

# Outcomes in Different Residential Settings for People With Intellectual Disability: A Systematic Review

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## Abstract

Large-scale reviews of research in deinstitutionalization and community living were last conducted about 10 years ago. Here we surveyed research from 1997 to 2007. Articles were included if the researchers based the study on original research, provided information on the participants and methodology, compared residential arrangements for adults with intellectual disability, and were published in English-language peer-reviewed journals. Sixty-eight articles were found. In 7 of 10 domains, the majority of studies show that community-based services are superior to congregate arrangements. These studies provide more evidence of the benefits of deinstitutionalization and community living and continue to indicate variability in results, suggesting that factors other than the basic model of care are important in determining outcomes.

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The replacement of large residential institutions by local, smaller services supporting people with intellectual disabilities in the community has been one of the most important shifts in adult social services in some Western countries in the past 30 years (Bigby & Fyffe, 2006; Mansell & Ericsson, 1996). Most progress has been made in Scandinavia, North America, Australasia, and the United Kingdom (Mansell, 2006). Elsewhere, deinstitutionalization has only just started or is not yet taking place. For example, in recent research investigators estimated that there are over one million people with disabilities in institutions in the European Union (Freyhoff, Parker, Coue, & Greig, 2004; Mansell, Beadle-Brown, & Clegg, 2004; Mansell, Knapp, Beadle-Brown, & Beecham, 2007).

The impact of different forms of residential supports on the quality of life of people with intellectual disabilities has attracted considerable attention. Emerson and Hatton (1994) reviewed 71 articles published in 1980–1994 in the United Kingdom. Young, Sigafos, Suttie, Ashman, and Grevell (1998) reviewed 13 Australian studies

published between 1980 and 1998. Kim (2001) reviewed the behavioral outcomes of deinstitutionalization for people with intellectual disabilities in studies published in the United States between 1980 and 1999. McConkey (2000), Heller (2002), and Beadle-Brown, Mansell, and Kozma (2007) reviewed papers reporting on any aspect of deinstitutionalization or community services for people with intellectual disabilities during periods of one year. A number of reviewers have focused on specific aspects of deinstitutionalization, such as engagement in activity and resident–staff interactions (Felce, 1998), community integration (Myers, Agers, Kerr, & Myles, 1998), and costs (Walsh, Kastner, & Green, 2003). These reviews suggest that the weight of research favored community-based services in most domains considered, although there were exceptions, and reviewers also frequently drew attention to the variability of results found in service models of the same type.

In the present study we provide a comprehensive review of more recent research on

outcomes in residential settings for people with intellectual disabilities, including both deinstitutionalization and postdeinstitutionalization studies. All research published in English from different countries since 1997 were considered. There are four main reasons why a new review of the literature is needed: (a) exploration of whether more recent experiences in different countries continues to provide evidence on the benefits of community living for people with intellectual disabilities; (b) deinstitutionalization, the expansion of community-based services, and the contraction of institutions are still underway in many countries, and research evidence remains useful to policymakers for deciding about the allocation of resources to different types of living arrangements; (c) it is very likely that the last decade included the move of more people with more severe disabilities to community services than occurred in earlier stages of the process, making more recent studies of interest; (d) the system of community-based services in some countries is now relatively well-established and new forms of residential arrangements (e.g., supported and independent living) are increasingly common, which challenge and provide alternatives to more traditional models of community living. The outcomes of these arrangements are also worth reviewing.

## Method

### *Selection of Studies*

We used three methods to identify studies for this review: (a) electronic search with a combination of key terms (deinstitutionalisation/deinstitutionalization, learning/intellectual disabilities, mental retardation, living arrangements, community services, resettlement, transition to community care, relocation, hospital/institution closure, residential care institution) on academic search engines (Web of Science, PsycINFO, and Google Scholar); (b) search of selected journals (e.g., *Mental Retardation*, *American Journal on Mental Retardation*, *Journal of Applied Research in Intellectual Disabilities*, *Journal of Intellectual Disability Research*, *British Journal of Learning Disabilities*); and (c) follow-up of references in relevant papers and publications. We found 107 that were potentially relevant and screened them more thoroughly using the following criteria: (a) published either in print or electronically between

1997 and 2007, (b) appeared in a peer-reviewed English-language journal, (c) based on original qualitative or quantitative research and contained information on the participants and methodology, and (d) compared two or more residential arrangements for adults with an intellectual and/or developmental disability in terms of clearly defined user outcomes.

For the final review, we selected 68 studies that met all the above criteria. These articles were also checked with a recent unpublished review (Noonan Walsh et al., 2007). Investigators reporting on the Hissom closure in Oklahoma (Conroy, Spreat, Yuskas, & Elks, 2003; Spreat & Conroy, 2002; Spreat, Conroy, & Fullerton, 2005) that met all the inclusion criteria were excluded in the light of recent controversy (Walsh & Kastner, 2006).

### *Review Procedure*

We reviewed the 68 studies and coded them according to country, research design, instruments, number of participants, settings, outcome domains, and results. Studies mainly came from English-speaking countries, and only 9 articles reported on experiences elsewhere (the Netherlands, Finland, Taiwan, Norway). In the majority of studies (49), researchers evaluated the impact of deinstitutionalization and compared institutions with a variety of community-based settings. In postdeinstitutionalization studies (19) (Stancliffe, Emerson, & Lakin, 2004), researchers compared outcomes of different community-based residential supports.

Definitions of *institution* and *community-based services* varied country by country. Common features of institutions typically included large size, atypical architectural design, segregation from the local community, and highly regulated restrictive environments. Community-based settings included a variety of arrangements, such as dispersed or clustered, ordinary or purpose-built group homes, and supported living. Researchers reported the size (range) of settings, but structural or functional characteristics were rarely discussed (Stancliffe, Emerson, & Lakin, 2004).

Twenty-seven studies had a cross-sectional design with matched samples and 23, a longitudinal design. In 18 studies investigators combined both and either compared “movers” and “stayers” or people moving to different types of residential arrangements.

Researchers used different methods to control for the impact of participant characteristics on the individual outcomes of residential arrangements. In longitudinal studies investigators relied on pre-post designs with or without comparison groups. For cross-sectional studies they used matched groups or statistical procedures.

The majority of studies (42 of 68) had a sample size of 100 or more participants; however, in 11 studies researchers used a small sample with less than 50 participants. These studies might lack statistical power and, therefore, their results should be viewed with caution. Investigators did not commonly report sampling strategies. Convenience samples were relatively widespread. In a few, more recent studies (e.g., Emerson, 2004b), researchers used representative sampling techniques (Noonan Walsh et al., 2007).

In most studies (66 of 68) investigators took a quantitative approach, using a variety of instruments. People with intellectual disabilities had virtually no input into the design of studies. Researchers in only two papers (Emerson, 2004b; Emerson & McVilly, 2004) from the same study reported some participation of people with intellectual disabilities, although there are good examples in recent research (Miller, Cooper, Cook, & Petch, 2008).

