Transitions from Large Congregate Settings to Community Settings

Chapter 4

The movement to deinstitutionalize people with intellectual and other developmental disabilities (I/DD) has been very successful, particularly in moving people out of large state developmental centers…Today only 9% of people with I/DD live in residential facilities in the United States.

Overview

Before 1970, most people with intellectual and other developmental disabilities (I/DD) received services in large residential developmental disability centers or lived with their families with very little support from the government. During the late 1960s and 1970s, the movement by advocates, families, individuals with I/DD, and others to deinstitutionalize people with I/DD challenged the idea that people with I/DD needed to receive services in large congregate settings. They argued that people with I/DD could live in the community with the appropriate supports.[1] As a result, states began moving towards a community-based system of services and supports for individuals with I/DD. The movement to deinstitutionalize people with I/DD has been very successful, particularly in moving people out of large state developmental centers.[a,2] Nine states and the District of Columbia have closed all state-operated developmental centers.[b,3] Today only 9% of people with I/DD live in residential facilities in the United States.[2]

While the total population of individuals with I/DD receiving residential services increased by more than 75% between 1977 and 2007, from 248,000 to 438,000, the percentage living in large settings has declined 47%, from 227,000 to 121,000.[4] As states have embraced the community-based system of services and supports for people with I/DD, there has been a dramatic shift towards serving individuals with I/DD in small (6 or fewer) settings.[c] In 1977, fewer than 10% of people with I/DD received residential services in small settings; by 2007, more than 70% of people with I/DD received residential services in small settings.

There are four factors that have contributed to the decline in the number of people living in large institutions nationally: 1) personal preferences for community living arrangements, 2) expansion of Medicaid funding for home and community-based services, 3) *Olmstead vs. LC*, 527 US 581 (1999), a US Supreme Court decision that supported greater choice in living arrangements for people with disabilities, and 4) the higher costs states incur serving people in large public and private Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR) (including state developmental centers).

People with I/DD, families, and advocates generally prefer smaller community settings to larger settings when offered appropriate supports and services.[5] Research also shows that people with I/DD experience better outcomes in adaptive behavior, social participation, choice-making, self-determination, and

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[a] Unless otherwise noted, large residential settings are those serving seven or more people.

[b] Alaska, District of Columbia, Hawaii, Indiana, Maine, New Hampshire, New Mexico, Rhode Island, Vermont, and West Virginia.

[c] Unless otherwise noted, small residential settings are those serving six or fewer people.

functional behavior when living in the community with appropriate and necessary services and supports.

Medicaid funding for home and community-based services has made it easier for states to pay for the services and supports needed to help people live in smaller, more family-like community settings. State Medicaid agencies have a number of different ways in which they can pay for community-based services. First, any individual who qualifies for Medicaid can obtain coverage for health-related services. Additionally, in 1981, Congress began to give states the option of covering a broader array of home and community-based services under Medicaid. Services under the Home and Community-Based Services (HCBS) program include service coordination and case management, in-home supports, vocational services (that are not covered under the Vocational Rehabilitation Act), day habilitation services, and respite care. HCBS funds cannot be used for room and board.[4]

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In 1999, the US Supreme Court issued an opinion which gave further support for deinstitutionalization. In Olmstead vs. LC, the Supreme Court held that the unjustified institutionalization of people with disabilities could be considered unlawful discrimination under the Americans with Disabilities Act (ADA). The Court did not hold that all individuals had to be served in the community. Rather, the Supreme Court held that the individuals should be served in the community if the individual desired to live in the community, and treatment professionals determined that individual could be appropriately served in the community. Under the ADA, states must make reasonable accommodations to serve people in the community when the other two conditions are met. States are not, however, required to make “unreasonable” accommodations that would require fundamental alteration of the State’s services and programs.[d] Nor are states required to close all institutions under the Olmstead opinion.

