



Deinstitutionalization Toolkit: COMMUNITY – in**DETAIL**

This section of the Deinstitutionalization Toolkit includes the supportive detail on the subject of Community. The research and detailed information are intended to provide background for the Deinstitutionalization Toolkit:

➤ COMMUNITY – in**BRIEF**

Community-Based Setting—Characteristic, Types, and Populations

Characteristics

Historically, out-of-home “community-based” settings were defined as small group homes with three to five residents and 24-hour paid staff. Over time, that model has evolved. In 2009, the most recent data available, 321,463 people (Lakin et al., 2010) received residential services in small community-based settings such as these:

- **Shared Living/Home Provider:** Individualized shared-living arrangements offered within a contracted provider’s home for one or two people.
- **Supervised Living:** Regularly scheduled or intermittent supports provided to a person (or two) who lives in his or her own home.
- **Group Living:** Group living arrangements for three to six people, staffed full-time by providers.
- **Staffed Living:** Residential living arrangements for one or two people staffed full-time by providers.
- **Small *Intermediate Care Facilities for the Developmentally Disabled (ICF/DD)*:** A highly structured residential setting for up to six people that provides intensive medical and therapeutic services.

Types and Trends

Figure 1 displays information from the National Core Indicators (NCI) 2009–2010 survey (the most recent data available). This survey focuses on the level of community participation experienced by community-based service consumers and then compares the scores with the average scores from 16 states; Orange County, California; and the



District of Columbia. Figure 1 presents the percentages of the total population surveyed in the different type of residences. Although the percentages may differ between states and from the states that were not part of the survey field, these numbers may reflect an accurate representation of the percentages of total community-based setting model populations.

Figure 1. Type of Residence (N = 11,429)



Source: NCI 2009–2010 survey.

People with Intellectual Disabilities and Developmental Disabilities (ID/DD) Who Leave Institutions—Where They Go: Proponents of community living warn that merely closing an institution does not ensure that residents will be relocated to the community. As table 1 shows, nationwide 80 percent of people discharged from an institution moved to the community in 2008. However, this 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).



Table 1. New Place of Residence of People Discharged from Large State Facilities between Fiscal Years 1985 and 2008

New Place of Residence	1985	1998	2008
Community Placements			
Group home (15 or fewer residents, including small private ICFs/DD and other group homes)	40.4	50.9	49.4
Semi-independent/Supported living	1.4	9.2	12.8
Home of parents or relative	17.1	10.8	5.7
Foster/host family home	7.1	6.3	3.2
<i>Total Community Placements</i>	<i>66.0</i>	<i>77.2</i>	<i>71.1</i>
Institutional Settings			
Group home (16–63 residents)	7.4	3.7	6.2
Nursing facility	4.1	2.6	5.1
State facility	10.1	6.1	4.9
Mental health facility	1.4	1.5	2.6
Correctional facility	0.2	0	1.6
Nonstate facility	3.8	0.7	0.9
<i>Total Institutional Settings</i>	<i>27.0</i>	<i>14.6</i>	<i>21.3</i>
Unknown/Other	6.9	8.1	6.5
Total	100	100	100

Source: Data from Lakin et al. (2009) table 1.

Choice of Setting by Individual with ID/DD: Advocates and self-advocates want their state developmental disabilities service systems designed to provide choices and self-direction, as well as protection from abuse and neglect. Research shows that there is no trade-off of health and wellness or freedom from abuse or safety when community affiliation, choice, and self-determination are increased (Gardner, 2003)

Although the settings may differ in characteristics and size, an essential component of the larger benefit to people with ID/DD in the community is the availability of choice in the type of setting in which they reside. Table 2 presents the proportion of people who chose their community setting from the surveyed state’s participants from the NCI 2009–2010 survey.



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Table 2. Proportion of People Who Chose the Place Where They Live (Adjusted Variable), by State

	N (observed)	Adjusted Proportion
WY	359	83%
KY	425	63%
GA	423	58%
OK	344	51%
ME	391	48%
DC	330	47%
IL	330	45%
NC	864	41%
OH	487	40%
AR	385	40%
NY	1,088	38%
RCOC	544	36%
PA	1,205	35%
MO	390	32%
LA	317	31%
NJ	400	27%
AL	436	16%
TX	n/a	n/a
Total	8,718	43%*

Source: Consumer Outcomes – Phase XII Final Report 2009–2010 Data.