The outcome domains reported by these researchers were coded into 10 categories: (a) community presence and participation, (b) social networks and friendships, (c) family contact, (d) self-determination and choice, (e) quality of life, (f) adaptive behavior, and (g) user and family views and satisfaction. Authors of 29 studies reported on more than one domain.

We briefly summarized the results of each study; the overall direction of change and magnitude of outcomes are indicated in the summary tables (e.g., better, more, declined). For quantitative studies we used statistical significance and for qualitative studies employed the strength of opinion as an arbiter in reporting outcomes. Unless otherwise stated results reported in the summary tables are significant; we noted nonsignificant or inconclusive results. We also highlighted internal variations of outcomes and the factors associated with internal variation.

The results are presented below by domain. In each section we provide a brief summary of the general results, highlight the factors associated with variation, and present a summary table of the studies.

## Results

### *Community Presence and Participation*

The presence of people with intellectual disabilities in the community, their participation in community-based activities, and use of community facilities are often seen as one of the core indicators of their social integration (Emerson & Hatton, 1994). Authors of 14 publications reported on some aspect of community integration, most often measured as the use of mainstream community facilities (e.g., services, leisure) and participation in activities outside the home (Table 1).

Small-scale community arrangements were found to offer more community involvement to users than were larger settings (Ager, Myers, Kerr, Myles, & Green, 2001; Chou, Lin, Pu, Lee, & Chang, 2008; Felce et al., 1998). Researchers found that semi-independent or supported living arrangements provided more community integration than did traditional residential services (Emerson et al., 2001; Howe, Horner, & Newton, 1998; Stancliffe & Keane, 2000). Community-based services did not, however, guarantee better outcomes. Community participation was also found to be associated with adaptive behavior (Baker, 2007), level and complexity of needs (McConkey, Walsh-Gallagher, & Sinclair, 2005), and the individual's social competence. It was associated with service factors, including the quality of supports. Results also suggest that the community presence and participation of people with intellectual disabilities was very limited across all settings. People with more severe disabilities in particular are at risk of having limited community experiences (Baker, 2007).

### *Social Networks and Friendships*

Meaningful friendships and social relationships are important determinants of emotional and physical well-being (Emerson & McVilly, 2004). In 9 studies investigators reported on some aspects of social networks and friendships (Table 2). Researchers typically focused on the size and density of networks and friendships, finding that friendships and social networks of people with intellectual disabilities were associated with living arrangements as well as personal characteristics. In terms of number of friends, people in small settings with low staff turnover had more friends. Those in supported living arrangements had more friends outside the home, were more

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**Table 1.** Community Presence and Participation

Study	Country	N	Design <sup>a</sup>	Results
Ager et al. (2001)	UK	76	L (1.6), <sup>b</sup> QN	People moving from hospital (95+ residents) to community homes (1–10 residents) increased community participation; however, most outings took place in groups.
Baker (2007)	UK	60	L (1.5), CS, QN	People resettling into staffed group homes (6 residents) from a hospital increased community participation. People already in community provision experienced no change in the same period.
Chou et al. (2008)	Taiwan	248	CS, QN	People in small homes (max. 6 residents) had more community involvement than those in larger homes (max. 50 places) and institutions (50+ places).
Emerson (2004)	UK	910	CS, QN	People in community houses experienced better community participation than people in cluster housing (3 or more houses grouped together).
Emerson et al. (2000b)	UK	500	CS, QN	People in community homes (1–8 residents) and intentional communities (28–179 residents on site) had higher community involvement than people living on campus settings (94–144 residents on site).
Emerson et al. (2001)	UK	281	CS, QN	People in supported living (1–3 residents) arrangements participated in more community activities than people in small (1–3 residents) or larger homes (4–6 residents).
Felce (1998); Felce et al. (2000)	UK	34	CS, QN	People with severe challenging behavior in community settings (1–9 residents) had higher community participation than did those in hospitals (10–188 residents).
Heller, Factor et al. (1998)	USA	232	L (3), QN	People who moved from nursing homes (mean size 207 residents) to community settings (1–8 residents) and larger homes (ICF/MR settings with 20+ residents) had higher level of community inclusion and participation than did nonmovers.
Heller, Miller et al. (2002)	USA	186	L (8), CS, QN	People who relocated to community settings (1–18 residents) and ICF/MR settings (20+ residents) had higher level of community integration than did people who stayed in nursing homes (91–417 residents).

(Table 1 continued)

**Table 1.** Continued

Study	Country	N	Design <sup>a</sup>	Results
Howe et al. (1998)	USA	34	CS, QN	People in supported living arrangements (1-3 residents) had higher community participation than did people in larger homes (2-20 residents).
McConkey (2007)	Ireland, UK	620	CS, QN	People in small homes (max. 6 residents), and dispersed and clustered supported living used more community amenities than did people in large homes (avg. 20 residents) or in campus settings (100+ residents on site).
Stancliffe & Keane (2000)	Australia	54	CS, QN	People in semi-independent living arrangements (1-4 people living together) used more community facilities than did people who lived in group homes (3-7 residents).
Stancliffe & Lakin (1998)	USA	187	CS, QN	People in community settings (2-15 residents) enjoyed greater community participation than residents in institutions (16+ residents).

<sup>a</sup>CS = cross-sectional; L = longitudinal; QN = quantitative; QL = qualitative. <sup>b</sup>The number in parentheses indicates the length of the study in years.

likely to be known by their neighbors, and have visitors (Emerson & McVilly, 2004; Forrester-Jones et al., 2006; McConkey, 2007). Service characteristics, such as the implementation of active support (Stancliffe, Jones, Mansell, & Lowe, 2008), may moderate the effect of setting size and are associated with larger social networks (Robertson, Emerson, Gregory et al., 2001). Friendship and social network were also associated with individual characteristics, such as adaptive skills and (lack of) severe challenging behavior (Emerson & McVilly, 2004).

Although more able people in dispersed supported living were at relatively higher risk of being isolated (McConkey, 2007), there was no strong evidence of a relationship between loneliness and small setting size, including supported living. Loneliness was found to be associated with incompatibility between residents, which is more likely to happen in larger settings, and feeling unsafe in the local community (Stancliffe et al., 2007). Friendship activities with other people who have intellectual disabilities typically took place in the public domain. These relationships were characterized by high stability and reciprocity and were highly valued by people themselves (Emerson & McVilly, 2004; Forrester-Jones et al., 2006; Robertson, Emerson, Gregory et al., 2001).

*Family Contact*

Family contact has been associated with social and psychological well-being and social inclusion of people with intellectual disabilities (Robertson, Emerson, Gregory et al., 2001; Stancliffe & Lakin, 2006). Investigators in 8 studies in the current review reported on some aspect of family contact, most often frequency and form (Table 3).

Resettlement in the community was shown to be an opportunity to re-establish family contact, which tended to remain stable over time (Spreat, Conroy, & Rice, 1998; Stancliffe & Lakin, 2006). Very large size was associated with less family contact (Chou et al., 2008); but, overall, form and frequency of family contact were not related to type and size of living arrangement; rather they were correlated to distance to the family home and personal characteristics, such as ability and resident and parent age.

