base on which to base funding decisions and budget projections. An historic reliance on informal care from unpaid family and friends may not be sustainable as age and mobility burdens increase among the carers themselves.[12]

Objectives

To review systematically the evidence on the costs and cost-effectiveness of deinstitutionalisation for adults with intellectual disabilities.

Methods

Eligibility criteria

We used the PICOS (Participants, Interventions, Comparators, Outcomes and Study types)/PEOS (Participants, Exposure, Outcomes and Study types) frameworks to define review eligibility as follows:

Types of participants

Adults (aged 18 years and over) with intellectual disabilities. No pre-determined operational definition of intellectual disability was used; we followed author definition in the first instance and planned to resolve ambiguities through discussion and author contact if necessary.

Types of intervention/exposure/comparators

The intervention of interest in this review was deinstitutionalisation, i.e. the move from institutional to community settings. We chose not define these *ex ante*, e.g. according to the number of residents per unit, since no widely accepted cut-offs exist and any such cut-offs risked arbitrarily excluding studies of relevance. Moreover, deinstitutionalisation has occurred at different speeds in different countries over the last half century, in some cases incorporating phases of reinstitutionalisation (the residential move back from the community to an institution) and transinstitutionalisation (a residential move between institutions).[13]

We therefore defined our intervention/ exposure variable broadly so as to avoid arbitrary exclusion of relevant studies, and we assessed the characteristics of settings on a study-by-study basis on the information provided.

Types of outcomes

Our pre-specified primary outcome of interest was economic effects. For purposes of the review, economic effects were defined broadly as any cost-consequence framework (e.g. cost-effectiveness analysis, cost-utility analysis) or resource use quantified as costs. We did not require that resource use reflect the literal cost of provision for the study to be included, but also considered eligibility based on other approaches to calculating expenditures, such as insurance programme charges, frequency utilisation combined with unit cost data. We considered eligible any perspective typically considered to fall within the societal viewpoint (e.g. cost to payers, service-users, families, informal care costs).

Types of studies/reports

Prospective/retrospective before and after studies, randomised trials, qualitative/descriptive and exploratory studies that reported on economic evaluations were eligible for inclusion. We excluded studies that did not evaluate economic effects following a move, and cross-sectional studies comparing community-living and institutional arrangements for two different groups at a single point in time.

Search strategy

Database search

Our search methodology encompassed both published and grey (e.g. policy reports, national/international guideline documents, etc.) literature using multiple sources. We restricted inclusion of studies to English language publications, but noted potentially eligible non-English language papers to determine whether this might present as a possible source of language bias.

Electronic databases were searched from their date of inception to September 2017. Using search terms and Medical Subject Headings, developed by an information specialist (GS) following 'scoping' and pilot searches, and confirmed with the review team, the databases of MEDLINE, PsycINFO, CENTRAL, CINAHL, EconLit, Embase and Scopus were searched (see Appendix 1 for full details).

Other sources

Grey literature searching focused on non-academic publications, readily available online. Documents of interest included government, statutory organisation, non-statutory organisation (e.g. national disability organisations and university based centres of disability studies), guideline or policy documents or reports of clinical audit with available primary or secondary analytical data (see Appendix 2 for details).

Study selection and quality assessment

Screening citations

Titles and abstracts of retrieved citations were assessed independently by two reviewers (RLV and EM); full-text papers forwarded from title and abstract screening were assessed independently by two reviewers (RLV and PM;. Any differences of opinion on inclusion/exclusion at both stages were resolved between the reviewers based on discussion and consensus. A review manager software package, COVIDENCE (https://www.covidence.org/) supported screening and selecting relevant studies.

Assessment of methodological quality/risk of bias

The methodological quality of each included studies was assessed using the Critical Appraisal Skills Programme (CASP, http://www.casp-uk.net/casp-tools-checklists) standardised assessment tool appropriate to the included study's design, that is, CASP Case Control Checklist, CASP Economic Evaluation Checklist, or CASP Qualitative Checklist. All CASP checklists cover the three main areas of validity, results and clinical relevance. The CASP tool offers a set of 10 questions to which the reviewer assigns Yes, No or Can't tell judgements (Appendix 3). Those studies that receive all (or mostly) Yes assessments were judged to be of high quality (low risk of bias) and similarly, those receiving majority 'No' or 'Can't Tell' assessments were considered of moderate or low quality.

One reviewer (PM) assessed the studies' methodological quality and a second reviewer (CN) performed a rapid assessment to confirm judgements on quality. Conflicts were resolved through discussion and consensus. To limit bias and/or overestimates of effects that may arise from poorly designed, conducted and reported studies, studies were determined to meet a minimum of moderate to high quality of rigour to be included in the review (see Appendix 4).

Data analyses

Data extraction

Predesigned and piloted data extraction forms captured year of study, study setting, type of study design, descriptions of the population/participants, interventions and comparator, ethical issues (e.g. consent), cost outcome data (results) and authors' conclusions. One reviewer (PM) extracted the data from the included papers, and a second reviewer (CN) performed a rapid assessment to confirm accuracy and comprehensiveness of the extracted data. As before, any differences were resolved by discussion and consensus.

Data syntheses

Summary measures

The principal summary measure was the mean estimated effect of move in residential setting on costs or cost-effectiveness (from whatever perspective the study specified). Mean estimated effects on sub-categories of costs, as well as drivers of costs, were secondary measures of interest.

Analytical measures

A priori, our aim was to perform a meta-analysis of individual studies' data so as to achieve an overall (higher level) effect estimate of cost outcomes following a move from an institutional setting to a different/community-based setting. Statistical pooling of data across studies proved neither feasible nor appropriate due to inadequate information on post-discharge residences and associated costs. We therefore present a narrative synthesis of the data using descriptive statistics and thematic analyses.

Patient and Public Involvement

There was no involvement of any person with an intellectual disability or the wider public in this systematic review. A representative from the National Disability

Authority of Ireland,[14] an independent state body providing expert advice on disability policy and practice to the government and the public sector, participated in the design of the systematic search strategy to maximise relevance to current policy and practice.

Results

Search and selection results

Database search

The database search, which was a combined search of studies reporting on both cost and QoL, returned 25,853 citations for consideration against the review's eligibility criteria of which 6,568 were duplicate citations across databases, and were excluded. A further 19,000 citations were excluded during title and abstract screening as they clearly did not meet the review's pre-specified eligibility criteria (Figure 1). This left 285 papers for full text review; of these 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 data (46), opinion or commentaries and reviews (18), not in English language (12), not an adult population with intellectual disability (8) and miscellaneous (6).

