

RESIDENTIAL SUPPORTS FOR PERSONS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

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This article reviews the current and changing status of residential supports for persons with intellectual and developmental disabilities (ID/DD). It examines four major trends in those supports: (1) Decreasing use of larger institutions and increasing use of community housing; (2) Decreasing size among community settings; (3) Increasing numbers of people living in homes that they themselves own or rent; and (4) Decreasing out-of-home placements of children and youth. Within each trend the article provides a statistical description of the trend, its foundation in public policy, reviews the evidence of the trend's benefit to people with ID/DD, and identifies future challenges in sustaining the trend.

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MRDD Research Reviews 2007;13:151–159.

Key Words: intellectual disability; developmental disability; community living; residential; supported living

RESIDENTIAL SUPPORTS FOR PERSONS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Residential services and supports for persons with intellectual and developmental disabilities (ID/DD) have been changing along political, philosophical, and physical dimensions in recent decades. “Residential supports” refers to those services and supports provided to people with ID/DD who do not live at home with family. This distinguishes residential supports from family supports, the topic of another article in this issue [Turnbull et al., 2007]. This article is organized around four dimensions of the changing pattern of residential supports: (1) Decreasing use of larger institutions and increasing use of community housing; (2) Decreasing size of community settings; (3) Increasing numbers of people living in homes that they themselves own or rent; and (4) Decreasing out-of-home residential placements of children and youth. Each of these dimensions is documented, its policy foundation is described, the body of evidence regarding the benefits of the trend to people with ID/DD is reviewed, and the future challenges in sustaining the trend are examined.

FROM INSTITUTIONAL TO COMMUNITY SERVICES

Trend

Since 1967, and especially since 1977, a major shift has taken place in the use of institutional settings (defined here as places with 16 or more residents) to provide residential supports to persons with ID/DD. In June 1977, an estimated

207,356 (83.7%) of the 247,780 persons with ID/DD receiving residential services lived in public and private institutional settings with 16 or more residents. Twenty-eight years later, in June 2005, just 67,066 (16.3%) of the estimated 411,215 persons receiving residential services lived in institutional settings. During this same period, the number of residents in “community” settings with 15 or fewer residents increased from 40,424 to 344,152 persons and the number of persons with ID/DD living in nursing facilities decreased by 12,755 persons [Prouty et al., 2006].

Figure 1 shows the decreasing use of institutional services during the past three decades, specifically in June of 1977, 1987, 1995, and 2005. It shows the decreasing number of people with ID/DD in three types of institutional settings: (1) public institutions for persons with ID/DD; (2) private institutions for persons with ID/DD; and (3) nursing facilities. As a point of contrast it also shows the rapidly growing number of people with ID/DD receiving residential services in community settings of 15 or fewer persons in those same years.

Policy Foundation

The Center for Disease Control and Prevention's (CDC) Healthy People 2010 noted the importance of these changes for persons with ID/DD:

Institutionalization and other forms of congregate care are inconsistent with positive public health policy and practice. They diminish people's opportunities to realize essential features of human well-being: choice, control, ability to establish and pursue personal goals, family and community interaction, privacy, freedom of association and the respect of others (National Center on Birth Defects and Developmental Disabilities (NCBDDD), 2003, p. 181).

The federal government has supported these trends although not unambiguously until the passage of the Americans with Disabilities Act (ADA) [1990]. In *Olmstead et al. vs. L.C. et al.* [1999 (527 U.S. 581)], the US Supreme Court affirmed that the ADA requires states to provide services for people with disabilities in the “most integrated setting appro-