*Self-Determination/Choice*

Self-determination and choice are highly valued in Western cultures and are important

**Table 2.** Social Networks and Friendships

Study	Country	N	Design <sup>a</sup>	Results
Emerson et al. (2000b)	UK	500	CS, QN	People in community homes (1–8 residents) and intentional communities (28–179 residents on site) had larger social networks than did people living on campus settings (94–144 residents on site).
Emerson, Robertson, Gregory, Kessissoglou et al. (2000)	UK	40	CS, QN	People in community homes (1–8 residents) had larger social networks than did people living on campus settings (94–144 residents on site).
Emerson & McVilly (2004)	UK	1,542	CS, QN	People in smaller community-based settings (1–4 residents) and supported living arrangements (1–3 people living together) participated in more friendship activities than did people in larger settings. Other setting characteristics (type of provision, staffing) were also important predictors of friendship activities.
Forrester–Jones et al. (2006)	UK	213	CS, QN, QL	People in small community homes (2–5 places), supported and independent living arrangements and hostels (6+ residents, variable staff support) had more reciprocal relationships than did people in residential and nursing homes (6+ places, continuous staff support). Supported living and hostel residents reported more reciprocal relationships.
Heller, Factor et al. (1998)	USA	232	L (3) <sup>b</sup> , QN	People who moved from nursing homes (mean size 207 residents) to community settings (1–8 residents) and larger homes (ICF/MR settings with 20+ residents) visited more friends and received more visits than did nonmovers.
McConkey (2007)	Ireland, UK	620	CS, QN	People in clustered and dispersed supported living (1–3 people living together) were more likely to have friends and visitors from outside the home than people in small homes (max. 6 places), large homes (avg. 20 residents) or in campus settings (100+ residents on site).
Robertson, Emerson, Gregory et al. (2001)	UK	500	CS, QN, QL	People living in smaller community-based settings (1–8 residents) and intentional communities (28–179 residents on site) had larger social networks than did people living on campus settings (94–144 residents on site).

(Table 2 continued)

**Table 2.** Continued

Study	Country	N	Design <sup>a</sup>	Results
Stancliffe & Keane (2000)	Australia	54	CS, QN	No difference was found in the reported loneliness of people in semi-independent living arrangements (1–4 people living together) and people living in group homes (3–7 residents).
Stancliffe et al. (2007)	USA	1,002	CS, QN	People in larger settings (7–15 residents) reported greatest loneliness. People living alone did not report more loneliness than those in small (2–3 residents) settings.

<sup>a</sup>CS = cross-sectional, L = longitudinal, QN = quantitative, QL = qualitative. <sup>b</sup>The number in parentheses indicates the length of the study in years.

criteria of independent adult life. The opportunity to make choices is also associated with personal development (Heller, Miller, & Factor, 1998, 1999; Heller, Miller, & Hsieh, 2002). In 21 studies researchers examined the choice-making opportunities available to people in different residential arrangements (Table 4). Results show that smaller, more personalized community-based services generally offered more choice and opportunities for self-determination than did larger, congregate facilities (Emerson et al., 2000b; Kearney, Bergan, & McKnight, 1998; Robertson, Emerson, Hatton et al., 2001; Saloviita & Aberg, 2000; Stancliffe & Abery, 1997; Stancliffe, Abery, & Smith, 2000; Stancliffe & Lakin, 1998; Wehmeyer & Bolding, 1999).

Community-based and small size homes, however, did not guarantee better outcomes: staff practices and empowerment were found to be crucial in promoting choice. Self-determination was also associated with structural and procedural aspects of the services, for example, active support and home-like environment (Robertson, Emerson, Hatton et al., 2001). However, the availability of resources (costs, staffing levels), within reasonable limits, was not associated with opportunities for choice-making (Robertson, Emerson, Hatton et al., 2001; Young, 2006). Individual characteristics, particularly adaptive skills and level of disability, were associated with choice (Stancliffe & Abery, 1997). Most people with intellectual disabilities have very limited choice-making opportunities that are restricted to relatively minor, everyday decisions. They had no control over the most important aspects of their lives, such as where and with whom to live (Heller et al., 1999; Robertson, Emerson, Hatton et al., 2001; Stancliffe & Abery, 1997). Young and Ashman (2004a) highlighted that the increase in choice-making after resettlement in the community started to plateau after 2 years.

*Quality of Life*

Quality of life is a composite and multidimensional concept that involves some of the domains that are also discussed separately here. The most frequently referenced quality of life domains are Interpersonal Relations, Social Inclusion, Personal Development, Physical Well-Being, Self-Determination, Material Well-Being, Emotional Well-Being, Rights, Environment (Home/Residence/Living Situation), Family, Rec-

**Table 3.** Family Contact

Study	Country	N	Design <sup>a</sup>	Results
Chou et al. (2008)	Taiwan	248	CS, QN	People in small homes (max. 6 residents) received more family visits than did those in group homes (max. 50 residents) and institutions (50+ residents).
Emerson et al. (2000b)	UK	500	CS, QN	No significant difference was found in the level of family contact in community homes (1–8 residents), intentional communities (28–179 residents on site) and campus settings (94–144 residents on site).
Emerson, Robertson, Gregory, Kessissoglou et al. (2000)	UK	40	CS, QN	No significant difference was found between the level of family visits in community homes (1–8 residents) and in campus settings (94–144 residents on site).
Heller, Factor et al. (1998)	USA	232	L (3) <sup>b</sup> , QN	No difference was found in the frequency and pattern of family contact between people who moved from nursing homes (mean size 207 residents) to community settings (1–8 residents) and larger homes (ICF/MR settings with 20 or more residents) and those who stayed.
McConkey et al. (2005)	Ireland	106	CS, QN	No direct and significant relationship was found between type of accommodation (campus with 55 residents on site and homes with 5 residents) and family contact.
Spreat et al. (1998)	USA	80	L (5), CS, QN	People who relocated from nursing homes (avg. 50 residents) to community-based supported living arrangements (2–3 people living together) had increased contact with their families. People who remained in nursing homes experienced no change.
Stanciff & Lakin (1998)	USA	187	CS, QN	People in community settings (2–15 residents) had more contact with their families than did residents in institutions (16+ residents).
Stanciff & Lakin (2006)	USA	155	L (4), CS, QN	People who moved from institutions (16+ residents) to community settings (2–15 residents) increased family contact that remained stable. People remaining in institutions experienced greater loss of contact over time.

<sup>a</sup>CS = cross-sectional, L = longitudinal, QN = quantitative, QL = qualitative. <sup>b</sup>The number in parentheses indicates the length of the study in years.