Services and Supports

All states have been expanding services to people with ID/DD through community services programs, mostly funded through the Home and Community-Based Services (HCBS) Waiver program. This Medicaid program offers flexibility for the individualization of services. It is the most significant funding source available to states 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 their community's services are sufficiently funded and developed. To achieve successful community living, systems must focus on ensuring that each individual is integrated into the community to the maximum extent possible and has access to the supports and services needed to achieve personal goals.

Some of the services and supports required for a person with ID/DD will differ in the community setting from those required in the institution. These services and supports may include assistance with housing, transportation, financial management, and employment. Services and supports for people with ID/DD will also differ based on the level or severity of the disability. In the community, services and supports are made available based on an individual determination of need. This is a more targeted approach to service and support provision than the institutional approach.

Types of Community-Based Services and Supports

In the community, services and supports are provided by a variety of public, nonprofit, and for-profit service providers and are provided in various settings. The types of services and supports include the following:

- **At Home Supports:** These supports range from one-to-one assistance from a support worker with identified aspects of daily living (such as budgeting, shopping, or paying bills) to full 24-hour support (including assistance with household tasks such as cooking or cleaning, and personal care such as showering, dressing, and the administration of medication). The need for full 24-hour support is usually associated with difficulties recognizing safety issues (such as responding to a fire or using a telephone) or people with potentially dangerous medical conditions (such as asthma or diabetes) who are unable to manage their conditions without assistance.
- **Day Services:** Nonprofit and for-profit private agencies provide an array of day services such as teaching life skills, social and recreational activities, community outings, communication and mobility training, physical and occupational therapies, sheltered workshops, and vocational services leading to integrated employment or volunteer opportunities in the community.



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- **Other Services and Supports:** In addition to the services designed specifically for people with ID/DD, community residents use mainstream services for medical, dental, and other professional care. Their medical services are provided by doctors, nurses, personal care assistants, provider agency staff persons and trained family members. At times, specialized medical services must be created or packaged in order to meet specific needs: Medical equipment might be brought into a home, or round-the-clock nursing assistance might be provided to enable the person to live as normally as possible.

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

Individual Service and Supports

A core element of community living is ensuring that all people have the services and supports they need to live the fullest and most personally satisfying life possible in the community. Individualized planning is an absolute necessity, and planning prior to leaving the institution is mandatory. It is important that this process be as comprehensive and inclusive as possible, involving the individual, existing and potential care givers, professional care team members, and others.

It is also critical to initiate and maintain ongoing assessments of both the individual’s needs for services and supports and their availability within the community. The process is needed both for people living in the community and those entering the community from institutional settings.

Person-Centered Planning (PCP)

PCP is one approach to individualized planning. It is a process by which the person with the disability and people important to that person develop a vision of the person’s life going forward and identify the types of services and supports required to achieve that vision. PCP should be discussed with the team that will be working with the person in the community while the person is still in the institution and used to develop a transition plan, spelling out how the person will move, who will be responsible at the time of transition for continuity of support, and how problems will be solved (Thompson et al., 2009).



Research has found that PCP yields better outcomes for adults with intellectual disabilities than do traditional methods of service planning. It is a time-consuming process, and states have implemented PCP in varying ways. However, states are increasingly adhering to the following PCP process:

Five Steps in an Effective PCP Process

Step 1. Identify Desired Life Experiences and Goals: The primary purpose of a PCP is to find out what is important to the person, and it is essential that discussions are not constrained by available services or by perceived barriers such as fiscal restrictions or limitations in a person's skills (O'Brien and O'Brien, 2002).

Step 2. Determine the Pattern and Intensity of Support Needs: Gather information on the nature of supports the person requires to participate in an array of activities, especially those identified in the previous step. Some states use a standardized support needs assessment instrument (such as the Supports Intensity Scale) or the Inventory for Client and Agency Planning to evaluate an individual's support needs across different domains and identify exceptional medical and behavioral support needs. Other approaches include direct observation of the person in a variety of life activities and structured interviews with the person and his or her family members.

Step 3. Develop the Individualized Plan: Based on the findings in the first two steps, the team develops a plan that specifies (a) the settings for and activities in which a person is likely to engage during a typical week, and (b) the types and intensity of support that will be provided and by whom.

Step 4. Monitor Progress: Monitor the extent to which the person's individual plan was implemented.

Step 5. Evaluate: Evaluate the extent to which desired life experiences, goals, and personal outcomes are being realized.

Source: Based on Thompson et al. (2009).