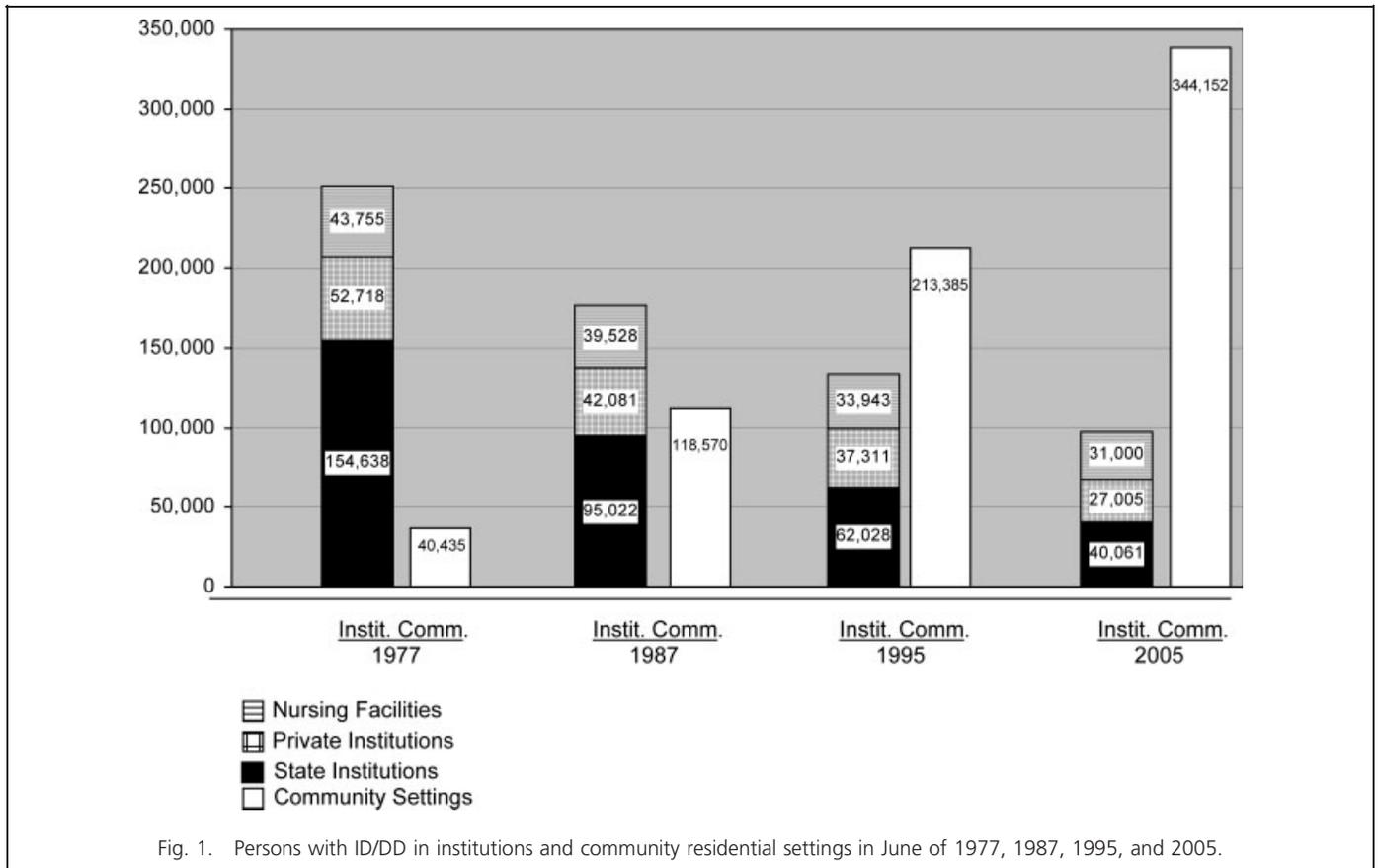
Grant sponsor: Administration on Developmental Disabilities; Grant number: 90DN0200/01.

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Received 3 January 2007; Accepted 5 January 2007

Published online in Wiley InterScience (www.interscience.wiley.com).

DOI: 10.1002/mrdd.20148



priate,” and that states are obligated to place people with disabilities in community settings when treatment professionals determine such settings are appropriate; the individuals themselves do not oppose such placement; and the state can reasonably accommodate community placement, given its available resources. On June 18, 2001, President George W. Bush signed an Executive Order acknowledging the Olmstead decision that “unjustified isolation or segregation . . . is a form of disability-based discrimination prohibited by Title II of the ADA” . . . and stated that the nation “is committed to community-based alternatives for individuals with disabilities.” Of course, states design and operate their own residential services programs; the federal government simply reimburses through Medicaid 50–76% of the costs of programs that meet minimum federal standards.

Evidence of Benefit

There has been extensive research comparing lifestyles of persons living in community and institutional settings. The research establishes clearly and consistently that individuals with ID/DD experience greater personal freedom, more participa-

tion in social activities, more frequent associations with family and friends when living in the community rather than institutional settings [Horner et al., 1988; Stancliffe and Lakin, 1998; Stancliffe and Lakin, 2005]. Perhaps such outcomes seem self-evident products of community inclusion as opposed to segregation. Other important outcomes are less so.

Functional skill improvement

One important outcome of residential supports is development of functional skills that increase individual independence. Since 1980, there have been more than 3-dozen studies comparing changes over time in functional skills associated with people’s movement from institutions to community settings. Kim et al. [2001] reviewed all US studies conducted between 1980 and 1999 that met a common set of research quality and design standards. This review analyzed 33-longitudinal studies of both experimental/contrast group and pre-and post-test designs that followed approximately 2,500 individuals with ID/DD for periods ranging from 6 months to 7 years of postinstitutional living. These studies document substantial and consistent longitudinal increases in functional skill levels (“adaptive behav-

ior”) for persons moving from institutions to community settings. Specifically, of 27 longitudinal studies of general adaptive behavior, 18 found statistically significant benefit to leaving institutions for community settings, and 7 found adaptive behavior improvements greater in people moving to the community but the difference did not reach statistical significance. Two studies, one reaching statistical significance, showed better outcomes for those remaining in institutions. In studies of specific skill areas, community samples demonstrated positive change in “social skills” in 13 of 13 studies; “self-care and domestic skills,” in 13 of 14 studies; and in “community living skills” in 10 of 10 studies.

