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Article

'Living in the community' the pros and cons: A systematic literature review of the impact of deinstitutionalisation on people with intellectual and psychiatric disabilities

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Abstract

● *Summary:* How did deinstitutionalisation affect the lives of people with intellectual disabilities and people with a psychiatric background? This paper contains a systematic literature review on the consequences of deinstitutionalisation for the target groups, their social network and society at large. PubMed and Online Contents were searched from 2004 till February 2016. Inclusion criteria were (1) article describes (a) consequence(s) of deinstitutionalisation, (2) in Western countries and (3) the target group(s) include people with psychiatric or intellectual disabilities. Sixty-one papers were found and analysed to establish positive, negative or mixed results.

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- *Findings:* The positive effects pertain to the quality of life of people with disabilities after deinstitutionalisation. They learned adaptive skills and receive better care. Negative effects relate to more criminal behaviour by the target groups, victimisation of the target groups and physical health issues. Life for the most severely afflicted people with disabilities deteriorated when they moved to smaller group homes in the community. Mixed effects were also found. It is not clear whether deinstitutionalisation leads to real inclusion in the community. It is equally unclear whether it is cheaper than large-scale institutional care. Only a few studies investigate the effects on family members but some show they are overburdened.
- *Applications:* Social workers catering for people with disabilities should pay attention to risks for their health and safety and keep an eye on family members. Those who are asked to advise on deinstitutionalisation should consider that this may not benefit the most severely afflicted.

Introduction

Within the context of disability studies the term deinstitutionalisation generally refers to this deferment of care for people with disabilities from hospitals to community-based settings (Kunitoh, 2013). Deinstitutionalisation pertains to the technical operation of the dismantling of large hospitals, but it also entails an ideal, namely the normalisation, social inclusion and participation of people with disabilities (Bouras & Ikkos, 2013; Chow & Priebe, 2013; Kunitoh, 2013; Nicaise, Dubois, & Lorant, 2014). The move towards deinstitutionalisation started in the 1950s in the UK, the USA and Italy and then rapidly spread to the remainder of continental Europe, Scandinavia and the Antipodes (Novella, 2010). Three causes for the move have been identified in the literature. The first cause was the development of effective psychotropic drugs in the 1950s (Becker & Kilian, 2006, p. 9). These enable patients with a psychiatric disability to live a relatively normal life in the community, supported by outpatient care facilities. The second cause was the emergence of a civil rights paradigm for disabled people. It states that they should be treated in the least restrictive environment possible. This principle of normalisation was affirmed in the United Nations Convention on the Rights of Persons with Disabilities (Chow & Priebe, 2013; Overmars-Marx, Thomése, Verdonschot, & Meininger, 2014). Large institutions usually do not qualify as 'least restrictive environment', as they may lead to hospitalisation and tend to increase dependency (Novella, 2010, p. 223; Trappenburg, 2013, p. 3). Moreover, institutionalised people risk (sexual) abuse: they are not just vulnerable, but completely dependent on staff; isolated as they are from the outside world (Crossmaker, 1991). Living in

the community, by contrast, is taken to lead to recovery and rehabilitation, and to the social integration of patients (Bouras & Ikkos, 2013; Novella, 2010). The third cause of deinstitutionalisation was the hope of cost reduction, since institutional care is notoriously expensive (Chow & Priebe, 2013; Parker, 2014).

Following the move towards deinstitutionalisation various forms of living in the community have been developed, usually amounting to either supportive independent housing (for people with intellectual disabilities and for people with a psychiatric background), transitional therapeutic communities in congregate residential programmes (for people with a psychiatric background) or community homes with 3–10 residents with continuous or variable staff support (for both groups). Sometimes supported living arrangements or group homes are clustered in small 'communities' with 20–100 residents living on a small site. Severely afflicted people with intellectual disabilities sometimes still reside in large-scale facilities. The ideal of social inclusion is to strive for social participation in ordinary workplaces (rather than specialised sheltered work) and mainstream organisations, but this is hard to accomplish, due to characteristics and capacities of people with intellectual disabilities or a psychiatric background, lack of supporting staff or hampering elements in mainstream society.

Many social workers work with psychiatric patients, both in what remains of large-scale institutions and in ambulatory care or outpatient facilities. Many other social workers work with people with an intellectual retardation in various settings (Cree & Davis, 2007; Davies, 2013; Forenza & Eckert, 2017). Often social workers are consulted or in charge of policies regarding people with psychiatric conditions or intellectual disabilities. Therefore, it is important that social workers are aware of the pros and cons of deinstitutionalisation. To establish these we performed a systematic literature review on the consequences of deinstitutionalisation for people with intellectual and psychiatric disabilities and their wider social environment like family members, neighbours, community members and society at large. We searched English-language peer-reviewed articles included in PubMed and Online Contents between 2004 and February 2016. Inclusion criteria were (1) article describes (a) consequence(s) of deinstitutionalisation, (2) in Western countries (a comparison to non-Western cultures goes beyond our expertise) and (3) the target group(s) include people with psychiatric or intellectual disabilities. We found and analysed 61 articles.

Our research question is: *What are the positive and negative effects of deinstitutionalisation for disabled people (people with intellectual and psychiatric disabilities) and their social environment?* The next section describes the methods used for this study. The 'Results' section presents the findings. In 'Study limitations' section we reach a final verdict on deinstitutionalisation and reflect on the merits and limitations of our findings.

Various researchers conducted (systematic) literature reviews on the effects of deinstitutionalisation, but they mostly focus on specific aspects, such as resident–staff interactions (McConkey & Collins, 2010), community integration (Forrester-Jones et al., 2006), costs (Knapp, Beecham, McDaid, Matosevic, & Smith, 2011) or

behaviour patterns in different residential settings (Kozma, Mansell, & Beadle-Brown, 2009). Most reviews pay relatively little attention to the consequences of deinstitutionalisation for the social environment surrounding disabled people: family members, neighbours, community members and society at large. Since social work is a professional discipline which tries to take the whole client and his or her environment into account, we feel that a more encompassing review will be useful to evaluate the effects of deinstitutionalisation.

Methods

Many different methods for synthesising articles have been developed in which the merits of different studies are compared in a sophisticated, quantitative way. Our broad research question requires a comparison of studies that differ hugely in focus, method and research question. Thus, we do not attempt to compare and weigh them in quantitative formulas. Instead we opted for a so-called meta-aggregative approach. Meta-aggregation takes the complex nature of the phenomenon under scrutiny (in this article deinstitutionalisation) into account. The studies are assessed to propose particular lines of action (Hannes & Lockwood, 2012, pp. 21–23). In our case we propose lines of action for social policymakers and future researchers.

We conducted a systematic literature review consisting of three phases with different search terms so as to be as thorough as possible. The search process is depicted in the flow chart in Figure 1. In the *phase 1*, we searched PubMed and Online Contents using the search terms 'deinstitutionalization' (3718 hits) and 'deinstitutionalisation' (172 hits). For practical reasons, the search was limited to a decade 2004–February 2016 and to articles written in English. This limited the total number of hits to 342 that seemed relevant for our research question. From these articles, titles and abstracts were studied, after which 32 articles remained in the selection. Inclusion criteria were (1) article describes (a) consequence(s) of deinstitutionalisation, (2) in Western countries (a comparison to non-Western cultures goes beyond our expertise) and (3) the target group(s) include people with psychiatric or intellectual disabilities. We included studies based on original qualitative or quantitative research, but also literature studies focusing on certain aspects of deinstitutionalisation. In analysing the results, articles focusing on social integration seemed under-represented. This might be a consequence of the search terms that were used and the databases that were searched.