Of the remaining 36 included studies, 21 of these were subsequently excluded based on methodological quality assessments using the CASP tool. Reasons for exclusion at this stage were failure to establish consent of study participants, and insufficient and negligible data on participants and/or outcomes (see Appendix 4). Of the 15 studies remaining, 13 addressed QoL outcomes only (reported separately[5]) and two reported on costs. No study was eligible for both the QoL review and this economics review. We reviewed references of two included studies and did not identify further eligible studies for inclusion.

Grey literature search

The grey literature search resulted in retrieval of 74 reports, of which 30 appeared relevant to deinstitutionalisation from a cost and/or QoL perspective, but on further review, only six provided pre- and post-move measures. Following a quality assessment of these six reports, none met the minimum standards, and all six were excluded from the review (see Appendix 2 for details).

Main results

Description of included studies

Two studies evaluated the impact on economic outcomes for people with intellectual disabilities who experienced a move in residential setting. Both studies follow a single cohort of people moving from long-stay hospitals in the UK National Health Service (NHS) and are summarised in Table 1. Beecham *et al.* examine costs at 12 months for adults moving from what were then called ‘mental handicap’ and psychiatric hospitals in Northern Ireland between 1990 and 1992;[15] Hallam *et al.* examine longitudinally costs after one, five and 12 years for adults moving from 12 different sites in England between 1984 and 1987.[16]

Both studies had a majority of ‘Yes’ responses using the CASP assessment tool (Table 2). Risk of bias within studies is considered low: each follows a single cohort of participants with each person effectively acting as their own control. Risk of bias across studies is difficult to ascertain: too little is known on both the populations and the interventions for strong conclusions to be drawn on representativeness of the study samples.

Table 1 Summary characteristics of included studies

Lead author& year	Location (country); dates of study	Aim	Study design	Description of study sample	Description of congregated setting	Description of community setting
Beecham *et al.* (1997)[15]	Northern Ireland, 1990-1993	To evaluate the effect on costs of discharging people with intellectual disabilities from long-stay hospitals to "community care"	One cohort assessed prior to leaving hospital and 12 months after doing so	Adults with learning disabilities. Of 214 adults moving during study period, 22 were lost to follow-up leaving a sample of 192. 57% male§ Median age 47 years§ Median hospital stay prior to move 20 years§ 7% low IQ score (<20), 52% medium IQ score (20-49), 33% high IQ score (50-69), and 8% not recorded§	Three mental handicap hospitals and four psychiatric hospitals	Residential facilities provided by statutory bodies (=30) Residential facilities provided by voluntary bodies (=20) Residential and nursing homes from private bodies (=141) Independent living arrangements (=1).
Hallam *et al.* (2006)[16]	England, 1984-1999	Evaluation of "community care" for people moving from mental handicap hospitals	One cohort assessed prior to leaving hospital and at 1, 5 and 12 years post-move	Adults moving from mental handicap hospitals. Of 397 recruited in hospital, 103 have cost data at all three outcome points.	12 long-stay hospitals across different regions	Residential/nursing home or hospice (=45)# Group home (=42) # Adult foster care or sheltered housing (=15) #

				47% Male Mean age at move 44 Mean hospital length of stay pre-move 27 years		Hospital (=1) Independent living (=0)

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

[#] All sample sizes for 12-year time point, some small divergence from these at one and five years. Categories grouped for this review according to number of residents: Residential/nursing home or hospice had six or more residents; Group homes had two to five residents; Adult foster care and sheltered housing don't specify sample size but are clients moving into established homes.

Table 2 Quality assessment: included 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*
Beecham *et al.* (1997)[15]	Yes	Yes	Can't tell	Yes	No	No	Yes	Yes	Yes	Can't tell	Can't tell	6	2	3
Hallam *et al.* (2006)[16]	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Can't tell	Can't tell	7	2	2

Both studies were parts of larger studies published in book form: Donnelly *et al.* (1994)[17] is the companion to Beecham *et al.*; Knapp *et al.* (1992)[18] and Cambridge *et al.* (1994)[19] present the main study for Hallam *et al.*.

Review of both papers and books revealed limited information on the characteristics of the specific samples studied in the cost papers. Beecham *et al.* do not report any sample characteristics although cost analyses are performed on a subset of the overall study's analytic sample of 497 and indicative age, IQ level and time in hospital pre-move are provided for this larger group.[17] Hallam *et al.* report age and time in hospital pre-move, but no baseline information on level of disability or disease burden;[16] in the supporting books the authors provide detailed baseline data (including gender, severity of intellectual disability, skills, behavioural issues, social interaction, depression, psychosocial function, life satisfaction) on the original recruited sample of people with intellectual disabilities (n=529) but it is not clear how representative is the sub-sample of 103 reported in the paper.[18 19]

An additional barrier to interpretation was the use of the term "community care". In the Beecham *et al.* study, only one person (total sample =192; 0.5%) is reported as moving to an independent living arrangement.[15] Of the other settings, Beecham and colleagues differentiate other categories according to provider (statutory, voluntary, private) but not setting characteristics such as specifying how many people lived in a single unit. A large majority of study participants (141; 73%) moved from hospital to "residential and nursing homes by private bodies". It is therefore possible that a significant number of people ended up in community living,[2 3] but it is not reported as such. In the Hallam *et al.,* study settings are delineated more clearly by characteristics.[16] At each time point post-move approximately half were living in established homes via foster care or sheltered housing, or group homes with two to five residents per unit; 30-40% of people were living in either nursing homes or hostels with six or more residents. Independent living was again highly unusual: two participants (2%) after one year; four (4%) after five years; 0 after 12 years

Key findings

Mean costs for hospital and "community" care for each study are presented in Table 3. In the Beecham *et al.* study, mean costs are reported as lower for "community" settings than hospital but this difference is not tested for statistical significance (and none is possible *ex post* using the reported data). Differences within types of post-move residence are large and found to be statistically significant but comparisons of specific types of residence are not reported. Per Table 1, "community" settings are characterised by the sector of the provider but no other descriptive data, making it impossible to infer the characteristics of services that offer cost-savings compared to hospital, beyond the fact that public facilities are more expensive and voluntary and private facilities are cheaper. These differences may reflect different levels of need among individuals and/or different levels and characteristics across provider (e.g. number of residents, environment) or they may reflect true differences in effect of provider type on cost of residential care for this population.