**Table 4.** Self-Determination/Choice

Study	Country	N	Design <sup>a</sup>	Results
Chou et al. (2008)	Taiwan	248	CS, QN	People in small homes (max. 6 residents) and community homes (max. 50 residents) had more opportunity to make choices than did those who lived in institutions (50+ residents).
Emerson et al. (2000b)	UK	500	CS, QN	People in community homes (1–8 residents) had greater choice than people in intentional communities (28–179 residents on site) and people in campus settings (94–144 residents on site).
Emerson, Robertson, Gregory, Kessissoglou et al. (2000)	UK	40	CS, QN	People in community housing (1–8 residents) had greater choice than people in campus settings (94–144 residents on site).
Emerson et al. (2001)	UK	281	CS, QN	People in supported living (1–3 people living together) had greater overall choice and more choice over with whom and where they lived than did people in small group homes (1–3 residents) and large group homes (4–6 residents).
Felce (1998); Felce et al. (2000)	UK	34, 34	CS, QN	People with severe challenging behavior in community settings (1–9 residents) had higher autonomy than people in hospitals (10–188 residents).
Heller, Miller et al. (1999)	USA	58	L (3) <sup>b</sup> , QN	People who relocated from nursing homes (91–417 residents) to community-based settings (1–92 residents, mean size=8) increased their autonomy and choice-making opportunities.
Heller et al. (2002)	USA	186	L (8), CS, QN	People who moved to small and more attractive community settings (1–18 residents) had more opportunity for choice-making, than did people who remained in nursing homes (91–417 residents) or larger, less attractive settings (ICF/MR homes with 20+ residents).
Kearney et al. (1998)	USA	122, 67	CS, L (1.25), QN	People who moved to small community-based facilities (6 or fewer residents) from large institutions (99–270 residents) experienced an increase in choice. availability.
Robertson, Emerson, Hatton et al. (2001)	UK	281	CS, QN	People in smaller community-based homes or supported living arrangements (1–3 people living together) and with more home-like architectural design had more opportunities for self-determination than did people living in larger community homes (4–8 residents).

(Table 4 continued)

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**Table 4.** Continued

Study	Country	N	Design <sup>a</sup>	Results
Saloviita & Aberg (2000)	Finland	54	CS, QN	People in group homes (5–12 residents) had more self-determination than did people in institutions (99 residents).
Stancliffe & Abery (1997)	USA	127	L (3), CS, QN	People who moved from an institution (16+ residents on site) to community settings (2–16 residents) had greater choice-making opportunities than did those who stayed in the institutions.
Stancliffe & Keane (2000)	Australia	54	CS, QN	People in semi-independent living arrangements (1–4 people living together) had more choice than people who lived in group homes (3–7 residents).
Stancliffe & Lakin (1998)	USA	187	CS, QN	People in smaller community homes (2–4 and 5–6 residents) had more choice than did residents in institutions (16+ residents) and larger community settings (7–15 residents).
Stancliffe, Abery, & Smith (2000)	USA	74	CS, QN	People in semi-independent living arrangements (up to 3 people living together) had more personal control and self-determination than did those in HCBS Waiver homes (2–6 people in one building) and ICF/MR settings (4–44 residents in one building).
Wehmeyer & Bolding (1999)	USA	273	CS, QN	People who lived in noncongregate (1–3 people living together) and congregate (4–6 residents) community settings had greater opportunities for self-determination than did people in congregate noncommunity settings (12 or more residents).
Young (2000, 2001); Young & Ashman (2004a)	Australia	32, 95, 104	L (1.5; 1.5; 2.5), QN	People had greater choice-making opportunities after relocation from an institution (160 residents) to community settings (2–4 residents).
Young (2006)	Australia	60	L (2.5), QN	People had greater choice-making opportunities after relocation from an institution (160 residents) to community settings (2–4 residents). People who lived in dispersed settings had more choice-making opportunities than did people in clustered group homes (up to 20–25 people on one purpose-built site).
Young & Ashman (2004b)	Australia	104	L (2.5), QN	People in all age groups had greater choice-making opportunities after relocation from an institution (160 residents) to community homes (2–4 residents).

<sup>a</sup>CS = cross-sectional, L = longitudinal, QN = quantitative, QL = qualitative. <sup>b</sup>The number in parentheses indicates the length of the study in years.

**Table 5.** Quality of Life

Study	Country	N	Design <sup>a</sup>	Results
Ager et al (2001)	UK	76	L (1.6) <sup>b</sup> , QN	People experienced better quality of life after moving from a long-stay hospital (95+ residents) to community homes (1–10 residents).
Golding et al. (2005)	UK	12	L (1), CS, QN	People had better quality of life following relocation from a hospital to specialist challenging behavior community settings (6 residents).
Jansen, Vreeke et al. (1999)	Holland	199	CS, QN	People living in dispersed community homes (1–18 residents, mean 9) and in group homes clustered on the site of the institution (1–18 residents, mean 9) had similar quality of life.
Young (2000, 2001)	Australia	32, 95	L (1.5; 1.5), QN	People had better life circumstances after relocation from an institution (160 residents) to community settings (2–4 residents).
Young (2006)	Australia	60	L (2.5), QN	People had better life circumstances after relocation from an institution (160 residents) to dispersed (2–4 residents) and clustered community settings (2–4 residents/setting, up to 20–25 people on one purpose-built site). People in dispersed settings had better quality of life than those in clustered settings.
Young & Ashman (2004a, 2004b)	Australia	104, 104	L (2.5; 2.5), QN	People had better life circumstances after relocation from an institution (160 residents) to community homes (2–4 residents), but there are considerable variations among individuals and settings.

<sup>a</sup>CS = cross-sectional, L = longitudinal, QN = quantitative, QL = qualitative. <sup>b</sup>The number in parentheses indicates the length of the study in years.

recreation and Leisure, and Safety/Security (Verdugo, Schalock, Keith, & Stancliffe, 2005). Quality of life measures to evaluate residential arrangements were used in 8 studies (Table 5).

Relocation to the community was generally associated with better quality of life (Ager et al., 2001; Young, 2000, 2001, 2006; Young & Ashman, 2004a), but there were considerable variations among people and settings in terms of gains associated with individual characteristics, staff practices, and service procedures (Young & Ashman, 2004b).

### *Adaptive Behavior*

Improving the adaptive skills, abilities, and competence of people with intellectual disabilities was one of the most important rationales during the early stages of deinstitutionalization (Emerson & Hatton, 1994). Level of adaptive behavior is an important determinant of quality of life. Researchers in 15 studies used adaptive behavior as an outcome indicator using standardized measures (Table 6).

Some investigators found no evidence of increases in adaptive behavior upon relocation to community housing. Others found improvements in certain areas but not in other domains (Heller, Factor, Hsieh, & Hahn, 1998; Macleod, Morrison, Swanston, & Lindsay, 2002; Young, 2000, 2001). People who remained in institutions or other congregate settings were more likely to experience a decline, whereas movers maintained or improved their abilities. Some evidence also suggests that as a result of resettlement people with more severe and profound disabilities gained more in adaptive skills than did people with mild/moderate intellectual disability (Young & Ashman, 2004b). Some researchers found that gains in adaptive skills were associated with environmental and service factors, including small size, attractiveness and stimulation of the physical environment, opportunities for choice-making (Heller, Miller et al., 1998; Spreat et al., 1998; Stancliffe, Hayden, Larson, & Lakin, 2002), teaching of skills and autonomy (Lerman, Apgar, & Jordan, 2005), and implementation of active support (Young, 2006; Young & Ashman, 2004a).