Some states have chosen to downsize or close large state-run developmental centers and large private ICFs-MR because of the cost. Operating private and public ICFs-MR while transitioning people into smaller community living arrangements is expensive, since there are certain fixed costs (e.g. facility costs and some staffing) that do not diminish proportionately as people are transitioned to community care settings.[3] As described in Chapter 2, state developmental center costs are higher than private ICFs-MR or Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities (CAP-MR/DD) services provided in the community. Part of the cost differential may be due to the different services covered in different settings. Part of the difference in payment may also be explained by the differences in level of needs among the populations living in both settings. However, national research has shown higher per person costs at state developmental centers compared to community-based settings after controlling for these characteristics.

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[d] The Supreme Court, in a plurality decision, provided some guidance on what is a reasonable accommodation. Reasonable accommodations include a consideration of the state’s overall resources available to serve people with mental disabilities. Thus, the state need not allocate disproportionate resources to specific individuals to serve them in the community, if the state can show that providing these resources would impair their ability to serve a larger group of people with disabilities.

North Carolina

From 1977 to 2007, the number of individuals with I/DD receiving residential services increased more rapidly in North Carolina (167%) than the nation (75%).[e,f,4] In 2007, North Carolina had 11,834 persons with I/DD in a residential setting compared to 4,424 in 1977. Due to the large increase in the number of people being served, the number of individuals with I/DD served in large settings has declined less in North Carolina than the United States as a whole (15% vs. 47%). However, of those individuals with I/DD served in residential settings, the percent in a large setting is similar for North Carolina and the country as a whole (30% vs. 28%). In North Carolina in 2007, more than 3,500 individuals with I/DD lived in large residential settings, of which about half lived in state-run developmental centers.[4]

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As states have embraced the community-based system of services and supports for people with I/DD, there has been a dramatic shift towards serving individuals with I/DD in small settings and with waiver services. In 1977, fewer than 10% of people with I/DD nationally received residential services in small settings; by 2007, more than 70% of people with I/DD received residential services in small settings with six or fewer individuals. In North Carolina, only 5% of individuals with I/DD receiving residential services lived in a small setting in 1977 compared to about 70% in 2007, indicating that North Carolina's transition away from large residential settings has been similar to that of the country as a whole.

Table 4.1
North Carolina Persons with Intellectual and Other Developmental Disabilities More Likely to Reside in Small Congregate Care Settings

	NC	US
All congregate	35.0%	28.3%
1-6 congregate	21.8%	16.0%
7+ congregate	13.2%	12.3%
Own/rent	7.0%	11.8%
Host family/Foster	2.4%	3.8%
Family	55.7%	56.2%
TOTAL	100%	100%

Source: Prouty R, Alba K, Lakin C, et al; Research and Training Center on Community Living, Institute on Community Integration/UCEDD, College of Education and Human Development, University of Minnesota. *Residential services for persons with developmental disabilities: Status and trends through 2007.* http://rtc.umn.edu/docs/risp2007.pdf. Published August 2008. Accessed February 12, 2009.

The major difference between North Carolina and the nation as a whole is the use of small congregate care settings.[g] (See Table 4.1.) Approximately 22% of North Carolinians with I/DD reside in these settings, compared to 16% nationally. Nationally, people with

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[e] In these data, Prouty et al. count people who are receiving some form of Medicaid-funded residential services or live in congregate care, host family, foster care, or the individual's own home. These data do not include people who are residing in psychiatric facilities, nursing facilities, or a person living in their natural or adoptive family's home.

[f] Another source for residential services for persons with intellectual and other developmental disabilities is *The State of the States in Developmental Disabilities* (Braddock, Hemp, and Rizzolo, 2008). Differences in survey methods and service definitions preclude direct comparisons, but when data are comparable, the conclusions are similar.

[g] Prouty et al. define congregate care as a residence owned, rented, or managed by the residential service provider.

I/DD are more likely to own or rent their own home (12% vs. 7%) or reside in a host family/foster care setting (3.8 % vs. 2.4 %) than in North Carolina. Residence in family settings is similar (both 56%) and, as stated above, North Carolina has a slightly higher use of large congregate care facilities.[4]

In North Carolina, there are currently three state-operated ICF-MR certified developmental centers for people with I/DD. Information for these centers is provided in Table 4.2.