Table 3 Key results from included studies

<table>
<tr><th>Author/ Year</th><th colspan="6">Mean (standard deviation) weekly costs in pounds sterling*, by residential location</th><th>Evidence</th></tr>
<tr><td rowspan="3">Beecham <i>et al.</i> (1997)[15]
#</td><td>Pre-move (No.)</td><td colspan="5">Post-move “community” settings (No.)</td><td rowspan="3">Mean costs are lower in “community” settings than long-stay hospital, although no statistical analysis is reported and there is considerable variation is observable between different “community” settings.</td></tr>
<tr><td>Hospital (192)</td><td>Public (30)</td><td>Voluntary (20)</td><td>Private (141)</td><td>Ind. living (=1)</td><td>All (192)</td></tr>
<tr><td>574 (-)</td><td>517 (165)</td><td>351 (72)</td><td>323 (45)</td><td>133</td><td>356 (106)</td></tr>
<tr><td rowspan="4">Hallam <i>et al.</i> (2006)[16]
§</td><td>Pre-move (No.=103)</td><td colspan="5">Post-move all “community” settings (No.=103)</td><td rowspan="4">Mean costs are higher in “community” settings than long-stay hospital at 1, 5 and 12 years; statistically significant in each case. No presentation or analysis of post-discharge costs by type of residence.</td></tr>
<tr><td>Hospital</td><td colspan="2">1 Year</td><td colspan="2">5 Years</td><td>12 Years</td></tr>
<tr><td>736 (136)</td><td colspan="2">899 (260)</td><td colspan="2">871 (301)</td><td>765 (324)</td></tr>
<tr><td>Paired t-test (df=102)</td><td colspan="2">+163 (t=4.96, p<0.001)</td><td colspan="2">+135 (t=35.04, p<0.001)</td><td>+29 (t=54.07, p< 0.001)</td></tr>
</table>

*In both cases, studies assessed formal costs per client (payer perspective) for hospital, community and accommodation services. # Costs in GBP, 1994/5 levels. § Costs in GBP, 2002/3 levels.

In the Hallam *et al.* study, mean costs are reported as higher for “community” care than hospital care at one, five and 12 years and these differences are statistically significant.[16] In this comparison between hospital and “community” costs, all “community” costs were pooled meaning that no cost comparison of established home or small group home *versus* hospital was reported (and none is possible *ex post* using the reported data). Established home or small group home costs cannot be separated from nursing home and hostel costs. Secondary analysis by the study authors shows that accommodation accounts for 81-86% of “community” costs post-move. Summary cost data disaggregated by destination at one and five years were reported separately in prior books,[18 19] but no formal evaluation of association between costs and specific destinations are reported.

Different categorisation of “community care” precludes meta-analysis. Both studies examine the same cost perspective: formal costs to the payer of a broad basket of hospital, community and accommodation services associated with each specific individual. This therefore implies the same limitations, and in particular an absence of informal care costs and out-of-pocket costs that may rise when people leave institutions for settings where on-site care is less comprehensive. While both overall studies to which the cost papers were attached did examine client outcomes, no cost-consequence analysis or ratio is reported in either study.

Discussion

Key findings

The two economic studies identified by our review report opposing headline findings: one concludes that “community care” was more costly per individual at one, five and 12 years than long-stay hospital care, and these differences are statistically significant. The other found that costs were lower for “community care”, although this association is not evaluated for statistical significance.

The greatest strength of the two included studies is the seriousness and detail with which costs were calculated for formal care services received by each specific participant. A comparable basket of health and community care services was assessed pre- and post-move in each study. One of the two studies also examined patterns over a 12-year window, an approach with growing value as the population of people with intellectual disabilities is aging and so understanding of changing needs becomes more important.

There are three principal barriers to interpreting these results, the apparent inconsistency between their key findings, and the lessons for contemporary policy and practice.

First, different types of destination are in ways that are ill-suited to our research question. Both studies group different destinations with different associated costs under the label “community care”, precluding identification of association between movement to specific accommodation types and costs. Second, some destination types (e.g. nursing home, hostel) would today be widely classified as institutions themselves, meaning that the reported association of “deinstitutionalisation” is questionable. Third, both studies analyse sub-samples of larger parent studies. While the overall samples are detailed in book form, limited detail on the analytic cost sub-samples is provided, making generalisabililty hard to ascertain.

In considering how the results of this cost literature may inform contemporary policy, there are additional inescapable limitations in the age of the studies. Priority populations for policymakers are older people with intellectual disabilities and serious medical illness, and younger people with very complex needs and challenging behaviours.[2 3] In the context of the UNCRPD and a growing emphasis on independent living,[1 3] there is a growing emphasis on autonomous decision-making and full participation in society for people with disabilities that was not prominent when the original studies were conducted. Numbers of people living independently following a move were negligible in both studies.

Strengths and limitations

This study has followed best practice guidelines in systematic evidence reviews where possible, following the PRISMA guidelines. The search strategy was developed by a team featuring subject experts, a systematic review specialist and an information specialist. The strategy's thoroughness resulted in a very large number of returned titles and abstracts from databases. These and advanced full texts were reviewed independently by two researchers. Likewise, all full texts accessed were independently reviewed by two team members. Quality assessment for eligible studies and data extraction for included studies was performed by one reviewer with a second reviewer's corroborating review.

Nevertheless, there are a number of important limitations to our work. In devising our search strategy we were faced with profound challenges in defining our intervention. While every effort was made to include all potentially studies through broad search criteria and no *ex ante* definition of institutional or community settings, it is possible that we overlooked some terms that would have captured other relevant material.

This choice of intervention – the process of deinstitutionalisation, and not comparative analysis of outcomes living in one setting versus another - reflected the interests of the Irish Department of Health, who commissioned this work to inform ongoing policy reforms. Those countries where the process is at an advanced stage and the majority of people with intellectual disabilities already live in the community, might find such comparative analyses to be more useful in informing policy. However, significant number of people in those countries continue to live in institutions, disproportionately those with the high support needs that are of particular policy interest.

Our search strategy did turn up a larger body of cross-sectional comparisons, e.g. of the cost of living in institutional settings versus community settings. Prior reviews have reported similarly mixed findings on the relative costs and there are additional concerns about the robustness of such comparisons and unobserved confounding, particularly with routinely collected data.[20] A strength of the studies included in our review is that confounding concerns are minimised by the use of participants as their own controls.

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, a standard practice in systematic reviews, did mean that a number of older studies were excluded as well as all of the grey literature. Future studies may wish to revisit this issue.

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.

Conclusion

A systematic review of the economic evidence of deinstitutionalisation for adults with intellectual disabilities identified two relevant studies, one of which found an increase in costs and one a decrease. Both were conducted on processes in the NHS in the 1980s and early 1990s, which limits relevance to 21st century international policy challenges. Economic studies of deinstitutionalisation for people with intellectual disabilities are therefore rare in the context of an ageing population with complex clinical and behavioural characteristics. Such research faces particular challenges in recruiting and retaining representative samples, defining and evaluating the causal effects of complex interventions often provided in multiple settings with multiple components, and maintaining study processes over long periods as people live months and years with serious illness and support needs. The growth in administrative datasets with the potential of standardised costs and shared definitions of key variables may offer an opportunity to better address these concerns. It is critical that more studies are conducted to understand both how to best support this growing population in leading independent lives of their choosing and the resources and resource allocations that will be needed to achieve this.

