

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.

Relevant Grey Literature
Conroy <i>et al.</i> (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.nasddd.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/ddd/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/5671ccbdcbed6829d5f191b/1450298557957/1990+Results+of+the+CARC+Vs+Thorne+Longitudinal+Study.pdf

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 <i>et al.</i> (2011)	<ul style="list-style-type: none"> • CASP screening question 2 • E.g. no information on ethics, recruitment
Bratt & Johnston (1988)	<ul style="list-style-type: none"> • CASP screening questions 1 & 2 • Aggregated adolescent and adult populations
Conneally <i>et al.</i> (1992)	<ul style="list-style-type: none"> • CASP screening question 2. • Aggregated child and adult populations
Conroy <i>et al.</i> (2003)	<ul style="list-style-type: none"> • CASP screening question 1 & 2 • E.g. PICO difficulties
Cullen (1995)	<ul style="list-style-type: none"> • 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 <i>et al.</i> (1995)	<ul style="list-style-type: none"> • CASP screening question 2 • E.g. No ethics or recruitment procedure detailed
Dagnan <i>et al.</i> (1996)	<ul style="list-style-type: none"> • CASP screening question 2
Dagnan <i>et al.</i> (1998)	<ul style="list-style-type: none"> • CASP screening question 2 • E.g. No ethics details provided
Donnelly (1996)	<ul style="list-style-type: none"> • CASP screening question 2

¹ CASP Reference

Donnelly (1997)	<ul style="list-style-type: none"> • CASP screening question 2 • E.g. no consent
Fish & Lobley (2001)	<ul style="list-style-type: none"> • CASP screening question 1 • E.g. PICO not met
Fleming & Stenfert-Kroese (1990)	<ul style="list-style-type: none"> • CASP screening question 1 & 2
Forrester - Jones (2002)	<ul style="list-style-type: none"> • CASP screening question 2 • E.g. no ethics, consent, sampling details provided
Hemming <i>et al.</i> (1981)	<ul style="list-style-type: none"> • CASP screening question 1 & 2
Mansell (1994)	<ul style="list-style-type: none"> • CASP screening question 1. • Children in the cohort
Marlow & Walker (2015)	<ul style="list-style-type: none"> • CASP screening question 1 and 2
Perry <i>et al.</i> (2011)	<ul style="list-style-type: none"> • CASP screening question 2. • E.g. not representative of defined population
Roy <i>et al.</i> (1994)	<ul style="list-style-type: none"> • Did not meet CASP screening question 2 • No ethics, statement of sampling, or generalizability, no mention of bias
Sines <i>et al.</i> (2012)	<ul style="list-style-type: none"> • CASP screening question 1 • E.g. no ethical considerations
Spreat & Conroy (2002)	<ul style="list-style-type: none"> • CASP screening question 1 & 2
Srivastava & Cooke (1999)	<ul style="list-style-type: none"> • No reporting of findings interim report; PICO not detailed precisely
Walker <i>et al.</i> (1995)	<ul style="list-style-type: none"> • CASP screening question 1.
Young (2003)	<ul style="list-style-type: none"> • 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	198 2	Social disruption and residential relocation of mentally retarded children	American Journal of Mental Deficiency	87	1	48-55
W. R. Cook	198 3	Economics of providing services to the mentally retarded	Mental Retardation & Learning Disability Bulletin	11	1	13-21
L.W. Heal; J. Chadsey-Rusch	198 5	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	198 5	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	198 6	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	198 6	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	198 6	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	198 7	From institution to foster care: Impact on nutritional status	American Journal of Mental Deficiency	91	4	321-327
E. A. Eastwood; G. A. Fisher	198 8	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	198 8	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	199 0	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	199 0	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	199 0	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	199 1	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	199 1	Life in the community: Four years after the closure of an institution	Mental Retardation	29	4	213-221
J. Barlow; N. Kirby	199 1	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	199 1	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	199 3	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	199 5	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	199 5	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	199 5	Voluntary transformation from an institutionally based to a community-based service system	Mental Retardation	33	5	317-321
A. G. Philaretou; S. Myrianthous	200 9	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'intégration 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 À 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 Behinderung. 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