### *Challenging Behavior*

Emerson and Hatton (1994) noted that challenging behaviors are

culturally unusual or unacceptable behaviors, such as self-injury or aggression, that place the health or safety of the person or others in jeopardy or are likely to lead to the person being excluded or denied access to ordinary community settings. (p. 17)

Challenging behaviors are, therefore, an important determinant of quality of life. In 13 studies researchers looked at individual challenging behavior and in 4 others compared responses to challenging behavior in different residential arrangements (Tables 7 and 8).

Most investigators reported no significant changes in challenging behaviors upon resettlement to different forms of community residences (Heller, Factor et al., 1998; Hundert, Walton-Allen, Vasdev, Cope, & Summers, 2003; Spreat et al., 1998; Stancliffe et al., 2002; Young & Ashman, 2004b); others, however, found a deterioration in certain behaviors, such as disruptive behavior and passivity (Nøttestad & Linaker, 1999, 2002). Others noted that although the level of challenging behavior as measured by standardized instruments remained the same, observation revealed changes in the nature of challenging behaviors and the reduction of certain problem behaviors after relocation (Golding, Emerson, & Thornton, 2005; Young, 2006; Young & Ashman, 2004a).

The ecobehavioral relationship between staff attention and challenging behavior was found to be similar in institutions and in the community: Problem behavior was associated with lack of staff attention, and staff tended to respond more to challenging behavior than to appropriate behavior across all setting-types (Hundert et al., 2003).

Treatment and management of challenging behavior were found to be associated with characteristics of the residence: institution personnel used more restrictive practices (Saloviita, 2002), and workers in community-based services were more likely to use sedation (Emerson et al., 2000a). People in community-based settings received more informal interventions, whereas those in institutions had more formal interventions and access to professional behavioral support (Stancliffe, Hayden, & Lakin, 1999).

### *Psychotropic Medication*

Psychotropic medication is widely used to manage and reduce challenging behaviors, although their efficacy is questionable (Matson et al., 2000). The use of psychotropic drugs is receiving increased attention; researchers in 4

**Table 6.** Adaptive Behavior

Study	Country	N	Design <sup>a</sup>	Results
Golding et al. (2005)	UK	12	L (1) <sup>b</sup> CS, QN	People who relocated from a hospital to specialist challenging behavior community settings (6 residents) gained domestic skills. People already living in community homes (6 residents) also showed improvements in adaptive skills.
Heller, Factor et al. (1998)	USA	232	L (3), QN	People who moved from nursing homes (mean size 207 residents) to community settings (1-8 residents) and larger homes (ICF/MR settings with 20 or more residents) improved adaptive behaviors, whereas nonmovers declined.
Heller, Miller et al. (2002)	USA	186	L (8), CS, QN	People who moved to community settings (1-18 residents) and ICF/MR settings (20 or more residents) maintained their adaptive skills, whereas people who stayed in nursing homes (91-417 residents) declined.
Heller, Miller et al. (1998)	USA	268	L (3), QN	People who relocated from nursing homes (82-485 residents, mean 285) to community-based settings (2-48 residents, mean 8) showed gains in adaptive skills, particularly those who moved to smaller homes.
Kearney et al. (1998)	USA	67	L (1.25), QN	People who moved from a large institution (99-270 residents) to community-based homes (6 or fewer residents) experienced positive changes in adaptive skills.
Lerman et al. (2005)	USA	220 (160)	L (7), QN	People who moved from an institution (1,190 residents) to community-based settings experienced an overall improvement in adaptive skills while stayers maintained or declined their adaptive behaviors.
Macleod et al. (2002)	UK	4	L (3), QN	People who moved from a long-stay hospital to a community home showed an increase in communication behaviors and an improvement in daily living skills as measured by standardized instruments. However, direct observation showed a decrease in adaptive behaviors.
Spreat et al. (1998)	USA	80	L (5), QN	People who relocated from nursing homes (avg. 50 residents) to community-based supported living arrangements (2-3 people living together) showed no changes in adaptive skills, but those who stayed in nursing homes experienced a decline.

(Table 6 continued)

Outcomes in residential settings

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**Table 6.** Continued

Study	Country	N	Design <sup>a</sup>	Results
Stancliffe et al. (2002)	USA	285, 148	L (3), <sup>b</sup> QN	Study 1: People who moved to small homes (1–5 residents) and those who stayed in the institution (16+ residents) had no changes in adaptive behaviors. People who moved to large homes (6–14 residents) showed a decline in adaptive behaviors. Study 2: People who moved to small community settings (1–5 residents) with more favorable staffing ratio experienced greater gains in adaptive behaviors than people who move to large settings (6–14 residents).
Young (2000)	Australia	32	L (1.5), QN	Relocation from an institution (160 residents) to community-based settings (2–4 residents) had no impact on standardized adaptive behavior scores. Direct observation showed an increase in adaptive behaviors.
Young (2001)	Australia	95	L (1.5), QN	People who relocated from an institution (160 residents) to community-based settings (2–4 residents) improved their adaptive skills, particularly in self-care, economic activity, and domestic skills.
Young (2006)	Australia	60	L (2.5), QN	People who moved from an institution (160 residents) to dispersed community settings (2–4 residents) showed greater improvements in adaptive skills than did people who moved to clustered community-based settings (2–4 residents/setting, up to 20–25 people on one purpose-built site).
Young & Ashman (2004a)	Australia	104	L (2.5), QN	People who relocated from an institution (160 residents) to community settings (2–4 residents) showed improvements in certain adaptive skills.
Young & Ashman (2004b)	Australia	104	L (5), QN	People with mild/moderate intellectual disabilities (ID) had few and nonsignificant gains in adaptive skills, people with severe/profound ID from all age groups gained most in terms of adaptive behavior after relocation from an institution (160 residents) to community homes (2–4 residents).

<sup>a</sup>CS = cross-sectional, L = longitudinal, QN = quantitative, QL = qualitative. <sup>b</sup>The number in parentheses indicates the length of the study in years.

**Table 7.** Challenging Behavior

Study	Country	N	Design <sup>a</sup>	Results
Golding et al. (2005)	UK	12	L (1), <sup>b</sup> CS, QN	People who relocated from a hospital to specialist challenging behavior community settings (6 residents) decreased observed challenging behaviors but had no changes in standardized scores. People already living in community settings (6 residents) showed no changes.
Hundert et al. (2003)	Canada	17	L (1.3), QN	People who relocated from an institution (70 residents) to dispersed community-based settings (5 residents) maintained challenging behavior at similar levels.
Macleod et al. (2002)	UK	4	L (3), QN	People who moved from a large hospital to a community home showed an increase in challenging behavior along with improvement in adaptive and communication skills.
Nøttestad & Linaker (1999)	Norway	109	L (8), QN	People who relocated from an institution (128 residents) to community settings showed increased aggression towards others, disruptive behavior, and passivity, but no changes in self-injury and destruction of objects.
Nøttestad & Linaker (2001)	Norway	68	L (8), QN	Development of self-injury after resettlement from an institution (128 residents) to community-based settings was not associated with setting size and type.
Nøttestad & Linaker (2002)	Norway	64	L (8), CS, QN	Development of aggressive behavior after relocation from an institution (128 residents) to community-based settings was not associated with setting size and type.
Spreat et al. (1998)	USA	80	L (5), CS, QN	People who relocated from nursing homes (avg. 50 residents) to community-based supported living arrangements (2–3 people living together) and people who stayed in nursing homes showed no changes in challenging behaviors.
Stanciff et al. (2002)	USA	285, 148	L (3), CS, QN	Study 1: Initial deterioration in challenging behavior after relocation from an institution (16+ residents) to community settings (1–14 residents) was found. On the longer term, no difference from institutional levels of problem behavior occurred. Study 2: Changes in challenging behavior were not related to community setting type (ICF/MR or HCBS Waiver).