Parent attitudes

Larson and Lakin [1991] analyzed 27 studies and found that prior parental satisfaction with institutional care and reservations about community living in time turn into positive attitudes about community services (more than 80% satisfaction in 9 of 10 studies). Tossebro and Lundeby [2006] reported a similar long-term change toward families preferring community services following deinstitutionalization.

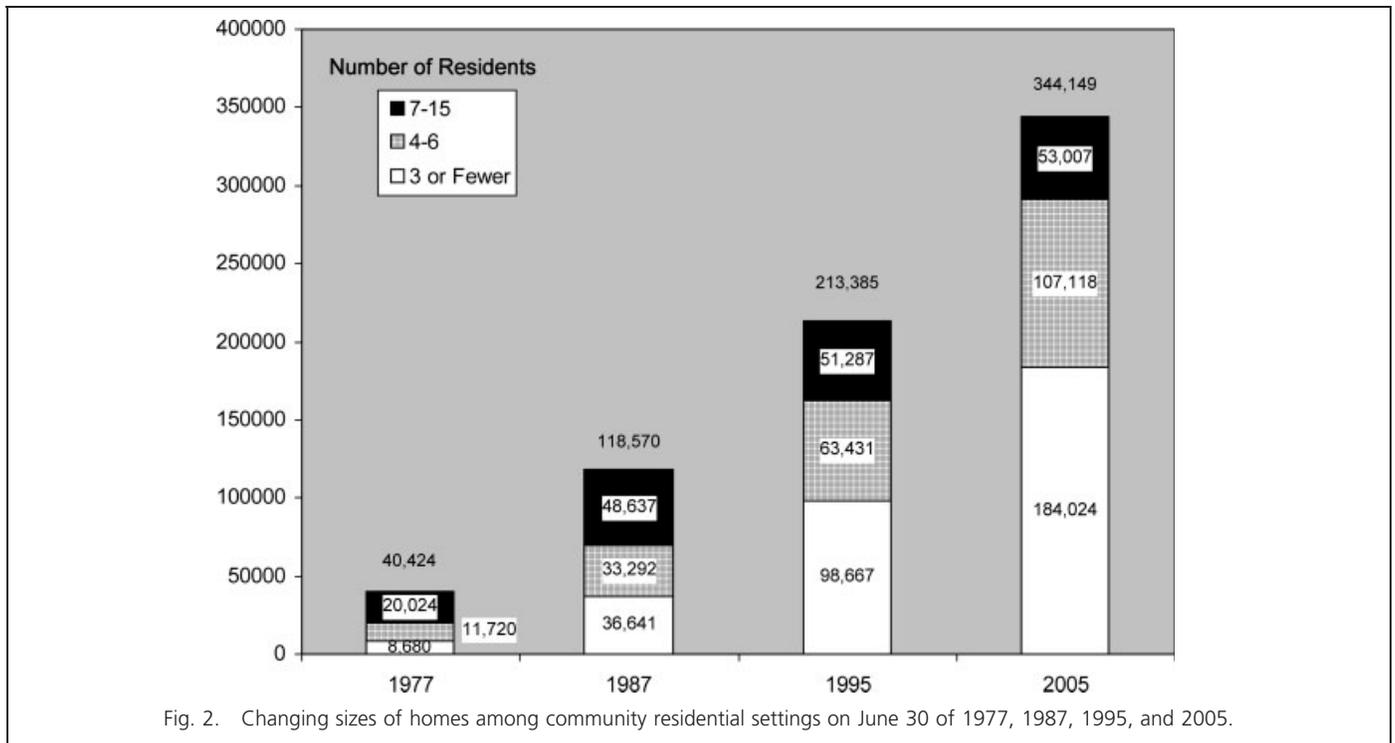


Fig. 2. Changing sizes of homes among community residential settings on June 30 of 1977, 1987, 1995, and 2005.

Cost effectiveness

With substantial, growing and often unmet demand for supports, the cost-effectiveness of residential services is highly relevant. Although institutional populations are decreasing, institutions' "fixed costs" remain [Stancliffe et al., 2005]. As state institution populations decreased from 154,638 to 40,061 between 1977 and 2005, the cost per person of operating institutions increased from \$52,077 per year (constant 2005 dollars) to \$148,810 per year [Prouty et al., 2006]. As a result, decreasing state institution populations by 74% only yielded real dollar savings of 24%.