Thus, in *phase 2*, we searched the databases PubMed and Online Contents, using the search terms 'social inclusion' and 'disabled' (combined). The initial search produced 326 results. Limiting the search to English articles published between 2004 and 2016 resulted in 203 potentially relevant articles. From these articles, the abstracts were studied using the same inclusion criteria mentioned above and double articles were excluded. Twenty-five articles remained in the selection. These articles provided relevant information about the social position
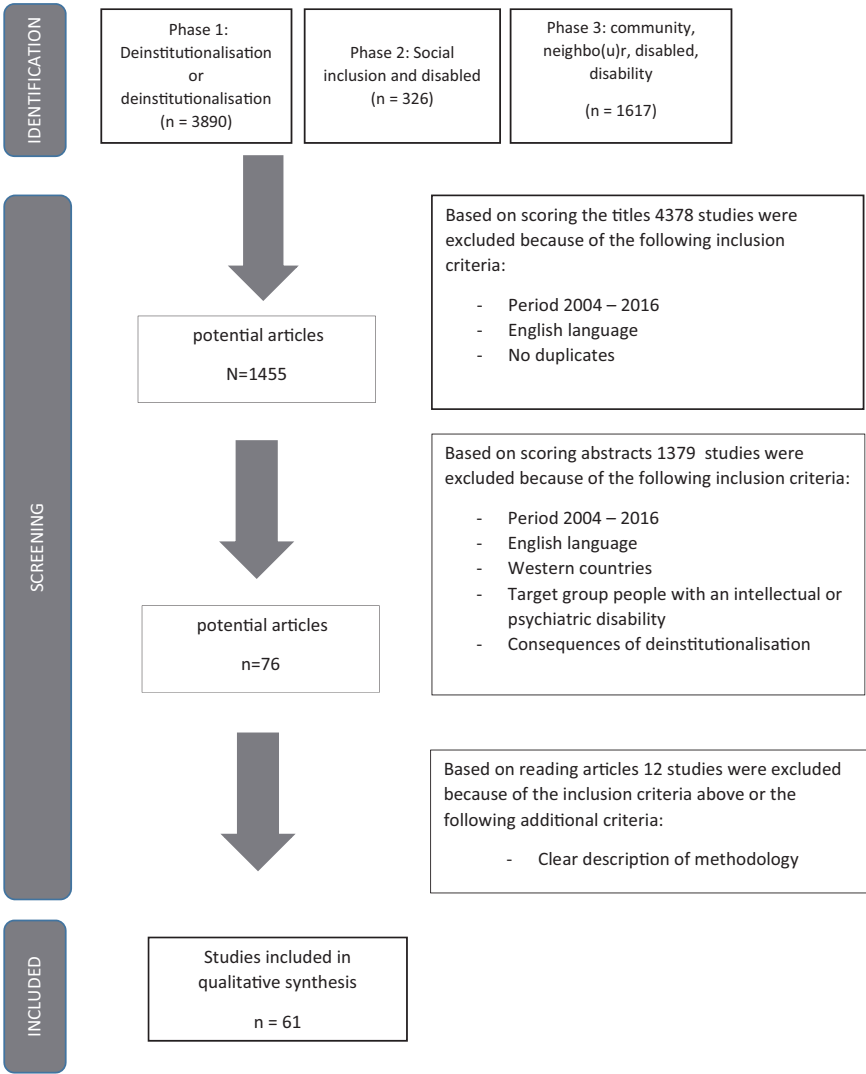
Figure 1. Flow chart.

of people with intellectual or psychiatric disabilities, but provided little insight in the consequences for the other people in the community.

Hence, in *phase 3* we used the search terms community, neighbor, neighbour, disabled and disability (1617 hits). When limited to articles published in English between 2004 and 2016, 910 hits remained. After studying the abstracts of those articles, using the same inclusion criteria and removing double hits, 19 additional articles were included. This resulted in 76 articles in our initial dataset.

We screened all studies. We included empirical studies with a clear description of the sampling strategy, the methodology chosen, the data collection procedures and the type of data analysis considered. We also included substantive literature studies and literature reviews. This led to a dataset of 61 articles.

We reviewed the 61 articles and coded them according to group (psychiatric or intellectual disability), research design, instruments, sample size, geographical area and aim of the study. Thirty-seven studies pertained to people with psychiatric disabilities and 24 dealt with intellectually disabled people. Twenty-nine studies were quantitative, 13 were qualitative, five were based on a combination of quantitative and qualitative methods and 14 studies were literature reviews. The measurements used are very different. Data were gathered through question-naires, interviews, focus groups and databases. Data were gathered during various time periods and in various countries (most researched countries: Australia 10, United Kingdom 8, Canada 5, USA 5, Sweden, 4). An overview of the included articles can be found in Table 1.

The articles in our dataset were coded by the three authors independently in a three-step procedure. We first studied whether the articles drew a largely positive or a largely negative conclusion or somewhere in between. We then inductively categorised (with the three authors) the type of effects described in the study, which was usually related to the research question of the study: e.g. quality of life, quality of care, number of people with psychiatric disabilities that were victims of crimes. We then sorted our articles to see how many studies on a certain type of effect of deinstitutionalisation drew a largely positive conclusion and how many ended with a negative verdict. For example we sorted all studies investigating changes in the quality of life of disabled people and found that most of them drew a positive conclusion. We sorted all studies investigating criminal behaviour by people with an intellectual or psychiatric disability before and after deinstitutionalisation and found that the majority reported increased criminal behaviour, thus ended with a largely negative conclusion about deinstitutionalisation. If studies on a topic did not provide an overall positive or negative picture we put them in a category 'mixed effects'. Thus, we found the following positive effects: improved quality of life, improved skills needed to live in society, better quality of care. The follow-ing negative effects were found: decreased health and well-being, more criminal behaviour and victimisation of disabled people, increased care burdens on family members and redistribution within target groups (deinstitutionalisation sometimes being to the detriment of more severe disabled people). Studies into social inclusion and financial consequences of deinstitutionalisation were categorised as reporting mixed effects. The categories are presented in Table 2. We finally analysed our findings to produce cross generalisations that led to recommendations for policymakers and future research.

In Table 3 we present an overview of positive, negative and mixed outcomes per category and per article. As explained above the labels pertain to the aggregate picture of the studies on a topic. This entails that some studies categorised as positive found large effects whereas others found no significant improvements.

Table 1. Included articles.

Authors	Year	Group	Design	Methods	Sample size	Country	Aim of the study
Arvidsson and Ericson	2005	Psychiatric disability	Empirical qualitative study	Case register study	10 years case register N49	Sweden	Investigate family care taking in relation to patient outcomes
Avieli et al.	2015	Psychiatric disability	Empirical qualitative study	In-depth interviews parents	N20	Israel	Study burden of care for parents of adult children with disability
Basta et al.	2013	Psychiatric disability	Empirical quantitative study	Case study of patients with psychiatric disabilities	N400	Greece	Examine residential/occupational status of discharged patients. Explore burden of family
Bigby	2008	Intellectual disability	Empirical qualitative longitudinal study	Interviews people with ID (24), survey family (20), case studies (11)	N24 people ID, N20 family members, N11 case studies	Australia	Study changes in informal network five years after leaving institution
Bigby	2012	Intellectual disability	Literature study	Systematic review in 2010 (no limit period covered)	S14		Examine social inclusion
Bigby and Fyffe	2006	Psychiatric disability	Empirical quantitative and qualitative study	Study 1: interviews staff, family members (N=27), participative observations people with disabilities (N=11), focus groups (N not defined)	N27 staff, family members N11 people with disabilities N not defined focus groups N400 survey	Australia	Investigate tensions between closure of institutions and goals of deinstitutionalisation

Table 1. Continued

Authors	Year	Group	Design	Methods	Sample size	Country	Aim of the study
				Study 2: survey staff, managers, family members (N=400), interviews staff, managers, family members (N=250)	staff, managers, family members N250 interviews staff, managers, family members		
Bruffaerts et al.	2008	Psychiatric disability	Literature study				Address contemporary problems of emergency psychiatry
Chan	2011	Psychiatric disability	Literature study				Examine burden of family caregivers of people with schizophrenia
Csipke et al.	2014	Psychiatric disability	Empirical quantitative and qualitative study	Participation in eight wards, survey service users inpatients	N116	United Kingdom	Examine quality of residential care since deinstitutionalisation
Davis et al.	2012	Psychiatric disability	Empirical quantitative study	Analysis of existing data: mental health care spending, quality of mental health services, mental health disability rates, employment status, housing		USA	Examine well-being after deinstitutionalisation

Table 1. Continued

Authors	Year	Group	Design	Methods	Sample size	Country	Aim of the study
				availability, incarceration people with psychiatric disabilities			
Duggan and Linehan	2013	Intellectual disability	Literature study	Systematic review 2000–2010	S46		Examine what support people receive from informal network
Dusseljee et al.	2011	Intellectual disability	Empirical quantitative and qualitative study	Survey/interviews	N653	The Netherlands	Study variation in community participation in work, leisure and social contacts
Forrestor-Jones et al.	2006	Intellectual disability	Empirical quantitative study	Network analysis	N213	United Kingdom	Investigate size of informal social networks and type of social support
Forrester-Jones et al.	2012	Psychiatric disability	Empirical quantitative study	Network analysis	N85	United Kingdom	Investigate size of informal social networks and type of social support
Fuller Torrey	2015	Psychiatric disability	Empirical quantitative study	Historical analysis		United States	Number of patients in institutions between 1955 and 2015; examples of criminal behaviour
Gray et al.	2014	Intellectual disability	Empirical quantitative study – follow-up	Survey cohort study young adults with ID	N536	Australia	Investigate changes in living arrangements