(Table 7 continued)

**Table 7.** Continued

Study	Country	N	Design <sup>a</sup>	Results
Young (2000, 2001)	Australia	32, 95	L (1.5; 1.5), QN	People who moved from an institution (160 residents) to community-based settings (2–4 residents) showed no improvement in challenging behavior.
Young (2006)	Australia	60	L (2.5), CS, QN	People who moved from an institution (160 residents) to dispersed community settings (2–4 residents) showed greater reduction in observed problem behaviors than people who moved to clustered community-based settings (2–4 residents/setting, up to 20–25 people on one purpose-built site). Relocation had no impact on standardized challenging behavior scores.
Young & Ashman (2004a)	Australia	104	L (2.5), QN	Relocation from an institution (160 residents) to community-based settings (2–4 residents) had no impact on standardized challenging behavior scores, but changes were observed in the nature of behaviors.
Young & Ashman (2004b)	Australia	104	L (5), CS, QN	People who moved from an institution (160 residents) to community-based settings (2–4 residents) showed no improvement in challenging behavior.

<sup>a</sup>CS = cross-sectional, L = longitudinal, QN = quantitative, QL = qualitative. <sup>b</sup>The number in parentheses indicates the length of the study in years.



studies addressed this issue (Table 9). Some found a decrease in the medication of people with intellectual disabilities moving to community settings (Spreat et al., 1998), others reported nonsignificant changes in the number of people on medication, dosage, and frequency (Nøttestad & Linaker, 2003).

McGillivray and McCabe (2005) showed a significant increase in psychotropic medication use in Australian community settings in the 1990s; the authors reported a similar percentage of people receiving drugs in the community and in institutions in 2000. However, polypharmacy was still more widespread in institutions (McGillivray & McCabe, 2005; Robertson, Emerson, Gregory, Hatton, Kessissoglou, & Hallam, 2000).

### *Health, Risk Factors, and Mortality*

Improving health and reducing lifestyle-related risks have been important in most countries. Not only are they central to the well-being of individuals, but poor health imposes significant costs on health and social services. Despite its relevance, relatively little is known about the health-related outcomes of different residential arrangements. Researchers in 6 studies surveyed health and lifestyle-related risk factors (Table 10).

Most researchers found no evidence of transfer trauma or transition shock nor of an increase in mental health problems among people moving to community settings (Heller, Factor et al., 1998; Nøttestad & Linaker, 1999; Read, 2004); however in some mortality studies (e.g., Strauss, Shavelle, Baumeister, & Anderson, 1998), researchers claimed that the higher rate of mortality shortly after relocation could possibly be attributed to a relocation syndrome.

The prevalence of certain health risk factors, particularly inactivity and obesity among people with intellectual disability, was high. Less restrictive living arrangements decreased the likelihood of inactivity but increased the probability of smoking, poor diet, and obesity. There were significant differences between men and women (Bryan, Allan, & Russell, 2000; Robertson et al., 2000).

A special aspect of community living is the exposure to crime and abuse, which has received limited attention in the literature (see Table 11). Higher perceived exposure to crime and verbal abuse were thought to be associated with supported, semi-independent, or independent living

arrangements (Emerson et al., 2001). People living in intentional communities or other clustered residences were perceived to be at less risk (Emerson, Robertson, Gregory, Kessissoglou et al., 2000).

The issue of mortality in community settings has received considerable attention mainly in the literature in the United States. Ten studies on this issue are included in the review (see Table 12). Some researchers found improvements (Conroy & Adler, 1998); others, no difference (O'Brien & Zaharia, 1998) or higher risk of mortality in the community (Shavelle & Strauss, 1999; Shavelle, Strauss, & Day, 2005; Strauss, Anderson, Shavelle, Sheridan, & Trenkle, 1998; Strauss, Kastner, & Shavelle, 1998; Strauss, Shavelle, Anderson, & Baumeister, 1998; Strauss et al., 1998). Higher risk was hypothesized to be the outcome of inadequate access to health care. Some results suggest that higher mortality was not related to relocation but rather to the presence of specific risk variables in the people selected for moving (Lerman, Apgar, & Jordan, 2003; Read, 2004).

### *User and Family Views and Satisfaction*

An important aspect of service provision is the satisfaction of its users. The utilization of subjective measures in evaluation has been contested (Hatton, 1998; Perry & Felce, 2005; Verdugo et al., 2005), and it is not very widespread. In 6 studies researchers surveyed the views of service users and their families by employing mainly quantitative techniques (Table 13).

Investigators found high satisfaction with community-based arrangements among both service users and their families. Movers were critical about institutions and did not want to return—even if they missed certain things, such as people and some activities (Gregory, Robertson, Kessissoglou, Emerson, & Hatton, 2001). Although a higher number of parents and family members had been critical of deinstitutionalization and the prospect of resettlement initially, the majority were positive once it happened (McConkey, McConaghie, Mezza, & Wilson, 2003; Noonan Walsh et al., 2001; O'Brien, 2001), and satisfaction remained stable over a period of 10 years (Tøssebro & Lundebj, 2006).

A limitation of these results should be kept in mind, however; researchers often used retrospective methods that are likely to distort opinion in

**Table 8.** Treatment of Challenging Behavior

Study	Country	N	Design <sup>a</sup>	Results
Emerson et al. (2000a)	UK	500	CS, QN	Community-based homes (1–8 residents) were more likely to use sedation; campus settings (94–144 residents on site) used more physical restraint.
Feldman et al. (2004)	Canada	625	CS, QN	Institutions (300–700 residents), group homes, and independent/semi-independent living arrangements are not different in terms of formality of interventions to manage challenging behaviors.
Saloviita (2002)	Finland	261	CS, QN	People who lived in institutions (159 residents) were subjected to more restrictive and negative practices to manage challenging behavior than were those in clustered community homes (5 residents/setting, 3 settings clustered together in the community) and group homes (5–10 residents).
Stancilffe, Hayden et al. (1999)	USA	151	L (3) <sup>b</sup> , QN	People who moved to community-based settings (2–15 residents, mean 6.6) had more informal interventions to manage challenging behaviors. Participants who stayed in institutions (16+ residents) were more likely to receive formal interventions and professional behavior support services.

<sup>a</sup>CS = cross-sectional, L = longitudinal, QN = quantitative, QL = qualitative. <sup>b</sup>The number in parentheses indicates the length of the study in years.

favor of current arrangements. Most parents reported high satisfaction with institutions (Larson & Lakin, 1991).