Challenges in Sustaining the Trend

The major challenge in sustaining the movement from institutional to community settings is major state differences in commitment to doing so. In 2005, more than 60% of all state institution residents lived in the one-third of all states (17) that have been slowest in depopulating state institutions. In 1990, those same 17 states had housed only 42% of all state institution residents [Prouty et al., 2006]. Because these slower moving states now house 60% of state institution residents, the average annual national decrease in state institution populations between 2001 and 2005 was the lowest since deinstitutionalization began in 1967 [Prouty et al., 2006].

DECREASING SIZE OF COMMUNITY SETTINGS

Trend

Recent decades have produced not only rapid growth in the overall number of people with ID/DD receiving residential supports in the community, but also an equally notable trend toward supports being provided in smaller residential settings. Figure 2 shows these trends between 1977 and 2005 [Prouty et al., 2006]. In 1977 almost half (49.5%) of the 40,424 persons receiving community residential supports in community settings of 15 or fewer residents lived in group homes of 7–15 residents. By 2005, the total number of people receiving community residential supports was 8.5 times greater than in 1977, reaching an estimated 344,149 people, but only 15.4% received community residential supports in places of 7–15 residents. In contrast, the number of people with ID/DD living in settings with three or fewer persons increased by 21 times from an estimated 8,680 people in June 1977 (21.5% of the total) to 184,024 people (53.5% of the total) in June 2005.

Policy Foundation

The ADA [1990] and the subsequent Olmstead decision recognized the interests of persons with disabilities in

avoiding segregation and their rights to accommodations to do so. Residential experiences in typical communities have been viewed as an important aspect of securing such benefits. Most of the early research on outcomes compared institutional and community settings, which involve differences in both residence size and type, thus providing little insight into the effect of size per se. This focus derived primarily from the policy issues arising in an era of deinstitutionalization, which persist in some states. However, the significance of institutions continues to decrease and with more than 80% of recipients living in community settings, research attention has shifted to the effects of size within the range of community settings.

Evidence of Benefit

Because size ranges in community residential settings are relatively restricted by the operational definition of community settings as not having more than 15 residents and also because 85% of persons living in community residential settings live in places of six or fewer, the power to discriminate differences is often limited. Still, a number of studies have indicated that smaller sizes within the range of community settings are associated with more desirable outcomes. Lakin et al. [2006] analyzed five states' data on (a) personal choice in

daily activities and choices related to homes, housemates and service providers; (b) nature and severity of disability, and (c) size of residence (1–2, 3–4, 5–6, 7–8, and 9+ persons living away from family and persons living with family members). Controlling for level of intellectual disability, “personal choice” in daily activities was associated with smaller sizes of residence as was “support related choice” regarding where they live, support agencies and individual direct support providers. In related analyses, residents of 1–2 person homes had more personal choices than residents in larger homes. Controlling for level of ID, size of residence had less notable, but still significant association with support-related choice. Stancliffe and Lakin [2005] found those living in settings of 1 or 2 people to have substantially more freedom from staff control than people living in larger community settings. Other researchers have reported similarly better outcomes for choice and self-determination among individuals living in smaller scale settings [e.g., Tøssebro, 1995; Stancliffe, 1997, 2005; Howe et al., 1998; Perry et al., 2000; Stancliffe and Keane, 2000 Stancliffe et al., 2000].

Stancliffe et al. [2006] analyzed self-reported satisfaction and well-being outcomes in six states and found residents of larger settings, especially >6 residents, more likely to report loneliness and less likely to say they liked where they lived. Of particular interest in this study were the higher ratings of well-being reported by the adults living with family members when compared with adults being supported outside the family home. Adults with ID/DD at home were less likely than others to report loneliness, feeling fear in the home, feeling sad, and more likely to report liking where they were living.

Findings of no association between residential setting size and desirable community living outcomes appear particularly likely to occur in studies, in which the range of setting sizes is relatively narrow and/or the sample size is relatively small [e.g., Stancliffe and Lakin, 1998; Felce et al., 2002]. Overall, the weight of evidence suggests various benefits of living like other citizens, in very small community settings. But findings of no size-related outcome differences have also been reported. A complicating factor in interpreting such research is that differences in residence size may also be associated with differences in service type (group home, semi-independent, supported living), staffing arrangements and

other factors, but few studies, generally because of small sample size, have been able to isolate the influence of such factors [Tøssebro, 1995].

Challenges in Sustaining the Trend

The continuation of movement of people to smaller community settings is challenged in many of the same ways as continuing the process of deinstitutionalization, with the two most prominent challenges being interstate variability and the demands placed on the direct support workforce [reviewed in Hewitt and Larson, in this issue].

Interstate variability

As shown in Figure 2, nationally in 2005 over one half (53.5%) of residential service recipients in the US lived in settings of three or fewer persons with ID/DD, however, states differed substantially on this statistic. In June 2005, in seven states more than 70% of more of residential service recipients with ID/DD lived in places with three or fewer residents while in 13 states fewer than 35% did.