Figure legend

Figure 1 PRISMA for economics search

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. PM co-designed the original review protocol, project-managed title/abstract and full text review, performed the quality assessment and data extraction, and led writing of the paper. RLV and EM reviewed return studies for eligibility at title and abstract, 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. 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.

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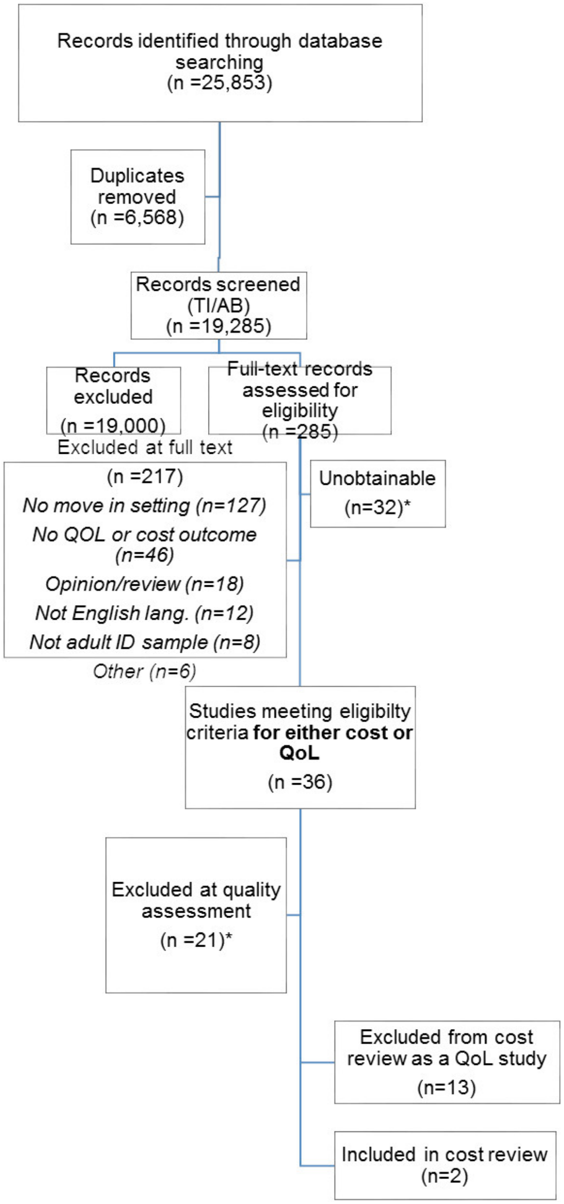

Figure 1 PRISMA for economics search

73x104mm (300 x 300 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)

Note: the term ‘1915’ was included to identify US studies of the relevant Medicaid waiver to meet the needs of people who prefer to get long-term care and supports in the community rather than an institution (https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/national-overview-1915-c-waivers.html).

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.

The subject experts decided *ex ante* to search based on country and centres of disability studies (and not specific grey databases such as OpenGrey, OpenSIGLE and GreyNet) as these were deemed the strongest source of potentially relevant material. 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
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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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Appendix 3 CASP Cohort Study Appraisal Questions

This review used the CASP suite of tools (https://casp-uk.net/casp-tools-checklists/). Both studies included in the review of cost papers were cohort studies with costs as the outcome of interest, and not analyses in the tradition of economic evaluation.

We therefore used the cohort study appraisal tool, which features 14 questions under 12 headers:

1. Did the study address a clearly focused issue?

2. Was the cohort recruited in an acceptable way?

3. Was the exposure accurately measured to minimise bias?

4. Was the outcome accurately measured to minimise bias?

5. (a) Have the authors identified all important confounding factors?

5. (b) Have they taken account of the confounding factors in the design and/or analysis?

6. (a) Was the follow up of subjects complete enough?

6. (b) Was the follow up of subjects long enough?

7. What are the results of this study?

8. How precise are the results?

9. Do you believe the results?

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

11. Do the results of this study fit with other available evidence?

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

Appendix 4 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 5 Unobtainable studies

Appendix Table 3 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 4 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

PRISMA 2009 Checklist

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.	3
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	6
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	7
METHODS			
Protocol a#]nd 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.	4
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.	7-8
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.	8-9
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).	9-10
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.	10
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	10
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.	9-10
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	10
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.	Impossibility of meta-

PRISMA 2009 Checklist

			analysis explained pg 18

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).	9-10
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/a
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.	11-12
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.	12
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).	12
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.	17
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	n/a
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	16
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	n/a
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).	18-20
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).	20-22
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	23
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.	1-2

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.

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

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Title

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

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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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N/A.

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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.

Data sharing

There are no unpublished data from this study.

Exclusive licence

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Abstract

Objective: To review systematically the evidence on the costs and cost-effectiveness of deinstitutionalisation for adults with intellectual disabilities.

Design: Systematic review.

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

Intervention: Deinstitutionalisation, i.e. the move from institutional to community settings.

Primary and secondary outcome measures: studies were eligible if evaluating within any cost-consequence framework (e.g. cost-effectiveness analysis, cost-utility analysis) or resource use typically considered to fall within the societal viewpoint (e.g. cost to payers, service-users, families, informal care costs).

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

Results: Two studies were included; both were cohort studies from the payer perspective of people leaving long-stay NHS hospitals in the United Kingdom between 1984 and 1992. One study found that deinstitutionalisation reduced costs, one study found an increase in costs.

Conclusion: A wide-ranging literature review found limited evidence on costs associated with deinstitutionalisation for people with intellectual disabilities. From two studies included in the review, the results were conflicting. Significant gaps in the evidence base were observable, particularly with respect to priority populations in

contemporary policy: older people with intellectual disabilities and serious medical illness, and younger people with very complex needs and challenging behaviours.

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Strengths and limitations of this study

- Examining a topic that was not previously the subject of a systematic review, we searched seven databases of peer-reviewed literature evaluating returned studies using two independent reviewers.
- Identified evidence therefore represents state of the science on a pressing policy question for an underserved population.
- We did not search books or monographs.
- Commissioned by policymakers to examine specifically the process of deinstitutionalisation, we did not include cross-sectional studies comparing outcomes for different populations in different settings.

