



## Deinstitutionalization Toolkit: **COMMUNITY – inBRIEF**

### **The Community Advantage**

What are the advantages of living in the community versus the experience of living in an institution? For people with intellectual disabilities and developmental disabilities (ID/DD), moving from an institution to a community is more than a mere change in location or setting. It is a clear statement that they have choices, which begin with deciding where they want to live and include how and with whom they want to spend their time. These choices are supported by the *Olmstead* decision, which says that people with ID/DD have a right to choose and to reside in “the least restrictive” setting. In the community, the door must be as “open” as possible. This results in a greater freedom of choice and a higher quality of life for the individual.

The choice of living “behind the door” of an institution or “beyond the door” in the community is an important consideration in the development of the services and supports provided in an institution versus those available in the community-based setting.

The objective of deinstitutionalization is to improve the quality of each individual life. This quality of life is a result of community living and inclusion, the continued availability of quality services and supports, a less restrictive environment, increased human interaction, and greater freedom of choice.

### ***Community-Based Setting Defined***

Many stakeholders and researchers use the words “community” and “community-based” without defining what the terms really mean. While the exact definition of “home” and “community” is beyond the scope of this document and is perhaps more important to policymakers than to advocates, identifying and articulating a concept of “community” is critical for advocacy so that deinstitutionalization efforts lead to true community living and do not simply move people from one type of institutional setting to another. Advocates and self-advocates want their state developmental disabilities service systems designed to provide choices, self-direction, and protection from abuse and neglect.



The Centers for Medicare and Medicaid Services (CMS) has proposed a definition of home and community-based settings that qualify for payment under the Home and Community-Based Services (HCBS) Waiver program. This should assist states in developing service systems under this program.

Many of the stakeholders interviewed for this project spoke passionately about what home and community living should look like. One stakeholder said, “We don’t mean evacuating the institutions and putting people into smaller institutions, group homes, or other facilities that recreate the same lack of individualizations. It is not enough to move people to a smaller setting where the residents have few choices about who comes and goes, what they eat, with whom they share a room.... We need to ask, ‘Who has control of the front door?’”

While there are many considerations in identifying the most appropriate living situation for a person with ID/DD, it is important for advocates and communities to know that living in the community is not only desirable for individuals, but that community placements have proven to yield better outcomes at either the same or reduced costs than institutional care.

Research reveals three important points to be considered. First, the quality of community care matters; second, where the person is residing affects the outcomes achieved; and third, the characteristics of the person receiving services is critical in assessing the impact of deinstitutionalization.

## **Community-Based Setting in General**

A variety of residential settings exist for people with ID/DD. These settings vary in dimension and type but are substantially smaller than institutional settings. One of the key elements of living in the community is the choice of the type of setting. Settings include both in-home with family settings and out-of home group settings and offer a variety of services and supports. The availability of various community-based settings and models and the individual’s needs for support and service are key considerations. Funding for the actual setting is a critical component. The different roles of Medicaid and the Social Security Administration program to fund community-based setting options are outlined in the Deinstitutionalization Toolkit:



- FINANCE – in**BRIEF**
- FINANCE – in**DETAIL**

Each type of setting may offer a different model or system for the provision of services and supports for people with ID/DD. The ability to choose the type and characteristics of the setting is an advantage available only in the community.

## **Community-Based Setting – Types and Characteristics**

Community-based settings are available in a variety of types, sizes, and characteristics. The characteristic of care, the relationship between provider and consumer, the number of residents, and the style of service and support delivery are among the attributes that differentiate the settings. Community-based setting types include specialized institutional facility; group home; apartment program; independent home/apartment; parent/relative's home; foster care/host home; nursing facility; and others.

The characteristics of a setting may include attributes describing the relationship of the provider to the consumer, the level of supervision, the relationship of residents and staffing, or the size of the setting in terms of population. Supportive housing models include shared living/home provider; supervised living; group living; staffed living; and small intermediate care facilities for the developmentally disabled (ICF/DDs).

The type and character of the community-based settings available are matched with the individual's resources and needs to determine the best fit. Individual choice among the available options should be a goal when developing supportive housing models within the community.

## **Community-Based Settings—Trends and Populations**

Proponents of community living warn that merely closing an institution does not ensure that residents will be relocated to the community. Nationwide, 80 percent of people discharged from an institution were moved to the community in 2008. However, this percentage varies by state. For example, when the Howe Center in Illinois closed in 2009, 38 percent of the residents were transferred to other large state institutions (based on statistics reported in Shannon, 2009).



States are providing a number of different residential options. Historically, out-of-home community-based settings were just small group homes with three to five residents and 24-hour paid staff. That model has been evolving, and now some states are offering a variety of supportive housing models such as home providers and supports in the individual's own home. See Section 4 "Community - in**DETAIL**" of the Deinstitutionalization Toolkit for a description of the type of residential services available and statistics on where residents of institutions have moved after deinstitutionalization.