FROM AGENCY HOUSING TO HOMES OF ONE’S OWN

Trend

Increasingly, national expectations regarding access to community living assume more than community housing. These expectations are often expressed in the concept of “supported community living” [Bradley et al., 1994; Lakin and Smull, 1995]. Supported living goals include that:

- People will have “real homes” in places where they “control their own front doors,” and choose their homes and the people with whom they live.
- Choice of settings for everyday living will not subsume choosing services and supports for those settings; i.e., people will not be compelled to choose certain living sites because assistance they need is located only in those sites.
- People will be helped to define the lifestyles they want and supported in achieving them, and where their experiences have been limited, people are helped to develop and express lifestyle preferences.

The reflection of such principles is found in statistics on the number of people living in homes that they (often

with financial help from their families) rent or own for themselves and into which residential supports are brought as needed. Figure 3 summarizes these trends.

As shown in Figure 3, in the decade between June 1995 and June 2005 the number of people with ID/DD receiving residential support outside of homes they shared with family members in homes that were owned or rented in their names (“own homes”) increased substantially. In June 1995 there were 40,881 persons with ID/DD receiving residential supports in their own homes (13.0% of all service recipients). By June 2000 the number of people with ID/DD receiving residential supports in their own homes had increased to a reported 73,147 persons (19.5% of all residential service recipients). In June 2005 states reported 101,143 persons with ID/DD receiving residential supports in their own homes (24.6% of all reported residential service recipients).

Policy Foundation

The principles of supported community living are intended to produce a fundamental shift in thinking about not just the places in which people live, but to shift power toward people with disabilities in decisions about how they live, work, and participate in their communities. Living in one’s own home changes the dynamics of service-delivery, because the home is not dependent on a continuing relationship with a service provider. It establishes an easily understood status, in which the person controls who enters their home. Specific living arrangements and the amount and arrangements of paid and natural supports are designed differently for each individual, based on decisions among competing priorities as with other citizens (e.g., the cost of housing against other spending options). A key feature in supported living is fostering and developing of natural supports [Bradley et al., 1994; Howe et al., 1998]. The growing understanding of the importance of natural supports and/or benefactors has led to efforts to structure “circles of support” made up of people committed to assisting the person in achieving personal life goals [Ducharme et al., 1994; Bradley et al., 2001]. Recently, efforts to limit formal, paid support providers, and to enhance opportunities for and commitment of “natural supports” has led to provisions within HCBS programs to allow payment to family members. Such pay-

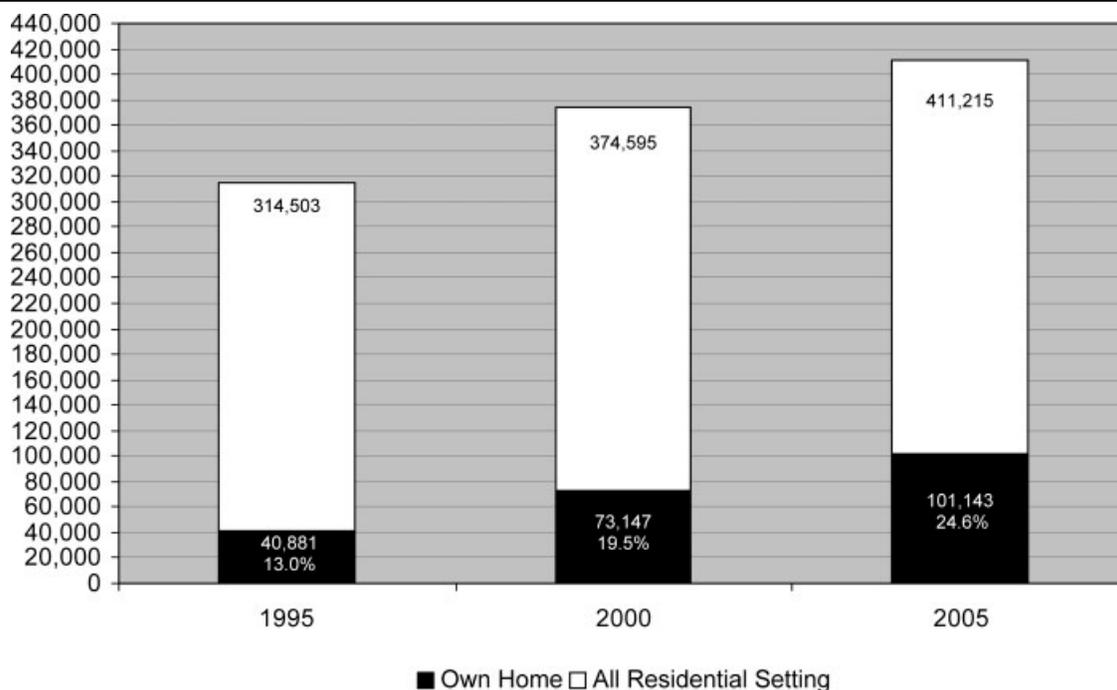


Fig. 3. Persons with ID/DD receiving residential support while living in their own homes (excluding nursing facilities).

ments often permit family members to provide the time needed to assure high quality support from people who know the individual best.