Introduction

Background/rationale

The 2006 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) emphasises the right to live independently in a place of one's own choosing.[1] The promotion of autonomous decision-making and full participation in society for people with disabilities and mental health problems through deinstitutionalisation – movement from living in institutional settings to community settings - has variously occurred in Scandinavia, the United Kingdom, United States, Canada and Australia since the 1960s.[2]

While significant numbers of people have moved out of institutional settings over the last half century, substantial numbers with disabilities, including intellectual disabilities, are still prevented from living in a place of their own choosing, instead being restricted to institutions or inadequate community-based services.[3] This is the case even in those countries where the process of deinstitutionalisation is quite advanced.[4]

In Ireland, a first wave of deinstitutionalization included movement to smaller living units on what are called campus settings.[5] A more decisive break from institutional to community arrangements for people with intellectual disability is now the stated policy priority.[5] The Irish government, wishing to benefit from the experience of others and the best available and most rigorous evidence, commissioned through the Health Research Board, a systematic review of the evidence on the effect of deinstitutionalisation on economic outcomes and on quality of life (QoL) for people with intellectual disabilities. Their interest was specifically in analysis of those moving residence, rather than in cross-sectional analysis of different people living in different settings. In this paper we report the search strategy for the whole systematic review, and the results for the economics studies. QoL results have been published previously.[6]

Economic evaluations comparing the costs and outcomes of different options may inform decisions on which of the available choices represents best use of the resources available.[7] The accurate estimation of resource use in providing services can inform budgeting, workforce planning and organisation of services in the short and long term when groups of interest, in this case people with intellectual disabilities, are growing in number and complexity of need, and account disproportionately for overall expenditures.[8]

The population of people with intellectual disabilities is changing in important ways that must be accounted for in planning and provision of services.[9] Life expectancy for children born with high levels of disability has increased markedly, meaning that supports must be provided to a growing number of people with very high needs, and increased life expectancy among the population of people with intellectual disabilities means rising prevalence of old age, multimorbidity and dementia.[9-12] Taken together, these trends mean that in the 21st century societies worldwide face never-before-seen populations of people with intellectual disabilities and high support needs, and a limited evidence base on which to base funding decisions and budget projections. An historic reliance on informal care from unpaid family and friends may not be sustainable as age and mobility burdens increase among the carers themselves.[13]

Objectives

To review systematically the evidence on the costs and cost-effectiveness of deinstitutionalisation for adults with intellectual disabilities.

Methods

Eligibility criteria

We used the PICOS (Participants, Interventions, Comparators, Outcomes and Study types)/PEOS (Participants, Exposure, Outcomes and Study types) frameworks to define review eligibility as follows:

Types of participants

Adults (aged 18 years and over) with intellectual disabilities. No pre-determined operational definition of intellectual disability was used; we followed author definition in the first instance and planned to resolve ambiguities through discussion and author contact if necessary.

Types of intervention/exposure/comparators

The intervention of interest in this review was deinstitutionalisation, i.e. the move from institutional to community settings. We chose not define these *ex ante*, e.g. according to the number of residents per unit, since no widely accepted cut-offs exist and any such cut-offs risked arbitrarily excluding studies of relevance. Moreover, deinstitutionalisation has occurred at different speeds in different countries over the last half century, in some cases incorporating phases of reinstitutionalisation (the residential move back from the community to an institution) and transinstitutionalisation (a residential move between institutions).[14]

We therefore defined our intervention/ exposure variable broadly so as to avoid arbitrary exclusion of relevant studies, and we assessed the characteristics of settings on a study-by-study basis on the information provided.

Types of outcomes

Our pre-specified primary outcome of interest was economic effects. For purposes of the review, economic effects were defined broadly as any cost-consequence framework (e.g. cost-effectiveness analysis, cost-utility analysis) or resource use quantified as costs. We did not require that resource use reflect the literal cost of provision for the study to be included, but also considered eligibility based on other approaches to calculating expenditures, such as insurance programme charges, frequency utilisation combined with unit cost data. We considered eligible any perspective typically considered to fall within the societal viewpoint (e.g. cost to payers, service-users, families, informal care costs).

Types of studies/reports

Prospective/retrospective before and after studies, randomised trials, qualitative/descriptive and exploratory studies that reported on economic evaluations were eligible for inclusion. To be consistent with the desire to understand the likelihood of increases in QoL and in cost consequences over time we excluded studies that did not evaluate economic effects following a move, and cross-sectional studies comparing community-living and institutional arrangements for two different groups at a single point in time.

Search strategy

Database search

Our search methodology encompassed both published and grey (e.g. policy reports, national/international guideline documents, etc.) literature using multiple sources. We restricted inclusion of studies to English language publications, but noted potentially eligible non-English language papers to determine whether this might present as a possible source of language bias.

Electronic databases were searched from their date of inception to September 2017. Using search terms and Medical Subject Headings, developed by an information specialist (GS) following ‘scoping’ and pilot searches, and confirmed with the review team, the databases of MEDLINE, PsycINFO, CENTRAL, CINAHL, EconLit, Embase and Scopus were searched (see Appendix 1 for full details).

Other sources

Grey literature searching focused on non-academic publications, readily available online. Documents of interest included government, statutory organisation, non-statutory organisation (e.g. national disability organisations and university based centres of disability studies), guideline or policy documents or reports of clinical audit with available primary or secondary analytical data (see Appendix 2 for details).

Study selection and quality assessment

Screening citations

Titles and abstracts of retrieved citations were assessed independently by two reviewers (RLV and EM); full-text papers forwarded from title and abstract screening were assessed independently by two reviewers (RLV and PM;. Any differences of opinion on inclusion/exclusion at both stages were resolved between the reviewers based on discussion and consensus. A review manager software package, COVIDENCE (https://www.covidence.org/) supported screening and selecting relevant studies.

Assessment of methodological quality/risk of bias

The methodological quality of each included studies was assessed using the Critical Appraisal Skills Programme (CASP, http://www.casp-uk.net/casp-tools-checklists) standardised assessment tool appropriate to the included study's design, that is, CASP Case Control Checklist, CASP Economic Evaluation Checklist, or CASP Qualitative Checklist. All CASP checklists cover the three main areas of validity, results and clinical relevance. The CASP tool offers a set of 10 questions to which the reviewer assigns Yes, No or Can't tell judgements (Appendix 3). Those studies that receive all (or mostly) Yes assessments were judged to be of high quality (low risk of bias) and similarly, those receiving majority 'No' or 'Can't Tell' assessments were considered of moderate or low quality. In a list with 11 categories, six 'Yes' verdicts was therefore sufficient for inclusion.

One reviewer (PM) assessed the studies' methodological quality and a second reviewer (CN) performed a rapid assessment to confirm judgements on quality. Conflicts were resolved through discussion and consensus. To limit bias and/or overestimates of effects that may arise from poorly designed, conducted and reported studies, studies were determined to meet a minimum of moderate to high quality of rigour to be included in the review (see Appendix 4).

Data analyses

Data extraction

Predesigned and piloted data extraction forms captured year of study, study setting, type of study design, descriptions of the population/participants, interventions and comparator, ethical issues (e.g. consent), cost outcome data (results) and authors' conclusions. One reviewer (PM) extracted the data from the included papers, and a second reviewer (CN) performed a rapid assessment to confirm accuracy and comprehensiveness of the extracted data. As before, any differences were resolved by discussion and consensus.