Table 4.2
Developmental Disability Centers Serving North Carolina's Three Regions

Name of Center	Location	Region	Number of Residents as of 12/8/2008
J. Iverson Riddle Developmental Center	Morganton	West	332
Murdoch Developmental Center	Butner	Central	495
Caswell Developmental Center	Kinston	East	426

Source: Donin, C. Assessment of needs for individuals residing at the state operated developmental centers. Presented to: the North Carolina Institute of Medicine Task Force on Transitions for People with Developmental Disabilities; January 21, 2009; Morrisville, NC.

Almost 70% of the 1,253 residents of developmental centers are older than age 45… Almost 90% of developmental center residents have severe (17%) or profound (72%) levels of cognitive impairment.

In addition to the developmental centers listed above, there are two other centers that were converted to specialized nursing facilities that continue to provide services and supports to residents with I/DD as of June 2007. The O'Berry Neuro-Medical Center in Goldsboro had 290 residents with I/DD, and Black Mountain Neuro-Medical Center had another 84 residents with I/DD as of June 2007.[4]

Almost 70% of the 1,253 residents of the developmental centers listed in Table 4.2 are older than age 45.[6] Nearly 60% of residents of the state developmental centers have been in the centers for more than 30 years and 83% have been in the centers for more than 10 years.[7] In 1995, a moratorium was placed on developmental centers so that they could no longer admit children for long-term care. Almost 90% of developmental center residents have severe (17%) or profound (72%) levels of cognitive impairment.[6] Those with less severe cognitive impairments have self-injurious or aggressive behaviors or have severe medical needs (such as tube feeding). With regards to activities of daily living, about two-thirds of residents need help with dining (including 13% of residents who are tube fed), two-thirds of residents need assistance with toileting, three-quarters need assistance with dressing, and 86% need assistance with communications.[h] Developmental centers provide a full range of services and supports, including medical, dental, psychiatry, physical and occupational therapy; speech therapy; adaptive equipment; social work; education, recreation and vocational therapy; and advocacy.

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[h] Some of the common diagnoses among residents of institutions include seizure disorders, cerebral palsy, dual diagnosis of intellectual and other developmental disabilities and mental illness, myocardial infarction, autism, visually or hearing impaired, diabetes, and medically fragile.

In addition to the ICF-MR certified developmental centers discussed above, North Carolina has 315 private ICFs-MR.[4] These ICFs-MR had 2,524 residents with I/DD as of June 2007. The vast majority (273 of the 315, or 87%) of these facilities had six or fewer beds. North Carolina also has a number of people living in developmental disability group homes. There are currently approximately 1,336 of these supervised living facilities, with a total of 6,544 beds.[8] Most of these are homes with six or fewer people. (See Table 4.3.)

Table 4.3
Most Developmental Disability Group Homes in North Carolina are Small, with Six or Fewer Beds

	Number of DD Group Homes	
Facility Size	**Adult**	**Child**
4 beds or fewer	531	21
5-6 beds	714	29
7-15 beds	37	-
16 beds or more	4	-

Source: Donin C. Assessment of needs for individuals residing at the state operated developmental centers. Presented to: the North Carolina Institute of Medicine Task Force on Transitions for People with Developmental Disabilities; January 21, 2009; Morrisville, NC.

State/County Special Assistance funds are available to pay room and board costs to licensed group homes for individuals with I/DD. State funds can be used to cover room and board costs in developmental disability group homes of various sizes as well as the costs of a person living at home. CAP-MR/DD funds provide services and supports to eligible recipients.[i]

Approximately 10% of North Carolinians with I/DD live in state developmental centers or private ICFs-MR with more than 16 individuals. While this percentage is similar to the national average, North Carolina could be more proactive in helping individuals with I/DD live more independently in the community when that is what they and their family members desire. However, recent efforts to move people from the state developmental centers to the community have met with limited success. Some of the barriers include the following:[9]

In North Carolina, recent efforts to move people from the state developmental centers to the community have met with limited success.

- ***Communication/collaboration with Local Management Entities (LMEs):*** Successful transitions to the community require a significant amount of communication and collaboration between the developmental centers, providers, and the LMEs. In order to be successful, private providers need to be aware of those people who want to move to a community setting, and providers need to communicate to LMEs when they have openings for new people needing services. In addition, all of the parties need to collaborate and maintain open communications during the transition period.