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Individual Budgeting

At the center of a system promoting self-direction is a personal budget allocation the individual may apply, within the bounds of an approved service plan, to buy needed supports (Agosta et al., 2009). The state determines the budget amount for each individual by assessing the individual's support needs, coupled with reasonable reimbursement rates for providers.

Some states have experimented with consumer-directed funding (also known as cash and counseling), whereby the consumer or a family member has more control over the expenditures. The Cash and Counseling original multiyear demonstration projects were sponsored in 15 states by The Robert Wood Johnson Foundation and the United States Department of Health and Human Services. The Cash and Counseling state demonstration projects proved to be "an excellent option for states seeking to improve consumer and caregiver well-being" (Brown et al., 2007).

Community Resource and Planning Consideration

In the planning and budgeting process, it is very important to ask the right questions. In 1999, the University of Minnesota developed a guide identifying some of the key areas and questions to ask when making choices about living arrangements and community supports and services. Here is a brief overview of these issues. For more information, check out this link:

<http://rtc.umn.edu/questions/>



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Categories	Types of Questions to Ask
Finding the Community Service Provider That Best Fits the Individual's Needs	How can I compare service providers? What should I look for?
Qualifications, Licensure, and Other Indicators of Quality Service Provision	Is this living arrangement licensed by the state? Is it routinely inspected? Do staff have to receive specific training to work here? If so, what types of training are required?
Medical and Dental Health	How will mental and dental health services be provided? Who will select the provider?
Self-Determination and Choice	To what extent is the individual engaged in decision making and allowed to make choices about daily living activities?
Social Relationships	To what extent is the individual free to establish and maintain social relationships with individuals of his or her own choosing, who may or may not live in the same house or facility?
Home Environment	Does this environment "feel" like a home? Does the individual have a key to the front door? Can the individual have friends in for visits?
Home Visit Checklist	What should you look for when visiting a home or facility that you are considering?
Supports	What supports are available to individuals living in this situation? Do they foster independence?
Family Involvement	Is family involvement encouraged and supported? Are there limits to a family's access to family member?
Transportation	What types of transportation are available? Are there separate costs involved? How is it arranged?
Recreation and Community Activities	Are individuals encouraged to participate in recreational and community activities? How is this involvement fostered and supported?
Vulnerability and Safety	Is there an individual assessment of risks related to the individual in this particular environment? What measures are in place to ensure the safety of the residents?



Community-Based Setting—Quality of Life

A substantial body of research has evaluated the impact of deinstitutionalization on quality of life, behavioral outcomes, life satisfaction, competence in activities of daily living, and challenging behaviors. The studies, regardless of analytical technique or country of origin, find that living in the community yields positive results. Quality of life has many elements. It involves personal health and well-being, a sense of home, a network of friends, the availability of choices, self-respect, and personal fulfillment. These are desired by all people. Researchers have found that quality of life for people with ID/DD involves eight domains (Schalock and Verdugo, 2004):

- Interpersonal Relations: Interactions, Relationships, Supports
- Social Inclusion: Community Integration and Participation, Community Roles, Social Supports
- Self-Determination Autonomy/Personal Control, Goals and Personal Values, Choices
- Human Rights (Respect, Dignity, Equality) and Legal Rights (Citizenship, Access, Due Process)
- Material Well-Being: Financial Status, Employment, Housing
- Personal Development: Education, Personal Competence, Performance
- Emotional Well-Being: Contentment, Self-concept, Lack of Stress
- Physical Well-Being” Health and Health Care, Activities of Daily Living, Leisure

Measuring “quality of life” characteristics to determine the success of deinstitutionalization and to provide feedback to improve the delivery of necessary services and supports in community-based models is an important activity. The NCI 2009–2010 survey shows some of these quality of life characteristics. Figures 2–6 are charts provided from the data collected in the 2009–2010 survey. They illustrate choice and decision making, community inclusion, relationships, and satisfaction (see Human Services Research Institute/ National Association of State Directors of Developmental Disabilities Services, National Core Indicators, 2011).