### Discussion

In this review we have presented the outcomes of deinstitutionalization and a comparison of different residential arrangements for people with intellectual disabilities using studies published between 1997 and 2007. In these studies researchers have predominantly reported on mature service models from countries where deinstitutionalization has been unfolding for decades and has made considerable progress. Five main conclusions emerge from this literature: (a) the overall picture is comparable to previous reviews, namely, small-scale arrangements are superior to large, congregate options in most domains; (b) there is considerable variability in individual outcomes based on individual and service characteristics; (c) there are three areas where community-based services do not provide better outcomes; (d) experiences are similar in different countries; and (e) despite significant improvements, people with intellectual disabilities are still one of the most disadvantaged groups of society. Finally, some implications for future research are highlighted.

*Similar outcomes to earlier studies.* In the evaluation literature, researchers have largely focused on objective components of quality of life measurements (Verdugo et al., 2005) using standardized instruments. Community participation, choice, and adaptive and challenging behaviors are the most often used outcome measures, but new issues have also received attention, such as psychotropic drug use, risks, and lifestyle-related risk factors.

Results have confirmed the picture that had emerged from previous research: People in small-scale community-based residences or in semi-independent or supported living arrangements have a better objective quality of life than do people in large, congregate settings. Particularly, they have more choice-making opportunities; larger social networks and more friends; access more mainstream facilities, and participate more in community life; have more chances to acquire new skills and develop or maintain existing skills; and are more satisfied with their living arrangements. In a recent unpublished review, Noonan Walsh et al. (2007) found similar results.

**Table 9.** Psychotropic Medication

Study	Country	N	Design <sup>a</sup>	Results
Spreat Conroy et al. (1998)	USA	80	L (5) <sup>b</sup> , CS, QN	People received less medication after relocation from nursing homes (avg. 50 residents) to supported living arrangements (2–3 people living together) than those who stayed in nursing homes.
Nøttestad & Linaker (2003)	Norway	109	L (8), QN	Number of people receiving medication before and after relocation from an institution (128 residents) to community settings declined nonsignificantly.
McGillvray & McCabe (2005)	Australia	762, 873	L (8), CS, QN	No difference between proportion of people in community settings and institutions who received medication to manage challenging behaviors. Initial differences in level of drug use between institutions and community settings were reduced.
Robertson, Emerson, Gregory, Hutton, Kessissoglou, & Hallam (2000)	UK	500	CS, QN	People who lived in campus settings (94–144 residents on site) were more likely to receive psychotropic medication and more than one type of psychotropic medication than were people in intentional communities (28–179 residents on site) and community settings (1–8 residents).

<sup>a</sup>CS = cross-sectional, L = longitudinal, QN = quantitative, QL = qualitative. <sup>b</sup>The number in parentheses indicates the length of the study in years.

**Table 10.** Health and Risk Factors

Study	Country	N	Design <sup>a</sup>	Results
Bryan et al. (2000)	UK	118	L (1) <sup>b</sup> , QN	People resettling from a long-stay hospital into small community homes increased the likelihood of experiencing unintentional weight changes.
Heller, Miller et al. (2002)	USA	186	L (8), CS, QN	Moving to community settings (1–18 residents) and ICF/MR settings (20+) from nursing homes (91–417 residents) was not associated with changes in health status.
Heller, Factor et al. (1998)	USA	232	L (3), QN	People who moved from nursing homes (mean size 207 residents) to community settings (1–8 residents) and larger homes (ICF/MR settings with 20+ residents) benefited from improved physical health and mobility. Stayers had no similar gains.
Heller, Miller et al. (1998)	USA	268	L (3), CS, QN	People who relocated from nursing homes (size range 82–485 residents, mean 285) to community settings (2–48 residents, mean 8) had better health than did nonmovers.
Nøttestad & Linaker (1999)	Norway	109	L (8), QN	People who moved from an institution (128 residents) to community settings had high prevalence of psychiatric health problems before and after relocation; no changes were associated with the move.
Robertson, Emerson et al. (2000)	UK	500	CS, QN	People who lived in campus settings (94–144 residents on site) were more likely to be inactive. People in less restrictive community settings (1–8 residents) were more likely to be obese, smoke, and have a poor diet and less likely to access regular health checks.

<sup>a</sup>CS = cross-sectional, L = longitudinal, QN = quantitative, QL = qualitative. <sup>b</sup>The number in parentheses indicates the length of the study in years.

**Table 11.** Risks in the Community

Study	Country	N	Design <sup>a</sup>	Results
Emerson et al. (2000b)	UK	500	CS, QN	People in intentional communities (28–179 residents on site) were relatively less exposed to crime and (verbal) abuse than were people in community (1–8 residents) or campus settings (94–144 residents on site). Community settings were safer in terms of accidents.
Emerson et al. (2001)	UK	281	CS, QN	People in supported living (1–3 residents) arrangements were perceived to be at higher risk of abuse than were people in small group homes (1–3 residents) or larger group homes (4–6 residents).
Standliffe & Keane (2000)	Australia	54	CS, QN	No difference in the perceived safety of people in semi-independent living arrangements (1–4 people living together) and people living in group homes (3–7 residents).

<sup>a</sup>CS = cross-sectional, L = longitudinal, QN = quantitative, QL = qualitative.

*Variability of outcomes.* Although people generally have a better life in the community, research continues to highlight disparities within the same type of living arrangement. These are particularly salient in the domains of Community Participation, Social Networks, and Self-Determination. There are two main patterns of variability: variations in the outcomes associated with the characteristics of service users, and those associated with the characteristics of the services.

Positive outcomes are generally associated with better adaptive skills and abilities, and people with high or complex support needs, including challenging behaviors, are at greater risk of experiencing poorer outcomes in community services. The provision of ordinary environments is not enough to achieve quality and positive outcomes in community services (Mansell, Felce, Jenkins, de Kock, & Toogood, 1987). Felce (1998) argued that three factors are necessary to create real opportunities for people with more severe disabilities in community settings: available activity, available personal support, and effective assistance. Mansell et al. (2003) found that, among a range of organizational and staff variables, adaptive behavior and care practices were the only factors predictive of engagement in meaningful activities in community settings.

The variability of outcomes in community services might threaten the consensus supporting deinstitutionalization and community living policies by removing the evidence that community services are better for everyone (Mansell, 2006). Recent debates on the worth of clustered arrangements seem to be evidence of this (Bigby, 2004; Cummins & Lau, 2004; Emerson, 2004a).

Countries that implemented deinstitutionalization now face the challenge of strengthening the implementation of community living. This requires more than the adoption of certain residential arrangements (Bigby, 2004). Evaluation research in these countries can be used to identify factors associated with positive outcomes and good practices in community living.