Table 1. Continued

Authors	Year	Group	Design	Methods	Sample size	Country	Aim of the study
Hall and Hewson	2006	Intellectual disability	Empirical qualitative study	Diary records; time spent outside and inside the house	N63	United Kingdom	and participation of young adults with ID Investigate informal social contacts in 1995 and 2002
Hamden, Newton, McCauley-Elsom and Cross	2011	Psychiatric disability	Empirical quantitative cohort study	Interviews people with PD and analysis of existing data: database of hospital admissions which provided demographic and contact details of people with psychiatric disabilities	Cohort 1: N16 Cohort 2: N15	Australia	Examine quality of life
Hamelin et al.	2011	Intellectual disability	Literature study	Systematic review	S23		Study effects of deinstitutionalisation on adaptive behaviour
Heila et al.	2005	Psychiatric disability	Empirical quantitative study	Analysis of existing data: national hospital discharge register for patients with schizophrenia: national population register for data of the general population; mortality data	N 58761 patients	Finland	Study mortality rate of people with schizophrenia after deinstitutionalisation

Table 1. Continued

Authors	Year	Group	Design	Methods	Sample size	Country	Aim of the study
				in the national causes of death register			
Jeppesen et al.	2016	Psychiatric disability	Empirical quantitative study	Register data hospitals	Denmark		Study number of hospital admissions due to schizophrenia from 1970 till 2012
Kalucy et al.	2005	Psychiatric disability	Empirical quantitative study	Analysis of existing data: attendance records emergency department	N10 year records	Australia	Study patterns of attendance of emergency department hospital after deinstitutionalisation
Killaspy et al.	2012	Psychiatric disability	Empirical quantitative and qualitative study	Survey and interviews people with PD and managers on 202 care units in 10 European countries	N=202 care units in 10 European countries	Europe	Study quality of services and impact on autonomy and care
Knapp et al.	2011	Psychiatric disability	Literature study	Systematic review 1948–2008	S11	England, Germany, Italy	Determine financial consequences of reinstitutionalisation
Kozma et al.	2009	Intellectual disability	Literature study	Systematic review 1997–2007	S68		Provide comprehensive research residential settings during deinstitutionalisation and post deinstitutionalisation

(continued)

Table 1. Continued

Authors	Year	Group	Design	Methods	Sample size	Country	Aim of the study
Kramp and Gabrielsen	2009	Psychiatric disability	Empirical quantitative study	Analysis of existing data 1997–2007: the national commissioners annual reports (crimes, arsons and violence data), Danish psychiatric central register (deinstitutionalised people with psychiatric disabilities)		Denmark	Study effects of deinstitutionalisation on crime especially homicide, arson and violence
Kunitoh	2013	Psychiatric disability	Literature study	Systematic review 2000–2012	S14		Study influence of deinstitutionalisation on discharged long-stay patients
Livingston et al.	2011	Psychiatric disability	Empirical quantitative study	Cohort design study	N171	Canada	Compare patients discharged before and after deinstitutionalisation in Canada
Machado et al.	2012	Psychiatric disability	Literature study	Systematic review 1997–2010	S16		Study readmissions in context of deinstitutionalisation
Martinez-Leal et al.	2011	Intellectual disability	Empirical qualitative study	Interviews	N1269	Europe	Compare health status and health risk factors in and outside institutions

(continued)

Table 1. Continued

Authors	Year	Group	Design	Methods	Sample size	Country	Aim of the study
Martinsson et al.	2012	Psychiatric disability	Empirical qualitative study	Interviews	N7	Sweden	Study the experiences of older people living on their own because of deinstitutionalisation
McConkey	2007	Intellectual disability	Empirical quantitative study	Survey	N620	Northern Ireland	Compare the social inclusion of tenants living in two forms of supported living schemes
McConkey and Collins	2010	Intellectual disability	Empirical quantitative study	Survey staff	N245	Northern Ireland	Describe the tasks of support staff in relation to social inclusion
Nicaise et al.	2014	Psychiatric disability	Empirical qualitative study	Content analysis policy documents and ex ante evaluation		Belgium	Examine whether the Belgian mental health care reform can achieve its goals
Nilsson and Logdberg	2008	Psychiatric disability	Empirical quantitative study	Analysis of forensic autopsy reports 1952–2005		Sweden – Malmo	Analyse the consequences of deinstitutionalisation for social isolation
Overmars-Marx et al.	2014	Intellectual disability	Literature study	Systematic review 2000–2010	S28		Show the complex interactions between environmental and personal factors that

(continued)

Table 1. Continued

Authors	Year	Group	Design	Methods	Sample size	Country	Aim of the study
							facilitate or hinder social inclusion
Picardi et al.	2006	Psychiatric disability	Empirical quantitative study	Survey comparing hospitalised patients to outpatients and healthy controls	Survey N1492 hospitalised people PD, N162 outpatients with schizophrenia N62 healthy controls	Italy	Compare quality of life of residents in institutions with outpatients and healthy subjects
Power	2013	Intellectual disability	Empirical qualitative study	Interviews government officials, social workers, representative's disability organisations	N60 participants	Canada and Ireland	Reflect on the meaning of belonging and social inclusion in the community
Psarra et al.	2008	Psychiatric disability	Empirical quantitative study	Survey policemen	N142	Greece	Examine attitudes of policemen towards mentally ill
Raphael and Stoll	2013	Psychiatric disability	Empirical qualitative study	Analysis of US census data		USA	Analyse whether deinstitutionalisation led to reinstitutionalisation in prisons
Rossow-Kimball and Goodwin	2014	Intellectual disability	Empirical qualitative case study	Focus groups staff, interviews visitors, observation	N3 focus groups; N11 interviews	Canada	Examine social inclusion of older people with disabilities in

(continued)

Table 1. Continued

Authors	Year	Group	Design	Methods	Sample size	Country	Aim of the study
							community based-senior centres
Salokangas	2007	Psychiatric disability	Literature study				Study medical problems in schizophrenics living in the community
Saz-Parkinson et al.	2011	Psychiatric disability	Empirical quantitative study	Analysis of existing data hospital morbidity survey		Spain	Assess how hospital admissions for schizophrenic patients have changed between 1980 and 2004
Schmetzer	2007	Psychiatric disability	Literature study				Explore a link between deinstitutionalisation, dual diagnosis and violence, victimisation
Sealy and Whitehead	2004	Psychiatric disability	Empirical quantitative study	Analysis of existing data: reports from Statistics Canada and Canadian Institute for Health Information for inpatient bed days and expenditures. Annual reports of provinces for expenditures on		Canada	Analyse the implementation of deinstitutionalisation of psychiatric services over 40 years

(continued)

Table 1. Continued

Authors	Year	Group	Design	Methods	Sample size	Country	Aim of the study
Sealy	2012	Psychiatric disability	Empirical quantitative study	Analysis of existing data: reports from Hospital Mental Health Services in Canada. Annual Demographic Statistics. Reports from Canadian Community Health Survey: mental health and well-being mental health services		Canada	Evaluate use of mental health services by patients after deinstitutionalisation
Short et al.	2013	Psychiatric disability	Empirical quantitative study	Analysis of criminal records from Victoria Police Law Enforcement Assistance Program. Data from Victoria Psychiatric Case Register		Australia	Compare crime victimisation of persons with schizophrenia with rates among general population
Simpson et al.	2004	Psychiatric disability	Empirical quantitative study	Analysis of data from various New Zealand databases according to homicide, criminal		New Zealand	Provide accurate information about contribution of mental illness to homicide rates

(continued)

Table I. Continued

Authors	Year	Group	Design	Methods	Sample size	Country	Aim of the study
				prosecutions, mental health service dispositions			
Slayter	2010	Intellectual disability	Empirical quantitative study	Analysis of beneficiaries and demographic variables in data programme Medicaid		USA	Present baseline data on the characteristics and service utilisation patterns of people with and without ID after deinstitutionalisation
Teplin et al.	2005	Psychiatric disability	Empirical quantitative study	Survey	N936	Chicago USA	Determine crime victimisation among persons with psychiatric disabilities and compare with general population
Thiblin et al.	2004	Psychiatric disability	Empirical quantitative study	Analysis of national records of inpatient hospital care, computerised mortality records, Department of Forensic Medicine in Stockholm		Sweden	Test hypothesis that isolated death and alcohol and drugs abuse have increased due to deinstitutionalisation
Tossebro and Lundeby	2006	Intellectual disability	Empirical quantitative study	Longitudinal survey family members	N 222/ N176	Norway	Describe hesitations of family members about deinstitutionalisation