Evidence of Benefit

Contemporary research comparing different types of community living arrangements shows that smaller, more normalized community living arrangements, such as (semi-)independent living and supported living are associated with better outcomes.

Semi-independent and independent living

Comparisons of individuals living in group homes (full-time staffing) or in smaller semi-independent households (drop-in staff support) reveal better outcomes for semi-independent settings on: choice, self-determination, autonomy, satisfaction, independence, lifestyle normalization, physical and social integration, domestic participation, community participation, and personal well being [Burchard et al., 1991; Stancliffe and Wehmeyer, 1995; Stancliffe, 1997, 2005; Wehmeyer and Bolding, 1999; Stancliffe and Keane, 2000; Stancliffe et al., 2000]. Loneliness, self-care, domestic management, personal safety, money management, and health are potential areas of concern for semi-independent residents, but Stancliffe [2005] and Stancliffe and Keane [2000] reported that these outcomes did not differ from those experi-

enced by group-home residents, even though the former received much less staff support.

Supported living

Supported living participants generally own or rent their own home (controlling one's own home is a central aspect of supported living). Supported living participants have been reported to experience a greater variety and frequency of community and social activities, more participation in preferred activities, better compatibility with living companions, and greater self-determination than participants in 'traditional' community services [Howe et al., 1998]. Individuals receiving support in their own homes exercise greater control over choice of living companions than residents of more traditional community settings [Howe et al., 1998; Emerson et al., 2001].

Choosing where and with whom to live is a defining feature of supported community living [see Howe et al., 1998]. Gardner and Carran [2005] found a consistent and significant positive relation between the outcome "People chose where and with whom to live" and a number of other important outcomes, such as safety, and freedom from abuse and neglect.

Head and Conroy [2005] found substantial increases in control by service users and/or their families over

services, supports, and where and with whom to live following implementation of consumer-directed services in Michigan, although it was not clear to what extent this was achieved through living in one's own home. Even so, these findings do illustrate that considerable increases in control are possible with reform of traditional funding and service provision arrangements. However, it is important to note that such control does not pass "automatically" to consumers when reform is implemented. For example, Howe et al. [1998] found that supported community living residents did not determine the supports they received to any greater extent than residents of traditional services.

It has not been established empirically, which features of supported community living are functionally linked to better client outcomes. Stancliffe [2005] found better outcomes for people living semi-independently than for group-home residents, and argued that because of frequent staff absence, people with intermittent support in their own homes not only had opportunities for independent participation, their circumstances demanded participation.

How broadly applicable are the results just discussed to individuals with differing support needs? Almost all of the studies cited earlier involved people with lower support needs, but individuals with severe disability likely do poorly

given little support. Where independent living had the best outcomes for those with mild/moderate ID, those with severe/profound disability achieved the poorest outcomes when living independently, and did better in supported living arrangements with more support [Gardner and Carran, 2005]. Jones et al. [2001] found that increased staff support for participation resulted in greater resident participation in activities. However, the benefits were greater for individuals with more severe disability. So, while regularly undertaking activities independent of staff support is associated with skill development and achievement of personal outcomes for people with lower support needs, it is not for persons with severe disability, who instead require active support from caregivers for successful participation in meaningful activities.

Challenges in Sustaining the Trend

The higher level of support needed by people with more severe disabilities provides a greater challenge in assisting them to live in personal housing. The per-person cost of providing paid supports is one important such challenge. Felce and Emerson [2005] reviewed the evidence related to economies/diseconomies of scale in residential services research in the United Kingdom. They concluded that no economies of scale could be established in the existing research, except in very small residential settings, in which the decreased number of people in the home necessitated an increased staffing ratio. The critical point is reached at which there is a need for one staff member at all times, so that if the number of people in the home further decreased, the ratio of staff to residents necessarily increases. Unless nonpaid or differently paid supports are introduced, the per-person cost of support increases. "Such diseconomies of very small scale apply only in residential services when the service model or the residents' support needs require continuous paid staff presence" [Lakin and Stancliffe, 2005, p. 324]. This is most often the case for persons with severe disabilities.

Environmental accommodations are designed to change environmental demands and expectations so that an individual can fulfill a typical social role. Accommodations may permit an individual to live in their own home without full-time care and supervision, and in the process reduce levels of support and cost, while yielding the benefits described earlier. Accommodations may include physi-

cal modifications (e.g., ramps, redesigned kitchens and bathrooms), technologies (e.g., alerting systems, one-touch dial phones), modified supports (e.g., phone calls, training in independent living skills rather than personal care, coresidency with a person without disability), or carefully selecting environments (e.g., choosing housing located near shops, family, and/or work to decrease travel demands for a person without independent public transportation skills). Expansion and improvement of quality and accessibility accommodations is central to the growing efforts to assist people to live in homes of their own with as much independence as possible.