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[i] As noted in Chapter 6, the state does not routinely collect data on the number of people with intellectual and other developmental disabilities who are living in assisted living facilities or private skilled nursing facilities.

- *Case management issues:* North Carolina only allows providers to bill for case management services for up to 60 days of transition planning prior to the person leaving the state developmental centers. Federal law allows coverage of case management services for up to 180 days of transition planning. Limiting coverage to 60 days allows insufficient time to successfully develop and implement a transition plan. In addition, there is a high turnover among case managers which can limit the effectiveness of the case managers in helping with the transition.
- *Local Management Entity (LME) motivation:* LMEs face competing priorities and may perceive a lack of resources to devote to community transitions. This is exacerbated by the fact that LMEs may view people in institutions as having safe and stable living conditions compared to others they are trying to serve. Further, LMEs have no authority to manage admissions, funding, or discharges from the private ICFs-MR.
- *Private provider incentives:* Private ICFs-MR and developmental disability group homes are reimbursed based on bed/home level rather than the intensity of a person's need or the actual cost of delivering services. This payment methodology creates a disincentive for providers to work with people who have more intensive needs (or conversely, provides an incentive to select consumers with less intensive needs). Reimbursement to these providers is the same regardless of the quality or effectiveness of the provider. As a result, some providers that do work with people with high needs may cut corners because of inadequate reimbursement.[j]
- *Community capacity:* Communities do not necessarily have the capacity to support the higher level of support that people who transition out of residential facilities may need. Though there have been some recent efforts to improve community capacity (for example through the use of the Systemic, Therapeutic, Assessment, Respite, and Treatment (START) team model), these programs have not been in place long enough to have an impact. In addition to crisis programs, individuals need access to other services and supports in the community to meet their health, dental, mental health, housing, vocational, educational, or other support needs that were previously provided in the developmental center.

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- *Supports for more intensive needs:* Many of the people trying to transition out of the state developmental centers have more intensive medical, behavioral, and support needs that may not be easily supported at the community level. Community supports are not currently designed

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[j] Medicaid regularly provides inflationary increases in the reimbursement rates to providers (including Intermediate Care Facilities for Persons with Mental Retardation). However, rates for state-funded residential services are established by individual Local Management Entities in negotiation with providers. The Task Force heard from some of the providers that there has not been an inflationary increase for any state-funded services since the mid-1990s. Thus, these providers who rely on state-only funds to pay for services and supports have even more difficulty providing services to people with high needs.

or funded to provide the intensive and specialized 24-hour care provided at developmental centers. Community level providers may also be less experienced than center staff in working with such high need individuals and may not provide all of the services needed.[k] This inadequacy of services at the community level limits community placements.

- ***Residential preference:*** Many of the individuals in residential facilities are older and have lived in the facilities for decades. These individuals and their families may be happy with their living situation and not wish to transition into the community. In addition, community placements are not always available in the person's home community. Some guardians also prefer the state developmental centers over private ICFs-MR or other community placement because the developmental centers are perceived to provide more comprehensive services, on-site oversight, staff training, independent advocacy, and low staff turnover. Community supports are seen as being less stable. Some families have had experience with more than one unsuccessful attempt at community placement, while others have been forced to move from successful community placements when the community program closed.

As many people as possible should be moved to individualized settings of their choice.

Despite these barriers, several states have been successful in transitioning people out of developmental centers and into community settings.[10] First and foremost, these successes depended on strong, sensitive, and knowledgeable leadership to oversee the entire transition process, help create a shared vision built on common values, and then develop a comprehensive transition plan including both public and private providers of services and supports. Successful transitions focus first on building capacity within the communities rather than on closing institutions. States that have been successful have built the community service system by strengthening the training, supervision, and financing of community providers; developing comprehensive systems to manage community services; monitoring the health and welfare of individuals with I/DD; and implementing systems to monitor and improve quality of care. Creative options should be considered in building capacity. A successful transition plan includes open communication with staff and families of residents to build trust and credibility. Government administrators must be accessible and responsive to people with concerns and issues.