Table 1. Continued

Authors	Year	Group	Design	Methods	Sample size	Country	Aim of the study
							and assess whether these are temporary or lasting
Van Alphen et al.	2010	Intellectual disability	Empirical qualitative study	Interviews neighbours	N30	The Netherlands	Uncover details of interaction between neighbours and people with ID
Van Asselt-Govers	2013	Intellectual disability	Empirical qualitative study	Network analysis	N33	The Netherlands	Examine structural and functional characteristics of social networks
Wallace et al.	2004	Psychiatric disability	Empirical quantitative study	Victoria Psychiatric Case Register, Database Victorian police department		Victoria, Australia	Examine the pattern of criminal convictions in persons with schizophrenia over 25-year period in era of deinstitutionalisation
Wang	2012	Intellectual disability	Literature study	Systematic review 2000–2001	S7		Assess care burden of families
Wiesel and Bigby	2013	Intellectual disability	Empirical qualitative study	Observation		Melbourne, Australia	Study encounters between people with and without disabilities in urban spaces
Wiesel and Bigby	2014	Intellectual disability	Empirical quantitative and	Interviews and survey people without disabilities	Survey N 260; interviews N22	Victoria, Australia	Analyse social and spatial dynamics of encounters people

Table 1. Continued

Authors	Year	Group	Design	Methods	Sample size	Country	Aim of the study
			qualitative study				with and without disabilities
Yoon and Bruckner	2009	Psychiatric disability	Empirical quantitative study	Analysis of data from National Centre for Health Statistics compressed mortality file, American Hospital Associations annual survey of hospitals, state mental health reports			Test whether public psychiatric bed reduction increases suicide rates
Young and Ashman	2004a	Intellectual disability	Literature study				Describe outcomes of deinstitutionalisation for people with intellectual disabilities
Young and Ashman	2004b	Intellectual disability	Empirical quantitative study	Longitudinal survey staff	N104	Australia	Study results of deinstitutionalisation in the long run with special attention for people with severe disabilities and the amount of maladaptive behaviour

Table 2. Effects of deinstitutionalisation.

Positive effects	Negative effects	Mixed effects
Improved quality of life	Decreased (physical) health and well-being	Inclusion in the community
Improvement of skills	Criminal behaviour and victimisation	Financial consequences
Better quality of care	Increased care family members	
	Redistribution within target groups	

Likewise, studies categorised under negative effects mostly found reported negative findings but sometimes found hardly any significant change after deinstitutional-isation. Some studies discuss several topics; for example, a study examines the social contacts of disabled people and the increased care responsibilities for family members. These studies are registered in both categories.

Results

Positive effects of deinstitutionalisation

Tables 2 and 3 present an overview of the effects of deinstitutionalisation. Before discussing the positive consequences in detail, it is necessary to make a general observation. Many of the positive effects that were found require a well-functioning community care system. For example, Knapp et al. (2011) state that community care is more cost effective, but only when it is properly set up and managed. Kozma et al. (2009) found that community care generally offered more choice and opportunities for self-determination, but add that staff practices and empowerment are crucial to attain this result. The community care system needs to meet certain requirements in order to accomplish these positive effects.

Better quality of life. The most prominent effect of deinstitutionalisation seems to be an improved quality of life of disabled people. Many studies that compared the situation before and after deinstitutionalisation found an increase in quality of life. Housing conditions improved: people moved from shared facilities (bathroom, toilet and bedroom) to individual accommodations (Bigby & Fyffe, 2006; Young & Ashman, 2004b). Moving to the community enabled former residents to establish proper daily routines (Young & Ashman, 2004b). However, Picardi et al. (2006) found that the quality of life of psychiatric disabled people living in residential facilities is not significantly poorer than their counterparts who live independently or with their families.

Improved skills. Some behaviour is not desirable in society like stereotyped and hyperactive behaviour, self-abusive behaviour or disturbing interpersonal behaviour. Living in society requires certain skills such as self-care, independent

Table 3. Positive, negative and mixed effects of deinstitutionalisation per article.

	Authors
Positive effects	
Quality of life	
In general	Picardi et al. (2006)
Physical domain	Young and Ashman (2004a)
	Bigby and Fyffe (2006)
	Young and Ashman (2004b)
Adaptive behaviour	
	Hamelin et al. (2011)
	Kozma et al. (2009)
	Young and Ashman (2004b)
	Kunitoh (2013)
Quality of care	
	Killaspy et al. (2012)
	Young and Ashman (2004b)
	Sealy (2012)
Negative effects	
Health and well-being	
Physical health	Salokangas (2007)
	Schmetzer (2007)
Substance abuse	Slayter (2010)
	Schmetzer (2007)
Emergency care/revolving door	Kalucy et al. (2005)
	Bruffaerts et al. (2008)
	Saz-Parkinson et al. (2011)
	Machado et al. (2012)
	Livingston et al. (2011)
	Heila et al. (2005)
	Matheson et al. (2005)
	Thiblin et al. (2004)
Social isolation	Nilsson and Logdberg (2008)
	Martinsson et al. (2012)
	Hall and Hewson (2006)
Redistribution within target groups	
	Arvidsson and Ericson (2005)
	Csipke et al. (2014)
	Simpson et al. (2004)
Criminal behaviour and victimisation	
Criminal behaviour	Kramp and Gabrielsen (2009)
	Schmetzer (2007)
	Wallace et al. (2004)
	Raphael and Stoll (2013)
	Toib (2006)
	Psarra et al. (2008)

Table 3. Continued

	Authors
	Fuller Torrey (2015)
	Davis et al. (2012)
Victimisation	Short et al. (2013)
	Teplin et al. (2005)
	Schmetzer (2007)
Burden of care: family members	
Family burden	Tossebro and Lundeby (2006)
	Basta et al. (2013)
	Wang (2012)
	Chan (2011)
	Gray et al. (2014)
	Avieli et al. (2015)
Mixed effects	
Social inclusion	
	Kozma et al. (2009)
	Duggan and Linehan (2013)
	McConkey and Collins (2010)
	McConkey (2007)
	Forrester-Jones et al. (2012)
	Young and Ashman (2004a) and
	Young and Ashman (2004b)
	Forrester-Jones et al. (2006)
	Amado et al. (2013)
Community participation:	Dusseljee et al. (2011)
Social distance	Ouellette-Kuntz et al. (2010)
	Wiesel and Bigby (2014)
	Rossow-Kimball and Goodwin (2014)
	Van Alphen et al. (2010)
	Hall and Hewson (2006)
Community access	Van Asselt-Goverts et al. (2013)
	Young and Ashman (2004a)
	Young and Ashman (2004b)
Financial consequences	
	Sealy and Whitehead (2004)
	Power (2013)
	Knapp et al. (2011)
	Martinez-Leal et al. (2011)
	Hamelin et al. (2011)

functioning, taking responsibility, self-direction and social skills. Several authors studied the improvement of these skills of disabled people after their relocation, sometimes in relation to a decline of maladaptive behaviour (Hamelin, Frijters, Griffiths, Condillac, & Owen, 2011; Kozma et al., 2009; Kunitoh, 2013; Livingston et al. 2011; Young & Ashman, 2004b). Kunitoh (2013) reviewed recent literature in

order to understand the influence of deinstitutionalisation on discharged long-stay psychiatric patients. He found that people who received rehabilitation training improved on social functioning. Deinstitutionalised patients who did not receive training did not improve. Hamelin et al. (2011) conclude that 'the data from the meta-analysis clearly [illustrate] the general habilitative effects associated with deinstitutionalisation and community living' (p. 67). Kozma et al. (2009) had similar findings and found in addition that people who remained in congregate settings were more likely to experience a decline, whereas movers maintained or improved their abilities depending on the quality and characteristics of the facilities they lived in.

Young and Ashman (2004b) followed intellectually disabled people over a two-year period as the institution in which they had been living was closed. They measured independent functioning, physical development, economic activity, domestic activity, self-direction, responsibility and socialisation. The outcome of this research shows initial improvements in skills needed to live in society. But after two years these skills begin to plateau in some areas, namely with regard to economic activity, domestic activity and responsibility. Young and Ashman (2004b) suggest that this is caused by over-controlling staff (pp. 39–40): although people learn new skills, the opportunities to use them or to develop them further are limited by staff, either because staff feel protective towards clients or because staff lack capabilities or resources to let clients exercise their skills. In short, it seems that deinstitutionalisation can result in more skills, if the residential facilities and care programmes are designed to support this goal.