Data syntheses

Summary measures

The principal summary measure was the mean estimated effect of move in residential setting on costs or cost-effectiveness (from whatever perspective the study specified). Mean estimated effects on sub-categories of costs, as well as drivers of costs, were secondary measures of interest.

Analytical measures

A priori, our aim was to perform a meta-analysis of individual studies' data so as to achieve an overall (higher level) effect estimate of cost outcomes following a move from an institutional setting to a different/community-based setting. Statistical pooling of data across studies proved neither feasible nor appropriate due to inadequate information on post-discharge residences and associated costs. We therefore present a narrative synthesis of the data using descriptive statistics and thematic analyses.

Patient and Public Involvement

There was no involvement of any person with an intellectual disability or the wider public in this systematic review. A representative from the National Disability Authority of Ireland,[15] an independent state body providing expert advice on disability policy and practice to the government and the public sector, participated in the design of the systematic search strategy to maximise relevance to current policy and practice.

Results

Search and selection results

Database search

The database search, which was a combined search of studies reporting on both cost and QoL, returned 25,853 citations for consideration against the review's eligibility criteria of which 6,568 were duplicate citations across databases, and were excluded. A further 19,000 citations were excluded during title and abstract screening as they clearly did not meet the review's pre-specified eligibility criteria (Figure 1). This left 285 papers for full text review; of these 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 data (46), opinion or commentaries and reviews (18), not in English language (12), not an adult population with intellectual disability (8) and miscellaneous (6).

Of the remaining 36 included studies, 21 of these were subsequently excluded based on methodological quality assessments using the CASP tool. Reasons for exclusion at this stage were failure to establish consent of study participants, and insufficient and negligible data on participants and/or outcomes (see Appendix 4). Of the 15 studies remaining, 13 addressed QoL outcomes only (reported separately[16]) and two reported on costs. No study was eligible for both the QoL review and this economics review. We reviewed references of two included studies and did not identify further eligible studies for inclusion.

Grey literature search

The grey literature search resulted in retrieval of 74 reports, of which 30 appeared relevant to deinstitutionalisation from a cost and/or QoL perspective, but on further review, only six provided pre- and post-move measures. Following a quality assessment of these six reports, none met the minimum standards, and all six were excluded from the review (see Appendix 2 for details).

Main results

Description of included studies

Two studies evaluated the impact on economic outcomes for people with intellectual disabilities who experienced a move in residential setting. Both studies follow a single cohort of people moving from long-stay hospitals in the UK National Health Service (NHS) and are summarised in Table 1. Beecham *et al.* examine costs at 12 months for adults moving from what were then called ‘mental handicap’ and psychiatric hospitals in Northern Ireland between 1990 and 1992;[17] Hallam *et al.*

examine longitudinally costs after one, five and 12 years for adults moving from 12 different sites in England between 1984 and 1987.[18]

Both studies had a majority of ‘Yes’ responses using the CASP assessment tool (Table 2). Risk of bias within studies is considered low: each follows a single cohort of participants with each person effectively acting as their own control. Risk of bias across studies is difficult to ascertain: too little is known on both the populations and the interventions for strong conclusions to be drawn on representativeness of the study samples.

Table 1 Summary characteristics of included studies

Lead author& year	Location (country); dates of study	Aim	Study design	Description of study sample	Description of congregated setting	Description of community setting
Beecham *et al.* (1997)[17]	Northern Ireland, 1990-1993	To evaluate the effect on costs of discharging people with intellectual disabilities from long-stay hospitals to "community care"	One cohort assessed prior to leaving hospital and 12 months after doing so	Adults with learning disabilities. Of 214 adults moving during study period, 22 were lost to follow-up leaving a sample of 192. 57% male[§] Median age 47 years[§] Median hospital stay prior to move 20 years[§] 7% low IQ score (<20), 52% medium IQ score (20-49), 33% high IQ score (50-69), and 8% not recorded[§]	Three mental handicap hospitals and four psychiatric hospitals	Residential facilities provided by statutory bodies (=30) Residential facilities provided by voluntary bodies (=20) Residential and nursing homes from private bodies (=141) Independent living arrangements (=1).
Hallam *et al.* (2006)[18]	England, 1984-1999	Evaluation of "community care" for people moving from mental handicap hospitals	One cohort assessed prior to leaving hospital and at 1, 5 and 12 years post-move	Adults moving from mental handicap hospitals. Of 397 recruited in hospital, 103 have cost data at all three outcome points.	12 long-stay hospitals across different regions	Residential/nursing home or hospice (=45)[#] Group home (=42)[#] Adult foster care or sheltered housing (=15)[#]

				47% Male Mean age at move 44 Mean hospital length of stay pre-move 27 years		Hospital (=1) Independent living (=0)

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

[#] All sample sizes for 12-year time point, some small divergence from these at one and five years. Categories grouped for this review according to number of residents: Residential/nursing home or hospice had six or more residents; Group homes had two to five residents; Adult foster care and sheltered housing don't specify sample size but are clients moving into established homes.

Table 2 Quality assessment: included 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*
Beecham *et al.* (1997)[17]	Yes	Yes	Can't tell	Yes	No	No	Yes	Yes	Yes	Can't tell	Can't tell	6	2	3
Hallam *et al.* (2006)[18]	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Can't tell	Can't tell	7	2	2

Both studies were parts of larger studies published in book form: Donnelly *et al.* (1994)[19] is the companion to Beecham *et al.*; Knapp *et al.* (1992)[20] and Cambridge *et al.* (1994)[21] present the main study for Hallam *et al.*.

Review of both papers and books revealed limited information on the characteristics of the specific samples studied in the cost papers. Beecham *et al.* do not report any sample characteristics although cost analyses are performed on a subset of the overall study's analytic sample of 497 and indicative age, IQ level and time in hospital pre-move are provided for this larger group.[19] Hallam *et al.* report age and time in hospital pre-move, but no baseline information on level of disability or disease burden;[18] in the supporting books the authors provide detailed baseline data (including gender, severity of intellectual disability, skills, behavioural issues, social interaction, depression, psychosocial function, life satisfaction) on the original recruited sample of people with intellectual disabilities (n=529) but it is not clear how representative is the sub-sample of 103 reported in the paper.[20 21]

An additional barrier to interpretation was the use of the term "community care". In the Beecham *et al.* study, only one person (total sample =192; 0.5%) is reported as moving to an independent living arrangement.[17] Of the other settings, Beecham and colleagues differentiate other categories according to provider (statutory, voluntary, private) but not setting characteristics such as specifying how many people lived in a single unit. A large majority of study participants (141; 73%) moved from hospital to "residential and nursing homes by private bodies". It is therefore possible that a significant number of people ended up in community living,[2 3] but it is not reported as such. In the Hallam *et al.,* study settings are delineated more clearly by characteristics.[18] At each time point post-move approximately half were living in established homes via foster care or sheltered housing, or group homes with two to five residents per unit; 30-40% of people were living in either nursing homes or hostels with six or more residents. Independent living was again highly unusual: two participants (2%) after one year; four (4%) after five years; 0 after 12 years