Cost is a fundamental barrier to people with ID/DD having their own home. Rental affordability has become markedly worse in recent years. This has a marked effect on people who depend on Social Security cash payment programs [O'Hara and Cooper, 2005]. In 2004 Federal Social Security Disability Programs (SSI) payments plus state SSI supplements averaged \$617 per month, while nationally, average rent for a one-bedroom unit represented 110% of this amount, and 96% for a studio/efficiency apartment (ranging from 61.7% in North Dakota to 162.2% in the District of Columbia) [O'Hara and Cooper, 2005]. This contrasts with the situation in 1998 when the average rent for a one-bedroom unit was 69% of SSI, and 58% for a studio/efficiency unit [O'Hara and Cooper, 2005].

Supports for housing affordability do exist, most notably rental assistance available under the Section 8 voucher program of the Department of Housing and Urban Development. However waiting lists are long, and the application process is challenging for individuals with ID/DD who do not have advocacy support [Galbraith, 2001]. The effect of the crisis in affordability of rental housing is that people with disabilities who depend on SSI (or SSDI) have no option but to share housing with others.

Home ownership remains much less likely for people with ID than the general community [Maughan et al., 1999]. The poverty of people with ID/DD is a central factor in limited home ownership, but Medicaid and SSI asset limits mean that most people with ID/DD are precluded from saving toward a down payment. Clearly, much more needs to be done regarding housing affordability if greater numbers of adults with ID/DD are to join their fellow

citizens in meaningful numbers in having a home of their own.

DECREASING OUT OF HOME PLACEMENTS OF CHILDREN AND YOUTH

Trend

At any one time, less than 20% of all persons identified as having ID/DD and about one-third of adults (18 and older) receive residential services outside their family homes [Jaskulski et al., 1995]. Without question, the entire system of residential support is dependent on sustaining high levels of family support for members with ID/DD. Still, most social policy and resources that support community access for persons with ID/DD have focused on people living outside their family homes. While it has been important that most people with ID/DD remain in their family homes, the social commitment to assure that children and youth do so has been especially strong and remarkably successful. Figure 4 depicts this success. As shown in Figure 4, in 1977 there were about 90,942 children and youth with ID/DD (birth to 21 years) living away from their family homes in residential settings operated under the auspices of state ID/DD program agencies. By 2005 that number had fallen to 26,395. Put another way, between 1977 and 2005 the total number of individuals of all ages living in residential settings for persons with ID/DD increased by 66% while the total number of children and youth in such settings decreased by 71%. The trend was even more notable for children with ID/DD 14 years and younger. Their numbers in residential settings for persons with ID/DD decreased by 79%.

Policy Formulation

One objective in the CDC Healthy People 2010 goals is to "reduce to zero the number of children [with disabilities] in congregate care" [NCBDDDD, 2003]. This objective to provide all children the opportunity for family life reflects a broad national commitment to permanency planning. Permanency planning is focused on providing the natural experiences and benefits of family life to children at risk of losing that important contribution to their development. In the order of priority, permanency planning encourages the following: (1) support and training to a natural family to assist with raising a child; (2) temporary out-of-home placement with support in preparing for family reunification; (3) if reunification is not

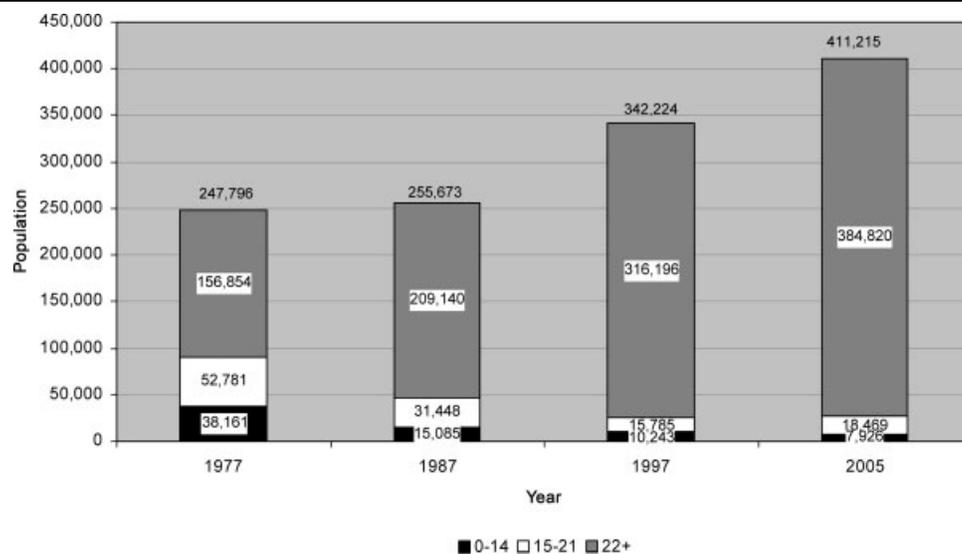


Fig. 4. Children, youth, and adults receiving out-of-home residential supports for persons with ID/DD, 1977–2005 (excluding nursing facilities).