Better quality of care. Two studies (Killaspy et al., 2012; Young & Ashman, 2004b) found that the quality of care for disabled people (therapeutic environment, treatments and interventions, social interface, self-management and autonomy, living environment, human rights, recovery-based practice) improved after their discharge to the community. Both conclude that care in community facilities was better than in hospital units. The difference is mostly explained by the fact that community facilities provide more space for autonomy and choice-making. Killaspy et al. (2012) observe that there is a direct link between the quality of an institution and its service users' experiences of care and autonomy. Sealy (2012) took a broader perspective and looked at the mental health of the whole community in Canada. Comparing 1989/1990 to 2002/2003, individuals with higher levels of psychological distress more often accessed mental health services in the latter period. Sealy attributes this to deinstitutionalisation, because this led to a greater availability of community-based mental health services. Community-based facilities enable citizens to seek help without significant travel or being separated from their social support network.

Negative effects of deinstitutionalisation

Deinstitutionalisation seems to come with unintended side effects. Our literature review showed five categories of negative findings: negative health or well-being

effects among the target group, redistributional effects within the target groups (i.e. better outcomes for part of the group to the detriment of others within the same group), negative aspects for family members because of increasing care responsibilities, criminal behaviour among the target group and victimisation of members of the target group.

Negative health or well-being effects. Salokangas (2007) did a review of studies into the physical health of deinstitutionalised people suffering from schizophrenia. They found that physical illnesses are highly prevalent among them and often remain undetected. Schmetzer (2007) found an increased prevalence of HIV and hepatitis among patients with a psychiatric diagnosis. Two studies (Schmetzer, 2007; Slayter, 2010) found an increased chance of substance abuse among deinstitutionalised intellectually disabled people (Slayter, 2010) and people with a psychiatric illness (Schmetzer, 2007). Other studies report an increased number of visits to emergency care (Kalucy, Thomas, & King, 2005) or emergency psychiatric care facilities (Bruffaerts, Sabbe, & Demyttenaere, 2008; Saz-Parkinson et al., 2011). According to Machado, Leonidas, Santos and Souza (2012) who did a review study into readmissions to hospitals of deinstitutionalised patients suffering from schizophrenia, they turn into revolving door patients, who leave a psychiatric hospital only to return shortly thereafter. Jeppesen, Christensen and Vestergaard (2016) drew the same conclusion in their study in Denmark: 'the reorganization of the mental health care system has created a problem of revolving door schizophrenia patients who since the 1970s have been increasingly hospitalized for shorter periods' (p. 1). Livingston et al. (2011), however, who did an empirical study with 335 psychiatric patients in Canada, found that most patients remained in community care, suggesting that the revolving door phenomenon could be related to the configuration of community care.

Three studies (Heila, Haukka, Suvisaari, & Lonnqvist, 2005; Matheson et al., 2005; Yoon & Bruckner, 2009) report increasing suicide numbers, especially among schizophrenic patients. One study found a slight increase in the number of isolated deaths (Thiblin et al., 2004).

Four studies found social isolation among deinstitutionalised patients: Nilsson and Logdberg (2008) looked at the fate of schizophrenic patients in Sweden and found that they were prone to substance abuse and social isolation. Martinsson, Fagerberg, Lindholm and Wiklund-Gustin (2012) did a small-scale, in-depth research on the well-being of elderly intellectually disabled people in Sweden. Their respondents felt powerless, vulnerable and disrespected at times. Hall and Hewson (2006) did a longitudinal study among intellectually disabled people in the UK. Shortly after leaving residential care they were an isolated group. Ten years later the researchers found no significant improvement.

Redistribution within target groups. Several studies conclude that community care is less suitable for more severely disabled people. Davis, Fulginiti, Kriegel and Brekke (2012) found that community care is most beneficial for mildly disabled

people. Arvidsson and Ericson (2005) studied psychiatric care use after deinstitutionalisation in one Swedish district. They report that good care for people suffering from schizophrenia was accompanied by a decrease in care for patients with other psychiatric needs. Csipke et al. (2014) found a marked deterioration of inpatient care during 50 years of deinstitutionalisation in the UK. Possibly deinstitutionalisation of patients goes to the detriment of those remaining in residential care who are offered less activities than their predecessors 50 years ago.

Criminal behaviour and victimisation. Several studies point out that deinstitutionalisation may lead to, in terms of Gostin (2008), 'new places of confinement'. Former patients no longer waste away in residential care but spend a large part of their lives in prison instead. Kramp and Gabrielsen (2009) found a significant correlation between deinstitutionalisation and the rise of crime (notably arson and homicide) in Denmark; they argue that people suffering from schizophrenia are guilty of the crimes for which they are committed but that they are also victims of a deficient system of mental health care. Schmetzer (2007) reports a rise in violence, citing studies that show that the number of psychiatric disabled people in prisons has risen in the United States and that more psychiatric disabled people, who live in the community are arrested for a crime. Substance abuse plays an important role in these arrests and convictions, and, as stated above, deinstitutionalisation has led to increased substance abuse problems. Fuller Torrey (2015) reports a growing number of incidents of violent behaviour, including homicides, committed by untreated psychiatric patients in the US since the deinstitutionalisation began. According to Davis et al. (2012) who investigated the fate of former residents after deinstitutionalisation, psychiatric patients who are seriously ill are often reinstitutionalised in less suitable institutions such as prisons and nursing homes. However, Simpson, Mckenna, Moskowitz, Skipworth and Barry-Walsh (2004) found that deinstitutionalisation in New Zealand could not be associated with an increased risk of homicide by psychiatric disabled people.

Wallace, Mullen and Burgess (2004) studied criminal records and found a rising number of convictions among schizophrenics in Australia. Raphael and Stoll (2013) report a high prevalence of psychiatric disabled people in US prisons. These findings suggest that psychiatric disabled people who live in the community risk ending up in prison instead of receiving treatment which could prevent their crimes. Toib (2006) and Psarra et al. (2008) argue that extra forensic care and police training are necessary to take proper care of psychiatric disabled people, since police officers do not always know how to deal with this target group.

Three studies found that mentally disabled people become victims of crime after deinstitutionalisation. Short, Thomas, Luebbers, Mullen and Ogloff (2013) compared schizophrenic patients with ordinary citizens in Australia and found that the mentally ill were much more likely to become victims of crime; similar findings were reported for the US by Teplin, McClelland, Abram and Weiner (2005). Schmetzer (2007) also points at the possibility of victimisation.

Increased care given by family members. Basta et al. (2013) found in a study in Crete (Greece) that when the psychiatric hospital was closed most patients returned to their families which significantly increased care given by family members which is sometimes felt as a burden, as a large majority of the former patients did not find paid employment. Wang (2012), Chan (2011) and Avieli, Smeloy and Band-Winterstein (2015) also found an increased burden of care on family caregivers, as did Gray et al. (2014) who specifically researched parents of adults with intellectual disabilities in Australia. They conclude: 'Parents caring for their adult child reported high levels of mental health problems and dissatisfaction with the long-term care arrangements for their child.' Tossebro and Lundeby (2006), however, found that while family members are sometimes critical about the present state of community care services, most family members prefer community care over institutions before and after resettlement.

Mixed effects – Positive and negative

Social inclusion. Social inclusion and participation in the community are central goals of deinstitutionalisation. The development of an individual's network of informal social relationships is one of the key means to achieve these aims. An informal social network is supposed to meet social, emotional and instrumental needs of disabled people. Social networks can be seen as the vehicle through which informal social support might be exchanged (Bigby, 2008, p. 148, 2012).

When it comes to social inclusion of disabled people the outcomes found in this literature review are diverse and ambiguous. Various authors are positive about the social inclusion and conclude on the basis of a literature review that people who live in the community have larger social networks and more friends than people in institutions. Their networks are not just larger, but also include more members who are neither staff, nor family nor others with disabilities. These authors suggest that the closer the living arrangements approximate independent living, the larger and more active social networks tend to be (Duggan & Linehan, 2013; Kozma et al., 2009; McConkey, 2007; McConkey & Collins, 2010; Young & Asman, 2004b). Dusseljee, Rijken, Cardol, Curfs and Groenewegen (2011) conclude that people living in non-campus settings have more opportunities to have social contact with people without an intellectual disability, because they are more involved in the community. Ouellette-Kuntz, Burge, Brown and Arsenault (2010) measured the social distance of adults in Ontario, Canada towards intellectual disabled people. The results of the study indicate that, overall, respondents have remarkably positive attitudes towards intellectually disabled individuals; suggesting that social distance should be minimal, which in turn ought to increase chances for social integration of intellectual disabled people.