Key findings

Mean costs for hospital and “community” care for each study are presented in Table 3. In the Beecham *et al.* study, mean costs are reported as lower for “community” settings than hospital but this difference is not tested for statistical significance (and none is possible *ex post* using the reported data). Differences within types of post-move residence are large and found to be statistically significant but comparisons of specific types of residence are not reported. Per Table 1, “community” settings are characterised by the sector of the provider but no other descriptive data, making it impossible to infer the characteristics of services that offer cost-savings compared to hospital, beyond the fact that public facilities are more expensive and voluntary and private facilities are cheaper. These differences may reflect different levels of need among individuals and/or different levels and characteristics across provider (e.g. number of residents, environment) or they may reflect true differences in effect of provider type on cost of residential care for this population.

Table 3 Key results from included studies

Author/ Year	Mean (standard deviation) weekly costs in pounds sterling*, by residential location						Evidence
Beecham *et al.* (1997)[17] [#]	Pre-move (No.)	Post-move “community” settings (No.)					Mean costs are lower in “community” settings than long-stay hospital, although no statistical analysis is reported and there is considerable variation is observable between different “community” settings.
	Hospital (192)	**Public (30)**	**Voluntary (20)**	**Private (141)**	**Ind. living (=1)**	**All (192)**	
	574 (-)	517 (165)	351 (72)	323 (45)	133	356 (106)	
Hallam *et al.* (2006)[18] [§]	Pre-move (No.=103)	Post-move all “community” settings (No.=103)					Mean costs are higher in “community” settings than long-stay hospital at 1, 5 and 12 years; statistically significant in each case. No presentation or analysis of post-discharge costs by type of residence.
	Hospital	**1 Year**	**5 Years**	**12 Years**			
	736 (136)	899 (260)	871 (301)	765 (324)			
	Paired t-test (df=102)	+163 (t=4.96, p<0.001)	+135 (t=35.04, p<0.001)	+29 (t=54.07, p< 0.001)			

*In both cases, studies assessed formal costs per client (payer perspective) for hospital, community and accommodation services. [#] Costs in GBP, 1994/5 levels. [§] Costs in GBP, 2002/3 levels.

In the Hallam *et al*. study, mean costs are reported as higher for “community” care than hospital care at one, five and 12 years and these differences are statistically significant.[18] In this comparison between hospital and “community” costs, all “community” costs were pooled meaning that no cost comparison of established home or small group home *versus* hospital was reported (and none is possible *ex post* using the reported data). Established home or small group home costs cannot be separated from nursing home and hostel costs. Secondary analysis by the study authors shows that accommodation accounts for 81-86% of “community” costs post-move. Summary cost data disaggregated by destination at one and five years were reported separately in prior books,[20 21] but no formal evaluation of association between costs and specific destinations are reported.

Different categorisation of “community care” precludes meta-analysis. Both studies examine the same cost perspective: formal costs to the payer of a broad basket of hospital, community and accommodation services associated with each specific individual. This therefore implies the same limitations, and in particular an absence of informal care costs and out-of-pocket costs that may rise when people leave institutions for settings where on-site care is less comprehensive. While both overall studies to which the cost papers were attached did examine client outcomes, no cost-consequence analysis or ratio is reported in either study.

Discussion

Key findings

The two economic studies identified by our review report opposing headline findings: one concludes that “community care” was more costly per individual at one, five and 12 years than long-stay hospital care, and these differences are statistically significant. The other found that costs were lower for “community care”, although this association is not evaluated for statistical significance.

The greatest strength of the two included studies is the seriousness and detail with which costs were calculated for formal care services received by each specific participant. A comparable basket of health and community care services was assessed pre- and post-move in each study. One of the two studies also examined patterns over a 12-year window, an approach with growing value as the population of people with intellectual disabilities is aging and so understanding of changing needs becomes more important.

This review was originally commissioned by policymakers to inform policy and cost projections in Ireland, which is in the relatively early stages of a comprehensive deinstitutionalisation compared to neighbouring countries. Unfortunately, the results have limited relevance for those commissioners. The headline results of the main two studies are at odds with one another, and there are three principal barriers to interpreting these results.

First, different types of destination are grouped in ways that are ill-suited to our research question. Both studies group different destinations with different associated costs under the label “community care”, precluding identification of association between movement to specific accommodation types and costs. Second, some destination types (e.g. nursing home, hostel) would today be widely classified as institutions themselves, meaning that the reported association of “deinstitutionalisation” is questionable. Third, both studies analyse sub-samples of larger parent studies. While the overall samples are detailed in book form, limited detail on the analytic cost sub-samples is provided, making generalisabililty hard to ascertain.

In considering how the results of this cost literature may inform contemporary policy, there are additional limitations in the age of the studies. Priority populations for policymakers are older people with intellectual disabilities and serious medical illness, and younger people with very complex needs and challenging behaviours.[2 3] In the context of the UNCRPD and a growing emphasis on independent living,[1 3] autonomous decision-making and full participation in society for people with disabilities that are prominent in ways that they were not when the original studies were conducted. Numbers of people living independently following a move were negligible in both studies. New studies that consider these changed circumstances have the potential to offer more useful findings.

The primary importance of our findings is that community care is not unambiguously less expensive than institutional care over time. Consistent with earlier non-systematic assessments of this issue, the data are inconclusive.[22 23] Advocates sometimes argue that deinstitutionalisation is what economists call a dominant strategy, i.e. one that both reduces costs and improves outcomes. However well-intentioned, this position is not supported by the best available evidence. This finding in no way undermines the position that all people should be supported to lead lives in places of their own choosing, and our QoL results suggest that deinstitutionalisation is associated with significant benefits.[6] Nevertheless, these benefits will not be realised without substantial resource commitments from government and other funding bodies.

Strengths and limitations

This study has followed best practice guidelines in systematic evidence reviews where possible, following the PRISMA guidelines. The search strategy was developed by a team featuring subject experts, a systematic review specialist and an information specialist. The strategy's thoroughness resulted in a very large number of returned titles and abstracts from databases. These and advanced full texts were reviewed independently by two researchers. Likewise, all full texts accessed were independently reviewed by two team members. Quality assessment for eligible studies and data extraction for included studies was performed by one reviewer with a second reviewer's corroborating review.