in the child's best interest, parental release and adoption of the child; (4) family foster care; and, (5) the least restrictive non-family placement with movement to a stable, permanent home as soon as possible. Backed up by special education services; SSI for low income families; state family subsidy programs; respite care, personal care, other in-home and out-of-home support services, and consumer-directed supports available in Medicaid state plan and HCBS programs, permanency planning commitments have importance in the major national success in reducing the number of children and youth with ID/DD who are living in residential settings.

Evidence of Benefit

There is a limited body of research on long-term experiences and outcomes in the following areas: families as primary care providers for adults with ID/DD [Krauss and Seltzer, 1993; Parish et al., 2004]; lifestyle, autonomy, and development of persons with ID/DD who live with their families well into adulthood [Seltzer, 1985]; contributions that adult children make to their families [Heller and Factor, 1993]; the need for and contributions of family supports to the well-being of family members with ID/DD [Hoyert and Seltzer, 1992]; variation in needs for and contributions of family supports across family life cycles [Roberto, 1993; Smith et al., 1995]; cost-benefits of family supports in home and community services programs [Hewitt et al., 2000; Lewis and Johnson, 2005]; and, general family quality of life [Poston

et al., 2003]. In interviews with more than 1,000 parents of children with ID/DD as a part of the National Health Interview Survey—Disability Supplement, 53% of families with children with ID/DD reported one or more of the following consequences: unemployment or underemployment; changing or reducing work schedules; quitting or changing jobs; changing sleep patterns; suffering severe financial problems. This compares with 23% of families with children with disabilities, but not ID/DD [Anderson et al., 2002]. Fujiura [1998] and Lewis and Johnson [2005] also reported serious financial problems for families caring for a family member with developmental disabilities.

Other researchers have identified similar effects on family economic life and the strain this may place on families as they approach midlife with lower income, savings, and retirement benefits levels [Parish et al., 2004]. In the past decade, policy makers have acknowledged the importance of specific supports for families with members with ID/DD living at home. In 2004, states reported spending an estimated \$1.98 billion dollars to support families of persons with ID/DD: \$95 million in cash subsidies and an estimated \$1.89 billion in direct family support services. This represented a 90% increase from four years earlier. Still, the expenditures reported by states for family support in 2004 were only 6.5% of all estimated expenditures for state services for persons with ID/DD, even though about 80% of all persons with ID/DD live with family members [Braddock et al., 2005].

Challenges to Sustain the Trend

While support to families appears to be increasing, the nature of family support programs, the needs for them and the uses of them are not well documented. As well as direct services and financial supports to families, there is also a need to develop the essential infrastructure of community support. Families need access to information; assistance in planning and managing support; greater access, equity and control of funding for persons living with their families; and availability of a qualified workforce, to fund and deliver the support [Lakin and Stancliffe, 2005].

Workforce issues also affect family support services. Lakin et al. [2005] found expenditures on family supports such as respite and in-home supports in Minnesota were only 70% of the authorized amounts, largely as a result of the non-availability of staff to provide the authorized hours of service. Failing to provide family support services should be of serious concern both because families are not getting the support they need and because of the impact on demand for much more expensive out-of-home services.

CONCLUSION

Generally the trends in residential supports for persons with ID/DD are in the directions of increased inclusion and self-determination as supported in national laws and other policy commitments. There are, however, reasons for significant concerns about the capacity to sustain the rates and directions of changes associated with these commitments.

Medicaid which is the primary source of financing services for persons with ID/DD has been increasingly a target of scrutiny and cost-containment initiatives at the federal and state level. A steadily aging population is increasing the challenge and perhaps eventually the outright competition for the resources needed of increasing numbers of persons with disabilities. Among the resources for which competition will likely occur is the essential human resource of the direct support workforce. Growing this already scarce resource will require adequate wages, benefits and career opportunities all of which themselves will compete with resource demands of the growing population of persons with disabilities. None of these are new challenges. The list of challenges today reads much like lists of the past and none of the challenges of the past has broken the patterns of progress described earlier. Still, concern lingers and grows that there may be an approaching limit to US society's capacity or commitment to sustain historical growth in services and expenditures. It is, therefore, of substantial importance that cost-effective alternatives be to traditional services and expenditures models be identified and tested as primary means of sustaining past achievements.

ACKNOWLEDGMENTS

The Research and Training Center on Community Living receives core support from the National Institute on Disabilities and Rehabilitation Research, US Department of Education (Agreement No. H133B031116). The contents of this article do not necessarily reflect the official position of any sponsoring agency.

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