However, other researchers are not so optimistic when it comes to the social networks of disabled people. The studies of Hall and Hewson (2006), Duggan and Linehan (2013), Forrester-Jones et al. (2006), Forrester-Jones et al. (2012), Van Asselt-Goverts, Embregts and Hendriks (2013) and Amado, Stancliffe, McCarron

and McCallion (2013) indicate that disabled people tend to have small social net-works typically consisting of paid caregivers, family members and other disabled people. Staff members when included in the study comprise a considerable pro-portion of the network.

Several studies observe that disabled people do not easily integrate in the com-munity. Wiesel, Bigby and Carling-Jenkins (2013) observed encounters between intellectually disabled people and others and found no genuine convivial encounters. In another Australian-based study Wiesel and Bigby (2014) found that intellectually disabled people are often ignored or excluded in the social realm. Rossow-Kimball and Goodwin (2014) found that people without disabilities in a Canadian leisure centre hosting a Retirement For All program did not feel they should include intellectually disabled people in their activities, not even when urged to do so by the centre's staff. Van Alphen, Dijker, van den Borne and Curfs (2010) found that neighbours without disabilities are generally positive about their intellectually disabled neighbours but want to keep some proper distance and lack support and mediation in coping with unexpected behaviour. Bigby (2008) found that friendships with non-co-resident friends or people without disabilities decreased over time and the initial increase in informal network size and family contact after the relocation was not sustained. However, a small portion of intellectually disabled people managed to form new friendships in the community. Another small group had a key informal person in their network who kept in touch and actively checked their well-being.

Financial consequences. Which type of care is most cost effective: grouping people together in large numbers with qualified staff or provide community care, assisted living and ambulatory treatment? The literature does not provide a clear answer. Knapp et al. (2011) did a systematic review on the economic aspects of deinstitu-tionalisation and conclude that community care may be better for former residents but does not lead to great savings. A few studies in our dataset report slightly negative financial outcomes of deinstitutionalisation. Sealy and Whitehead (2004) report that decreased spending on hospital care in Canada is equalled by an increase in spending on community care. Power (2013) argues that special places for disabled people are very important and should not be abolished to save costs. Although these are not outright negative results, it is necessary to stress in addition that many studies point out that adequate community care requires additional costs. Two studies found that the level of care for intellectually disabled people strongly influences their health (Martinez-Leal et al., 2011, in a comparative study in Europe) and skills needed to live in society (Hamelin et al., 2011) and underline that good care requires additional costs.

Study limitations

This article provided an overview of positive and negative effects that have thus far been identified. Due to the broad range of studies included in this chapter, it is

difficult to pinpoint the size of the effects. Different configurations of (community) care in different countries codetermine the outcomes of deinstitutionalisation.

In terms of generalisability of the findings of the studies, it is important to acknowledge that most of the included studies are limited in terms of target group, type of residential facility, outcome measure, studied effects and time period. In addition, studies come from a variety of Western countries. The specific effects mentioned in Table 2 are all covered by multiple articles, which allows for some degree of comparison in the extent and direction of the effect. Comparing articles from different categories proves more difficult, especially when studies are limited in geographical location, target group and type of residential facility.

Even then, it remains difficult to paint a generalised picture of the effects of deinstitutionalisation, since the studies are different in goals, subject, geographical location (which in turn influence care configuration) and research method. This is a limitation of this study. In order to effectively synthesise findings from different studies, it would be necessary to limit the variation of studies or to do separate reviews on all of the mentioned effects. However, this would have gone to the detriment of the comprehensiveness that we aimed for in this article.

Conclusion

The foregoing sections show that deinstitutionalisation has both positive and negative consequences for different groups of people involved.

Positive effects of deinstitutionalisation seem to be an improved quality of life – i.e. quality of living conditions and well-being – of the disabled people themselves. Quality of care has also increased, mostly because community care allows for a higher level of autonomy and choice-making than hospital care. We also found robust positive outcomes with regard to skills needed to live in society. Skills such as self-care, independent functioning, taking responsibility, self-direction and social skills improve when people move to society, due to rehabilitation training. These positive effects may not be feasible for all disabled people: people living in less restricted settings are often those with less severe disabilities. Moreover, improvement seems to be dependent on quality and characteristics of facilities and staff. There are some indications that health care has improved for the broader community as well: community (mental health) care is more accessible and available for everyone to use.

We found more studies which reported *negative effects* of deinstitutionalisation. As community care becomes the most important type of care, patients who remain in institutions are worse off. Some disabled people become revolving door patients in mental hospitals, or worse: end up in the criminal justice system. Living in the community provides this target group with risks they were previously sheltered from, such as undetected (physical) health problems, substance abuse, social isolation, victimisation of crimes and isolated death. Patients make more visits to emergency (psychiatric) care. Families of deinstitutionalised patients often resist deinstitutionalisation because they do not think that their disabled family member

can cope with the demands of independent living arrangements and because they assume that the care they need to give will increase significantly. In the wider community, citizens lack knowledge and skills about how to interact with intellectually and psychiatric disabled people as neighbours or as people they meet during leisure time. It seems health care institutions can undertake more steps to mediate. Some studies suggest a rise of crime committed by people with psychiatric or intellectual disabilities.

Recommendations and implications

What do these findings imply for social workers who (organise) care for people with intellectual disabilities and psychiatric conditions? It seems wise to acknowledge the downsides of deinstitutionalisation. Abusive situations and exploitation need to be fought. So do health problems and substance abuse among the target groups. Also, social workers need to recognise the increased burden of care that befalls the family members of disabled people in a regime of deinstitutionalisation; they may try to organise more professional help or widen the circle of potential caregivers. As social integration will not arise spontaneously as is proven by various studies, inclusion sometimes needs to be organised, for example, by organising programmes to take away stigma and prejudice.

For researchers, we might conclude that the effects of deinstitutionalisation on skills needed to live in society and quality of life for moderately disabled people have been sufficiently researched. Other issues warrant more attention. The fate of the most severely disabled in traditional residential care and in sheltered housing in the community seems to be a research gap. The same holds for the financial pros and cons of deinstitutionalisation, which also seems to be an under-researched topic. Most urgent perhaps is the need for further research into what increasing the burden of care means for family members, neighbours and other network members. Moreover, we think that broader studies that aim to identify all possible consequences of deinstitutionalisation would be helpful in weighing and reducing negative consequences for disabled people and for society at large. In addition, more long-term studies are necessary that can show how the situation develops over time and whether effects are permanent or change over time.

Ethics

This study was a review of documents and did not involve human subjects, therefore it did not require research ethics review.

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References

Amado, A. N., Stancliffe, R. J., McCarron, M., & McCallion, P. (2013). Social inclusion and community participation of individuals with intellectual/developmental disabilities. *Intellectual and Developmental Disabilities*, 51(5), 360–375. doi:10.1352/1934-9556-51.5.360

Arvidsson, H., & Ericson, B. C. (2005). The development of psychiatric care after the mental health care reform in Sweden. A case register study. *Nordic Journal of Psychiatry*, 59(3), 186–192. doi:10.1080/08039480510023061

Avieli, H., Smeloy, Y., & Band-Winterstein, T. (2015). Departure scripts and life review of parents living with abusive adult children with mental disorder. *Journal of Aging Studies*, 34, 48–56. doi:10.1016/j.jaging.2015.04.004

Basta, M., Stefanakis, Z., Panierakis, C., Michalas, N., Zografaki, A., Tsougkou, M., & Vgontzas, A. N. (2013). Deinstitutionalisation and family burden following the psychiatric reform. *European Psychiatry*, 28(1), 1. doi:10.1016/S0924-9338(13)76268-0

Becker, T., & Kilian, R. (2006). Psychiatric services for people with severe mental illness across western Europe: What can be generalized from current knowledge about differences in provision, costs and outcomes of mental health care? *Acta psychiatrica Scandinavia*, 113, 9–16. doi:10.1111/j.1600-0447.2005.00711.x

Bigby, C. H. (2008). Known well by no-one: Trends in the informal social networks of middle-aged and older people with intellectual disability five year after moving to the community. *Journal of Intellectual & Developmental Disability*, 33(2), 148–157. doi:10.1080/13668250802094141

Bigby, C. H. (2012). Social inclusion and people with intellectual disability and challenging behaviour: A systematic review. *Journal of Intellectual & Developmental Disability*, 37(4), 360–374. doi:10.3109/13668250.2012.721878

Bigby, C. H., & Fyffe, F. (2006). Tensions between institutional closure and deinstitutionalisation: What can be learned from Victoria s institutional redevelopment? *Disability & Society*, 21(6), 567–581. doi:10.1080/09687590600918032

Bouras, N., & Ikkos, G. (2013). Ideology, psychiatric practice and professionalism. *Psychiatriki*, 24(1), 17–26.