➤ **COMMUNITY – in**DETAIL****

## **Community-Based Care—Services and Supports**

All states have been expanding their services to people with ID/DD through community services programs, mostly funded through the HCBS Waiver program. This Medicaid program offers flexibility for the individualization of services. It is the most significant funding resource available to the state to provide community services to people who otherwise would be living in a Medicaid-funded long-term care facility.

Today, virtually all people with ID/DD can receive the support they need to maximize independence, be productive, and lead the lives they choose in the community if the services are sufficiently funded and developed in the community in which they chose to live. To achieve successful community living, systems must focus on ensuring that all people are integrated into the community to the maximum extent possible and have access to the supports and services they need to achieve their personal goals.

Some of the services and supports required for people with ID/DD will differ in the community setting from those required in the institution. Housing, transportation, financial management, and employment are among the services and supports required to live more independently within the community.

Services and supports for people with ID/DD will also differ based on the level or severity of the disability. In the community, the services and supports are made available based on an individual determination of need. This is a more targeted approach to service and support provision.



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In the community, services and supports are provided in various settings by a variety of public, nonprofit, and for-profit service providers. The types of service and supports include at-home supports; day services; and other services and supports.

Because these services need to be individualized and can be available through many different service providers, many states have developed “single points of entry,” and case management or service coordination programs to help people navigate the system of care.

### ***Individualized Services and Supports***

Before a person is discharged from an institution, an individualized service and treatment plan must be developed and the community setting must be evaluated to determine whether the necessary services and supports are in place. States must have a strong evaluation and quality assurance component in the implementation plan that looks to ensure quality of community service and supports and individual satisfaction.

### ***Person-Centered Planning***

A strong individualized planning process allows each person to choose the housing option that is most appropriate. The Person-Centered Plan (PCP) is gaining wide acceptance as a model approach to ensuring the availability of services and supports in the community. It includes five steps (Thompson et al., 2009):

- Step 1—Identify Desired Life Experiences and Goals
- Step 2—Determine the Pattern and Intensity of Support Needs
- Step 3—Develop the Individualized Plan
- Step 4—Monitor Progress
- Step 5—Evaluate

### ***Individual Planning and Budgeting***

In the planning and budgeting process, it is very important to ask the right questions. The state determines the budget amount for each person by assessing the person’s support needs coupled with reasonable reimbursement rates for providers. In some



states, consumer-directed funding allows the person to exercise a measure of control over expenditures.

Community services and supports may be provided in client's homes, in medical centers, in doctors' offices, in day centers, on job sites, or in community recreation centers.

The source of funding, the cost of services and supports, and the sustainability of resources are components of individual planning and budgeting. The Medicaid program through the services and supports provided in the HCBS Waiver program and the Social Security Administration through disability cash benefits are the primary sources of funding for services and supports for people with ID/DD. Some states provide state supplements as well. Additional information on finance issues and the costs of services and supports is available in the Deinstitutionalization Toolkit:

- FINANCE – in**BRIEF**
- COSTS – in**BRIEF**

## **Community Advantage—Quality of Life**

Individual choice within the community-based setting is the primary goal of deinstitutionalization. The ability of people with ID/DD to choose and to live within the least restrictive environment is a protected choice. The value of choice is an advantage of community living and inclusion, continued availability of quality services and supports, and opportunities for increased human interaction and independence.

A plethora of research has evaluated the outcomes associated with community care on quality of life, behavioral outcomes, life satisfaction, competence in activities of daily living, and challenging behaviors. The studies, regardless of the analytical technique or country of origin overwhelmingly find that living in the community yields positive results. For the most recent meta-analysis by Lakin, Larson, and Kim (2011), "Behavioral Outcomes of Deinstitutionalization for People with Intellectual and/or Developmental Disabilities: Third Decennial Review of U.S. Studies 1977–2010," see Section 4 of the Deinstitutionalization Toolkit:





## **Quality “Matters”**

The following are key indicators and factors that support success in community living. These characteristics “matter” when creating new systems of services and supports in the community-based setting. Community integration and participation, quality of community care, individual and personalized supports, and consumer choice are all elements of a quality community-based service model and cumulatively contribute to quality of life enhancements available in the community-based setting.

Measuring quality of life in the community for people with ID/DD is a challenge addressed by the Human Services Research Institute (HSRI) National Core Indicators (NCI). National Core Indicators evaluate the degree to which the community-based setting supports community inclusion, choice and decision making, relationships, and satisfaction within the community-based setting. The NCI HSRI 2009–2010 Survey measures core indicator outcomes and comparisons across states.

Some of the survey responses are available in the in**DETAIL** section of the Deinstitutionalization Toolkit:

➤ **COMMUNITY – in**DETAIL****

## **Myths and Realities**

For many people with ID/DD and their parents, the transition from living in an institution to living in the community is a challenging time, and they have many concerns. Some of these concerns are based in fact and some are based on myths and misinformation about community-based living. Understanding the reality of the community-based setting and the services and supports available can help to assuage these concerns. Some of the most common of these myths are discussed in the in**DETAIL** section of the Deinstitutionalization Toolkit:

➤ **COMMUNITY – in**DETAIL****



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### References

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