*Three domains where community services do not perform better.* Results also show that there are three outcome domains where community services might not do better than institutions: Challenging Behavior, Psychotropic Medication, and Mortality. Challenging behavior has long been shown not to be directly linked to community living (Emerson & Hatton, 1994; Kim, 2001). Many challenging behaviors are a response to

**Table 12.** Mortality

Study	Country	N	Design <sup>a</sup>	Results
Conroy & Adler (1998)	USA	1,154	L (8) <sup>b</sup> , QN	Decreased mortality was associated with the resettlement of the residents (1,154) of an institution (1,154 residents) in community settings.
Lerman et al. (2003)	USA	300	L (7), QN	Resettlement from institutions to community settings was not associated with increased risk of mortality.
O'Brien & Zaharia (1998)	USA	6,810	L (5), CS, QN	Resettlement from institutions to community settings was not associated with increased risk of mortality. Mortality rates in community facilities were declining.
Read (2004)	UK	111	L (1.5), QN	Higher mortality after relocation from hospital to community settings was not associated with service factors.
Shavelle & Strauss (1999)	USA	1,812	L (1), CS, QN	Update of the 1998 study by Strauss, Shavelle et al. Again found greater risk of mortality for those moving to community settings from an institution than those staying.
Shavelle, Strauss & Day (2005)	USA	1,776	L (3), CS, QN	Greater risk of mortality was found in community settings than in institutions.
Strauss, Anderson et al. (1998)	USA	48	CS, QN	Similar causes of death among institutional and community residents.
Strauss, Kastner et al. (1998)	USA	22,576	L (10), CS, QN	Risk-factor adjusted mortality was found to be higher in community settings than in institutions.
Strauss, Shavelle, Baumeister & Anderson (1998)	USA	1,878	L (3), CS, QN	Greater risk of mortality was associated with resettlement from institutions in community settings. The risk was higher shortly after the move.
Strauss, Shavelle, Anderson & Baumeister (1998)	USA	520	L (14), CS, QN	Certain external causes of death are more common in community settings than in institutions and vice versa.

<sup>a</sup>CS = cross-sectional, L = longitudinal, QN = quantitative, QL = qualitative. <sup>b</sup>The number in parentheses indicates the length of the study in years.

**Table 13.** User and Family Satisfaction

Study	Country	N	Design <sup>a</sup>	Results
Gregory et al. (2001)	UK	96	CS, QL	Service users expressed high overall satisfaction in community homes (1–8 residents), intentional communities (28–179 residents on site), and campus settings (94–144 residents on site). Residents of intentional communities were more satisfied with certain aspects of their lives.
Heller, Factor et al. (1998)	USA	232	L (3) <sup>b</sup> , QN	People who moved from nursing homes (mean size 207 residents) to community settings (1–8 residents) and larger homes (ICF/MR settings with 20+ residents) were more satisfied with their living arrangement and lifestyle than were nonmovers.
McConkey et al (2003)	UK	39, 34	L (5), QL, QN	Service users and their families were more satisfied with community settings (2–36 residents) than with hospitals.
O'Brien (2001)	New Zealand	46 staff, 22 parents, 9 service users	L (9), QL	Service users, families, and staff viewed relocation from an institution (61 residents) to community settings (5 residents) as clearly positive.
Tøssebro & Lundeby (2006)	Norway	222, 176	L (12), QN	Families expressed more satisfaction with community care than with institutions. Positive opinion remained stable longitudinally.
Walsh, Linehan et al. (2001)	UK, Ireland	291	CS, QN	Families were more satisfied with current living arrangements, community homes (1–8 residents), intentional communities (28–179 residents on site), and campus settings (94–144 residents on site) than with previous living arrangements, including hospital provision.

<sup>a</sup>CS = cross-sectional, L = longitudinal, QN = quantitative, QL = qualitative. <sup>b</sup>The number in parentheses indicates the length of the study in years.

demands in the environment. Although institutions often are a low-demand environment, community services provide more stimulation and demands. Certain challenging behaviors are a predictable response to these environments. There is a wealth of research on interventions for challenging behavior, but now priority should be given to put this into practice in services (Emerson, 2001).

Psychotropic medication is closely related to challenging behaviors. The most common reason for the use of such drugs for people with intellectual disabilities is the management of challenging behaviors, even though effectiveness is questionable (Matson et al., 2000). Investigators have suggested that community service providers are not well equipped to deal with individuals who have challenging behaviors that then leads to the overuse of medication. Research has also shown that medication can be substantially reduced if adequate clinical and environmental conditions are put in place in services (Ahmed et al., 2000).

Mortality is generally considered to be an objective, quantifiable, and comparable measure of health status. Institutions had very high mortality rates (see, e.g., Rothman & Rothman, 2005). In the late 1990s, an extensive debate developed in the United States as to whether community placement was associated with higher mortality. Evidence is inconclusive because a large number of studies were focused on one geographical area (California) and on the same period (1993–1999). This issue has received less attention elsewhere, and in those studies that were conducted, researchers found different results. Sutherland et al. suggested that increased mortality might be confounded by participant characteristics and is not, therefore, necessarily the outcome of the residential setting (Sutherland, Couch, & Iacono, 2002).

*Similar experiences across countries.* Similar results were reported from countries with different welfare arrangements, socioeconomic context, and service structures, suggesting that the model of community living for adults with intellectual disabilities is not bound to certain countries and can successfully be implemented in different situations. The fact that studies come from only a handful of countries, however, suggests that there is a gap in our understanding of residential supports for people with intellectual disabilities in other geographical areas and sociocultural, political, and economic contexts.

Many countries still rely on large institutions in the provision of services for people with disabilities (Freyhoff et al., 2004; Mansell et al., 2007). There is resistance towards deinstitutionalization and community living; policies and practices change slowly (Freyhoff et al., 2004; Vann & Šiška, 2006). The recent ratification of the United Nations Convention on the Rights of Persons With Disabilities by many of these countries (for details see <http://www.un.org/disabilities/default.asp?id=257>), however, might bring about a new wave of deinstitutionalization. The Convention declares the right of people with disabilities to live in the community.

For countries that consider implementing deinstitutionalization and community-living policies, published research provides a strong foundation for small-scale community-based arrangements. However, there is a need for more research on the living conditions, including the outcomes of different residential supports in other parts of the world.

*The importance of normative evaluations.* Better outcomes found in community services in comparison to congregate settings are not necessarily “good enough.” The evidence suggests that many people with intellectual disabilities have poorer life experiences compared with individuals in the general population. They have limited community experience, social networks, and choice-making opportunities. This should encourage researchers to make comparisons with the general population, including gender differences, and uncover the disadvantages and discrimination people with intellectual disabilities face in our societies.

The process of deinstitutionalization is far from complete; institutions still exist in many countries, and community-based alternatives face serious challenges of implementation in the context of societal and economic changes (Bigby, 2004; Emerson, 2004a; Fujiura & Parish, 2007; Mansell, 2006). Continued evidence of the relative merits of small, local services is likely to continue to be important. However, In this review we also identify how research is moving beyond simple structural characteristics of services and is turning to exploration of variations in outcomes, understanding the organizational determinants of quality services. As large institutions disappear, the policy problem will become one of sustaining good outcomes for everyone in the community, which will require understanding of the relative contribution of different factors in different



circumstances. A further trend is the shift from comparison with the past to comparison with the life experience of individuals in the general population, including the impact of recent trends in our societies upon the lives of people with intellectual disabilities. Increasingly, researchers need to focus on issues and use methods that apply to the whole population, including people with intellectual disabilities.

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