Nevertheless, there are a number of important limitations to our work. In devising our search strategy we were faced with profound challenges in defining our intervention. While every effort was made to include all potentially studies through broad search criteria and no *ex ante* definition of institutional or community settings, it is possible that we overlooked some terms that would have captured other relevant material.

This choice of intervention – the process of deinstitutionalisation, and not comparative analysis of outcomes living in one setting versus another - reflected the interests of the Irish Department of Health, who commissioned this work to inform ongoing policy reforms. Those countries where the process is at an advanced stage and the majority of people with intellectual disabilities already live in the community, might find such comparative analyses to be more useful in informing policy. However, significant number of people in those countries continue to live in institutions, disproportionately those with the high support needs that are of particular policy interest.

Our search strategy did turn up a larger body of cross-sectional comparisons, e.g. of the cost of living in institutional settings versus community settings. Prior reviews have reported similarly mixed findings on the relative costs and there are additional concerns about the robustness of such comparisons and unobserved confounding, particularly with routinely collected data.[23] A strength of the studies included in our review is that confounding concerns are minimised by the use of participants as their own controls.

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, a standard practice in systematic reviews, did mean that a number of older studies were excluded as well as all of the grey literature. Future studies may wish to revisit this issue.

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.

Conclusion

A systematic review of the economic evidence of deinstitutionalisation for adults with intellectual disabilities identified two relevant studies, one of which found an increase in costs and one a decrease. Both were conducted on processes in the NHS in the 1980s and early 1990s, which limits relevance to 21st century international policy challenges. Economic studies of deinstitutionalisation for people with intellectual disabilities are therefore rare in the context of an ageing population with complex clinical and behavioural characteristics. Such research faces particular challenges in recruiting and retaining representative samples, defining and evaluating the causal effects of complex interventions often provided in multiple settings with multiple components, and maintaining study processes over long periods as people live months and years with serious illness and support needs. The growth in administrative datasets with the potential of standardised costs and shared definitions of key variables may offer an opportunity to better address these concerns. It is critical that more studies are conducted to understand both how to best support this growing population in leading independent lives of their choosing and the resources and resource allocations that will be needed to achieve this.

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. PM co-designed the original review protocol, project-managed title/abstract and full text review, performed the quality assessment and data extraction, and led writing of the paper. RLV and EM reviewed return studies for eligibility at title and abstract, 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. 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.

Figure legend

Figure 1 PRISMA for economics search

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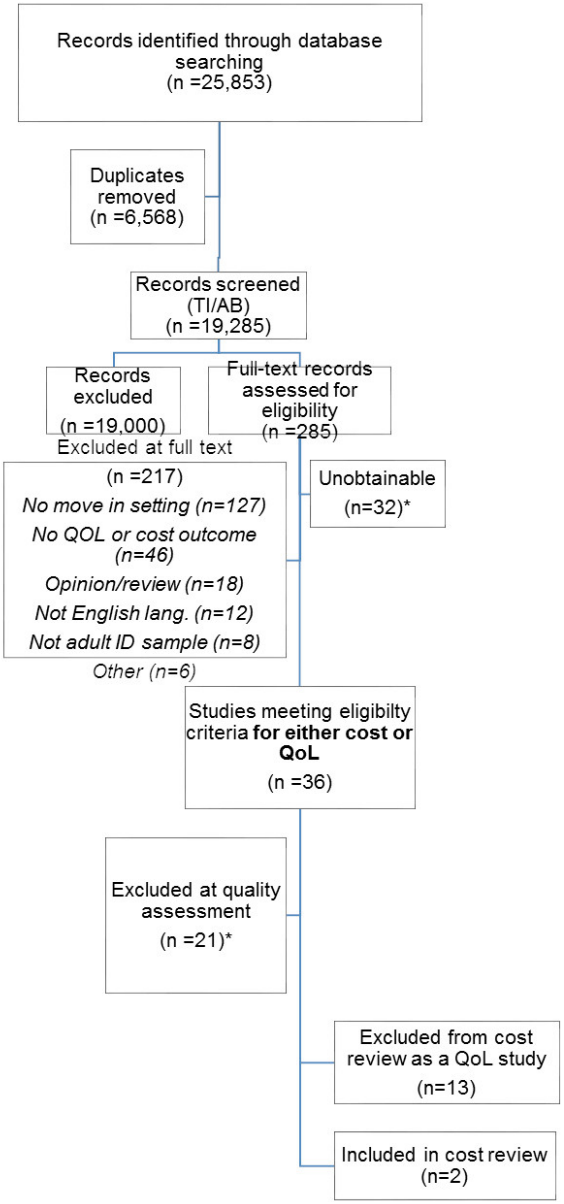

Figure 1 PRISMA for economics search

73x104mm (300 x 300 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 (**Error! Reference source not found.**) 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.

Supplementary Table 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).

Supplementary Table 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)

Note: the term ‘1915’ was included to identify US studies of the relevant Medicaid waiver to meet the needs of people who prefer to get long-term care and supports in the community rather than an institution (https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/national-overview-1915-c-waivers.html).

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.

The subject experts decided *ex ante* to search based on country and centres of disability studies (and not specific grey databases such as OpenGrey, OpenSIGLE and GreyNet) as these were deemed the strongest source of potentially relevant material. 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
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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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Appendix 3 CASP Cohort Study Appraisal Questions

This review used the CASP suite of tools (https://casp-uk.net/casp-tools-checklists/). Both studies included in the review of cost papers were cohort studies with costs as the outcome of interest, and not analyses in the tradition of economic evaluation.

We therefore used the cohort study appraisal tool, which features 14 questions under 12 headers:

1. Did the study address a clearly focused issue?

2. Was the cohort recruited in an acceptable way?

3. Was the exposure accurately measured to minimise bias?

4. Was the outcome accurately measured to minimise bias?

5. (a) Have the authors identified all important confounding factors?

5. (b) Have they taken account of the confounding factors in the design and/or analysis?

6. (a) Was the follow up of subjects complete enough?

6. (b) Was the follow up of subjects long enough?

7. What are the results of this study?

8. How precise are the results?

9. Do you believe the results?

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

11. Do the results of this study fit with other available evidence?

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

Appendix 4 Studies excluded at quality assessment (both cost and QOL studies)

Supplementary Table 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 5 Unobtainable studies

Supplementary Table 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

Supplementary Table 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

PRISMA 2009 Checklist

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.	3
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	6
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	7
METHODS			
Protocol a#]nd 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.	4
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.	7-8
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.	8-9
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).	9-10
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.	10
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	10
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.	9-10
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	10
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.	Impossibility of meta-

PRISMA 2009 Checklist

			analysis explained pg 18

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).	9-10
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/a
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.	11-12
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.	12
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).	12
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.	17
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	n/a
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	16
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	n/a
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).	18-20
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).	20-22
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	23
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.	1-2

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.

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