Bruffaerts, R., Sabbe, M., & Demyttenaere, K. (2008). Emergency psychiatry in the 21st century: Critical issues for the future. *Journal of Emergency Medicine*, 15(5), 276–278. doi:10.1097/MEJ.0b013e3282fc7616

Chan, S. W. (2011). Global perspective of burden of family caregivers for persons with schizophrenia. *Archives of Psychiatric Nursing*, 25(5), 339–349. doi:10.1016/j.apnu.2011.03.008

Chow, W. S., & Priebe S. (2013). Understanding psychiatric institutionalization: A conceptual review. *BMC Psychiatry*, 13(1), 169–184. doi:10.1186/1471-244X-13-169

Cree, V. E., & Davis, A. (2007). *Social work. Voices from the inside*. London, UK: Routledge.

Crossmaker, M. (1991). Behind locked doors – Institutional sexual abuse. *Sexuality and Disability*, 9(3), 201–219. doi:10.1007/BF01102393

Csipke, E., Flach, C., McCrone, P., Rose, D., Tilley, J., Wykes, T., & Craig, T. (2014). Inpatient care 50 years after the process of deinstitutionalisation. *Social Psychiatry and Epidemiology*, 49(4), 665–671. doi:10.1007/s00127-013-0788-6

Davies, M. (Ed.). (2013). *The Blackwell companion to social work*. Chichester, UK: Wiley-Blackwell.

Davis, L., Fulginiti, A., Kriegel, L., & Brekke, J. S. (2012). Deinstitutionalisation? Where have all the people gone? *Current Psychiatry Reports*, 14(3), 259–269. doi:10.1007/s11920-012-0271-1

Duggan, C., & Linehan, C. (2013). The role of 'natural supports' in promoting independent living for people with disabilities; a review of existing literature. *British Journal of Learning Disabilities*, *41*(3), 199–207. doi:10.1111/bld.12040

Dusseljee, J. C. E., Rijken, P. M., Cardol, M., Curfs, L. M. G., & Groenewegen, P. P. (2011). Participation in daytime activities among people with mild or moderate intellectual disabilities. *Journal of Intellectual Disabilities Research*, *55*(1), 4–18. doi:10.1111/j.1365-2788.2010.01342.x

Forenza, B., & Eckert, C. (2017). Social worker identity. A profession in context. *Social Work*, *63*(1), 17–26. doi:10.1093/sw/swx052/4621303.

Forrester-Jones R., Carpenter J., Coolen-Schrijner P., Cambridge P., Tate A., Beecham J., Hallam A., . . ., Wooff, D., (2006). The social networks of people with intellectual disability living in the community 12 years after resettlement from long-stay hospitals. *Journal of Applied Research in Intellectual Disabilities*, *19*(4), 285–295. doi: 10.1111/j.1468-3148.2006.00263.x

Fuller Torrey, E. (2015). Deinstitutionalisation and the rise of violence. *CNS Spectrums* 20(3), 207–214. doi:10.1017/S1092852914000753

Gostin, L. O. (2008). 'Old' and 'new' institutions for persons with mental illness: Treatment, punishment or preventive confinement? *Public Health*, *122*(9), 906–913. doi:10.1016/j.puhe.2007.11.003

Gray, K. M., Piccinin, A., Keating, C. M., Taffe, J., Parmenter, T. R., Hofer, S., . . . Tonge, B. J. (2014). Outcomes in young adulthood: Are we achieving community participation and inclusion? *Journal of Intellectual Disability Research*, *58*(8), 734–745. doi:10.1111/jir.12069

Hall, L., & Hewson, S. (2006). The community links of a sample of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *19*(2), 204–207. doi:10.1111/j.1468-3148.2005.00249.x

Hamden, A., Newton, R., McCauley-Elsom, K., & Cross, W. (2011). Is deinstitutionalization working in our community? *International Journal of Mental Health Nursing*, *20*(4), 274–283. doi:10.1111/j.1447-0349.2010.00726.x

Hamelin, J. P., Frijters, J., Griffiths, D., Condillac R., & Owen, F. (2011). Meta-analysis of deinstitutionalisation adaptive behaviour outcomes: Research and clinical implications. *Journal of Intellectual & Developmental Disability*, *36*(1), 61–72. doi:10.3109/13668250.2010.544034

Hannes, K., & Lockwood, C. (2012). *Synthesizing qualitative research. Choosing the right approach.* Chisester, UK: John Wiley & Sons.

Heila, H., Haukka, J., Suvisaari, J., & Lonnqvist, J. (2005). Mortality among patients with schizophrenia and reduced psychiatric hospital care. *Psychological Medicine*, *35*(5), 725–732.

Jeppesen, T., Christensen, T., & Vestergaard, C. H. (2016). Changes in the utilization of psychiatric hospital facilities in Denmark by patients diagnosed with schizophrenia form 1970 through 2012. The advent of revolving door patient. *Acta Psychiatrica Scandinavia*, *133*(5), 1–7. doi:10.1111/acps.12549

Killaspy, H., White, S., Wright, C., Taylor, T. L., Turton, P., Kallert, T., Schuster, M., . . ., Botbol M. (2012). Quality of longer term mentalhealth facilities in Eeurope: validation of the quality indicator for rehabilitative care against service users' views. *PLoS.ONE*, *7*(6). doi:10.1371/journal.pone.0038070

Kalucy, R., Thomas, L., & King, D. (2005). Changing demand for mental health services in the emergency department of a public hospital. *Australian and New Zealand Journal of Psychiatry*, *39*(1–2), 74–80. doi:10.1080/j.1440-1614.2005.01512.x

Knapp, M., Beecham, J., McDaid, D., Matosevic, T., & Smith, M. (2011). The economic consequences of deinstitutionalisation of mental health services: Lessons from a systematic review of European experience. *Health and Social Care in the Community*, *19*(2), 113–125. doi:10.1111/j.1365-2524.2010.00969.x

Kozma, A., Mansell, J., & Beadle-Brown, J. (2009). Outcomes in different residential settings for people with intellectual disability: A systematic literature review. *American Journal of Intellectual and Developmental Disabilities*, *114*(3), 193–222. doi:10.1352/1944-7558-114.3.193

Kramp, P., & Gabrielsen, G. (2009). The organization of the psychiatric service and criminality committed by the mentally ill. *European Psychiatry*, *24*(6), 401–411. doi:10.1016/j.eurpsy.2009.07.007

Kunitoh, N. (2013). From hospital to the community: The influence of deinstitutionalisation on discharged long-stay psychiatric patients. *Psychiatry and Clinical Neurosciences*, *67*(6), 384–396. doi:10.1111/pcn.12071

Livingston J.D., Nicholls, T., & Brink J., (2011). The impact of realigning a tertiary psychiatric hospital in British Columbia on other institutional sectors. *Psychiatric Services, 62*(2), 200–205.

Machado, V., Leonidas, C., Santos, M. A., & Souza J. (2012). Psychiatric readmission: An integrative review of the literature. *International Nursing Review*, *59*(4), 447–457. doi:10.1111/j.1466-7657.2012.01011.x

Martinez-Leal, R., Salvador-Carulla, L., Linehan, C., Walsh, P., Weber, G., Van Hove, G., ... Kerr, M. (2011). The impact of living arrangements and deinstitutionalisation in the health status of persons with intellectual disability in Europe. *Journal of Intellectual Disability Research*, *55*(9), 858–872. doi:10.1111/j.1365-2788.2011.01439.x

Martinsson, G., Fagerberg, I., Lindholm, C. H., & Wiklund-Gustin, J. (2012). Struggling for existence – Life situation experiences of older persons with mental disorder. *International Journal of Qualitative Studies on Health and Well-Being*, *7*(1), 18422–18428. doi:10.3402/qhw.v7i0.18422

Matheson, F., Creatore, M. I., Gozdyra, P., Moineddin, R., Bourke, S., & Glazier, R. H. (2005). Assessment of police calls for suicidal behaviour in a concentrated setting. *Psychiatric Services*, *56*(12), 1606–1609. Retrieved from https://ps.psychiatryonline.org

McConkey, R. (2007). Variations in the social inclusion of people with intellectual disabilities in supported living schemes and residential settings. *Journal of Intellectual Disability Research*, *51*(3), 207–217. doi:10.1111/j.1365-2788.2006.00858.x

McConkey, R., & Collins, S. (2010). The role of support staff in promoting the social inclusion of persons with an intellectual disability. *Journal of Intellectual Disability Research*, *54*(8), 691–700. doi:10.1111/j.1365-2788.2010.01295.x