Transition planning for people with I/DD should be person-centered and should involve others who know the person. Successful efforts also include the maximization of opportunities to develop individualized supports at the time of

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[k] One of the difficulties in transitioning some people from state developmental centers into the community is the lack of community providers who are trained and willing to provide physical interventions. Some people with intellectual and other developmental disabilities engage in self-injurious or aggressive behaviors. These individuals may occasionally need physical interventions to prevent them from harming themselves or others. Providers who use physical interventions must have specially-trained staff and must provide extensive documentation of the need for physical interventions. Many providers decline to use hands on behavioral techniques because of the increased staffing and documentation requirements. As a result, it is more difficult to find community placements for people with significant behavioral problems. See 10A NCAC 27E.0104.

closure. As many people as possible should be moved to individualized settings of their choice. Alternative uses for the state developmental centers or large ICFs-MR should be considered that would continue to meet the needs of people with I/DD. The roles of developmental center staff should be considered both during and after the closure of the developmental center. Staff should be involved in transition planning and monitoring and should be provided opportunities to work in the community and provide support in new ways. When appropriate resources are available in the community, the state should restrict new admissions to state developmental centers or ICFs-MR. Many of these issues are discussed in more detail in Chapter 6, as these issues arise across many types of transitions.

Although the primary motivation for downsizing large residential facilities for people with I/DD and transitioning them to community-based services is to serve the needs and preferences of people with I/DD and their families, some expect that this strategy could lead to long-term savings for the state. It is important to note, however, that in the short-run, costs may increase as community-based services are being developed and state-run developmental centers continue to operate.[11]

The Task Force discussed the relative strengths and weaknesses of each type of setting, and there were many strongly held beliefs about which setting is "best." Although some members of the Task Force wanted to adopt strong language supporting particular strategies, these types of recommendations were beyond the scope of the Task Force, which was specifically charged to facilitate the transition from developmental centers to the community. Due to the highly emotional nature of this topic, especially among family members of people with I/DD, broader recommendations aimed at dramatically reconstituting the relative use of each setting would take much more research and discussion among key stakeholders.

To facilitate transitions from North Carolina's large I/DD residential facilities to small community residential settings, the Task Force recommends:

Recommendation 4.1: Preadmission Review of Placements in State Developmental Centers and Private Intermediate Care Facilities for Persons with Mental Retardation

a) Each of the state-operated developmental centers should have an admissions review committee that includes representatives of multiple Local Management Entities (LMEs), the state or regional transition coordinator, family members, and others as deemed appropriate to review any request for general admission into the state developmental centers. The Committee should review the admission prior to placement to determine if the individual with intellectual and other developmental disabilities (I/DD) could be appropriately served in a community-integrated setting. Only those individuals whose needs are reliably determined to require the most intense and costly array of services should be admitted into the state developmental centers. The centers should continue to be viewed as placements of last resort.

b) Private Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR) should create admission committees that are similarly comprised. The ICF-MR admissions committee should review the admission prior to placement to determine if the individual with I/DD could be appropriately served in a community-integrated setting within available funding.

c) If the placement in subsections a or b is determined to be appropriate, the committee should develop plans to transition the individual with I/DD into a more integrated setting in the community. Placements in public or private ICFs-MR should be reviewed at least annually.

d) The North Carolina General Assembly should provide the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) with the authority to use existing state funds in a more flexible fashion to support community transitions or to avoid placements into state developmental centers or private ICFs-MR. Examples of funding strategies include blending of the Community Alternatives Program for Persons with Mental Retardation/ Developmental Disabilities (CAP-MR/DD) waiver funds with state dollars to support individuals with higher intensity of support needs. Other funding strategies may include the transition of more than one individual at a time to smaller residential settings of four or less individuals, with funds (and possible staff) from the state developmental centers following the individuals with I/DD, or increasing the level of in-home special assistance funds to the amount provided to support individuals in licensed group homes or assisted living facilities.

e) DMHDDSAS, the Division of Medical Assistance, and the Division of Health Services Regulation should implement policies to:

  1) Discourage providers from moving individuals with more significant I/DD or behavioral health needs into state developmental centers or private ICFs-MR.

  2) Help community providers provide the necessary supports and services to successfully maintain the individual in the community.

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