Nicaise, P., Dubois, V., & Lorant, V. (2014). Mental health care delivery system reform in Belgium: The challenge of achieving deinstitutionalisation whilst addressing fragmentation of care at the same time. *Health Policy*, *115*(2–3), 120–127. doi:10.1016/j.healthpol.2014.02.007

Nilsson, L., & Logdberg, B. (2008). Dead and forgotten – Postmortem time before discovery as indicator of social isolation and inadequate mental health care in schizophrenia. *Schizophrenia Research*, *102*(1–3), 337–339. doi:10.1016/j.schres.2008.03.011

Novella, E. J. (2010). Mental health care in the aftermath of deinstitutionalisation: A retrospective and prospective view. *Health Care Analysis*, *18*(3), 222–238. doi:10.1007/s10728-009-0138-8

Ouellette-Kuntz, H., Burge, P., Brown, H. K., & Arsenault, E. (2010). Public attitudes towards individuals with intellectual disabilities as measured by the concept of social distance. *Journal of Applied Research in Intellectual Disabilities*, *23*(2), 132–142. doi:10.1111/j.1468-3148.2009.00514.x

Overmars-Marx, T., Thomése, F., Verdonschot, J., & Meininger, H. (2014). Advancing social inclusion in the neighbourhood for people with an intellectual disability: An exploration of the literature. *Disability & Society*, *29*(2), 255–274. doi:10.1080/09687599.2013.800469

Parker, J. (2014). De-institutionalisation in psychiatry – Both sides of the coin. *South African Medical Journal*, *104*(1), 76. doi:10.7196/SAMJ.7733

Picardi, A., Rucci, P, Girolamo, G., Santone, G., Borsetti G., & Morosini, P. (2006). The quality of life of the mentally ill living in residential facilities. *European Archives of Psychiatry and Clinical Neuroscience*, *256*(6), 372–381. doi:10.1007/s00406-006-0647-5

Power, A. (2013). Making space for belonging: Critical reflections on the implementation of personalised adult social care under the veil of meaningful inclusion. *Social Science & Medicine*, *88*, 68–75. doi:10.1016/j.socscimed.2013.04.008

Psarra, V., Sestrini, M., Santa, Z., Petsas, D., Gerontas, A., Garnetas, C. H., & Kontis, M. (2008). Greek police officers' attitudes towards the mentally ill. *International Journal of Law and Psychiatry*, *31*(1), 77–85. doi:10.1016/j.ijlp.2007.11.011

Raphael, S., & Stoll, M. A. (2013). Assessing the contribution of the deinstitutionalization of the mentally ill to growth in the U.S. incarceration rate. *Journal of Legal Studies*, *42*(1), 187–222. Retrieved from https://gspp.berkeley.edu/assets/uploads/research/pdf/p71.pdf

Rossow-Kimball, B., & Goodwin, D. L. (2014). Inclusive leisure experiences of older adults with intellectual disabilities at a senior centre. *Leisure Studies*, *33*(3), 322–338. doi:10.1080/02614367.2013.768692

Salokangas, R. K. R. (2007). Medical problems in schizophrenia patients living in the community (alternative facilities). *Current Opinions in Psychiatry*, *20*(4), 402–405. doi:10.1097/YCO.0b013e328122d99b

Saz-Parkinson, Z., Medel, A., Cediel-García, P., Castellote, J., Bouza, C., & Amate, J. M. (2011). Trends on schizophrenia admissions during the deinstitutionalisation process in Spain (1980–2004). *Social Psychiatry and Epidemiology*, *46*(11), 1095–1101. doi:10.1007/s00127-010-0289-9

Schmetzer, A. D. (2007). Deinstitutionalisation and dual diagnosis. *Journal of Dual Diagnosis*, *3*(2), 95–102. doi:10.1300/J374v03n02_11

Sealy, P. (2012). The impact process of deinstitutionalization of mental health services in Canada: An increase in accessing of health professionals for mental health concerns. *Social Work in Public Health*, *27*(3), 229–237. doi:10.1080/19371911003748786

Sealy, P., & Whitehead, P. C. (2004). Forty years of deinstitutionalisation of psychiatric services in Canada: An empirical assessment. *Canadian Journal of Psychiatry*, *49*(4), 249–257. doi:10.1177/070674370404900405

Short, T. B. R., Thomas, S., Luebbers, S., Mullen, M., & Ogloff, J. P. R. (2013). A case-linkage study of crime victimisation in schizoprenia-spectrum disorders over a period of deinstitutionalisation. *BMC Psychiatry*, *13*(66), 66–75. doi:10.1186/1471-244X-13-66

Simpson, A. I. F., Mckenna, B., Moskowitz, A., Skipworth, J., & Barry-Walsh, J. (2004). Homicide and mental illness in New Zealand, 1970–2000. *British Journal of Psychiatry*, *185*(5), 394–398. doi:10.1192/bjp.185.5.394

Slayter, E. M. (2010). Disparities in access to substance abuse treatment among people with intellectual disabilities and serious mental illness. *Health & Social Work*, 35(1), 48–60.

Teplin, L. A., McClelland, G. M., Abram, K. M., & Weiner, D. A. (2005). Crime victimization in adults with severe mental illness. *Archives of General Psychiatry*, 62(8), 911–921. doi:10.1001/archpsyc.62.8.911

Thiblin, I. B., Fugelstad, A. B., Leifman, A. G., Romelsjö, A. B., Agren, G. S., & Sorimachi, K. Y. (2004). Relationships between the deinstitutionalisation of health care for patients with mental disorder, substance abuse, and isolated death. *Journal of Forensic Sciences* 49(2), 1–7. doi:10.1520/JFS2003199

Toib, J. A. (2006). Challenges for Israeli mental health law in the next decade. *Israel Journal of Psychiatry and Related Sciences*, 43(3), 198–208. Retrieved from https://cdn.doctor sonly.co.il/2011/12/2006_3_12.pdf

Tossebro, J., & Lundeby, H. (2006). Family attitudes to deinstitutionalisation: Changes during and after reform years in a Scandinavian country. *Journal of Intellectual & Developmental Disability*, 31(2), 115–119. doi:10.1080/13668250600681495

Trappenburg, M. J. (2013). Active solidarity and its discontents. *Health Care Analysis*, 23(3), 207–222. doi:10.1007/s10728-013-0260-5

Van Alphen, L. M., Dijker, A. J. M., van den Borne, B. H. W., & Curfs, L. M. G. (2010). People with intellectual disability as neighbours: Towards understanding the mundane aspects of social integration. *Journal of Community & Applied Social Psychology*, 20(5), 347–362. doi:10.1002/casp.1042

Van Asselt-Goverts, A. E., Embregts, P. J. C. M., & Hendriks, A. M. S. (2013). Structural and functional characteristics of the social networks of people with mild intellectual disabilities. Research in Developmental Disabilities, 34(4), 1280–1288. doi:10.1016/j. ridd.2013.01.012

Wallace, C., Mullen, P. E., & Burgess, P. (2004). Criminal offending in schizophrenia over a 25-year period marked by deinstitutionalization and increasing prevalence of comorbid substance use disorders. *American Journal of Psychiatry*, 161(4), 716–722. doi:10.1176/appi.ajp.161.4.716

Wang, K. Y. (2012). The care burden of families with members having intellectual and developmental disorder: A review of the recent literature. *Current Opinions in Psychiatry*, 25(5), 348–351. doi:10.1097/YCO.0b013e3283564248

Wiesel, I., & Bigby, C. (2014). Being recognised and becoming known: Encounters between people with and without intellectual disability in the public realm. *Environment and Planning*, 46(7), 1754–1769. doi:10.1068/a46251

Wiesel, I., Bigby, C., & Carling-Jenkins, R. (2013). Do you think I'm stupid? Urban encounters between people with and without intellectual disability. *Urban Studies*, 50(12), 2391–2406. doi:10.1177/0042098012474521

Yoon, J., & Bruckner, B. A. (2009). Does deinstitutionalisation increase suicide? *Health Services Research*, 44(4), 1385–1405. doi:10.1111/j.1475-6773.2009.00986.x

Young, L., & Ashman, A. M. (2004a). Deinstitutionalisation in Australia. Part I: Historical perspective. *The British Journal of Developmental Disabilities*, 50(1), 21–28. Retrieved from http://www.bjdd.org/new/pdf98/98,21-28.pdf

Young, L., & Ashman, A. M. (2004b). Deinstitutionalisation in Australia. Part II: Results from a long-term study. *The British Journal of Developmental Disabilities*, 50(1), 29–45. Retrieved from http://www.bjdd.org/new/pdf98/98,29-45.pdf