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Figure 2. Proportion of People Who Report Having Friends and Caring Relationships with People Other Than Support Staff and Family Members

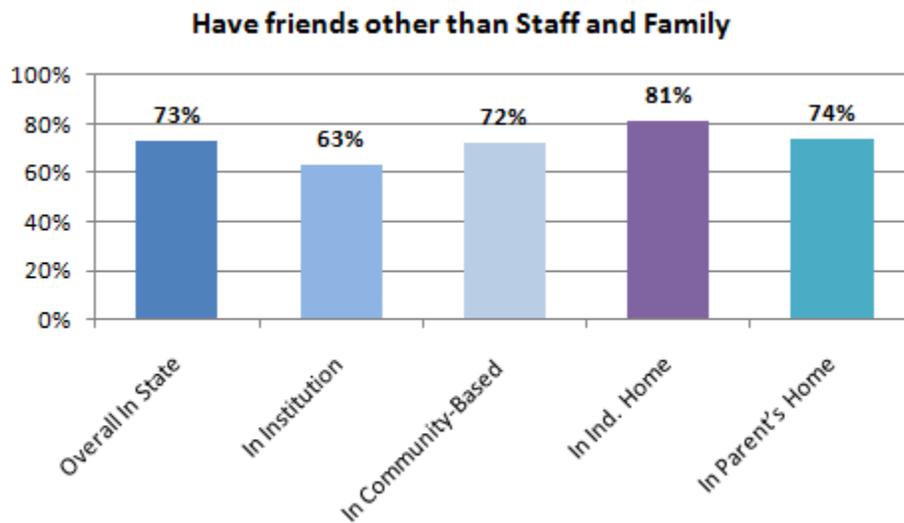


Figure 3. Proportion of People Who Like Their Home or Where They Live

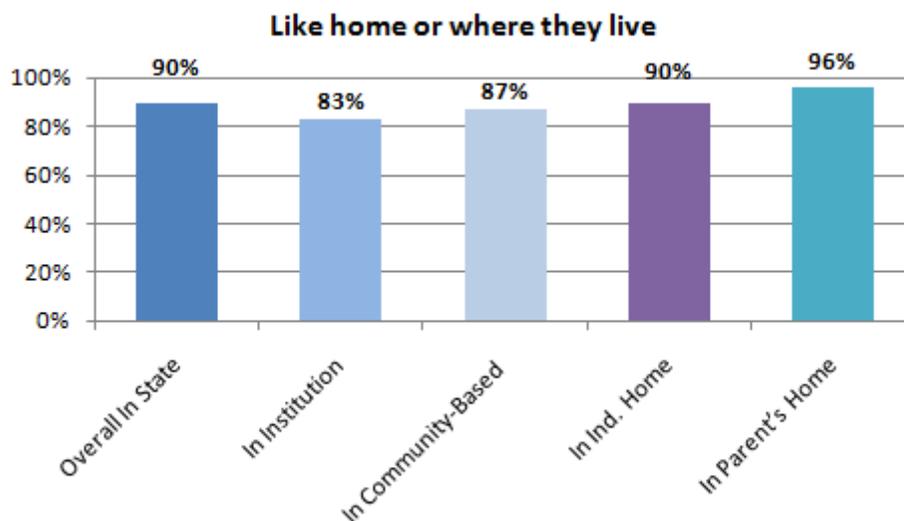




Figure 4. Proportion of People Who Would Like to Live Somewhere Else

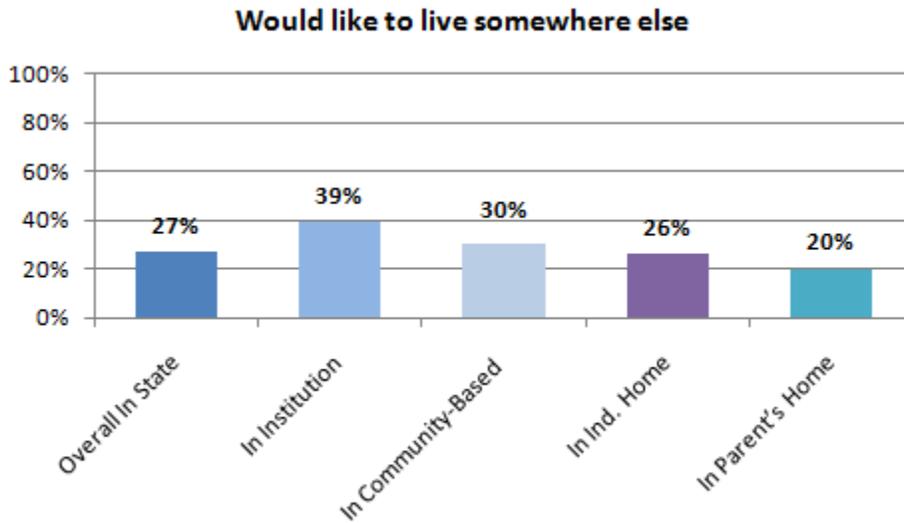


Figure 5. Proportion of People Who Report That They Never Feel Scared in Their Home

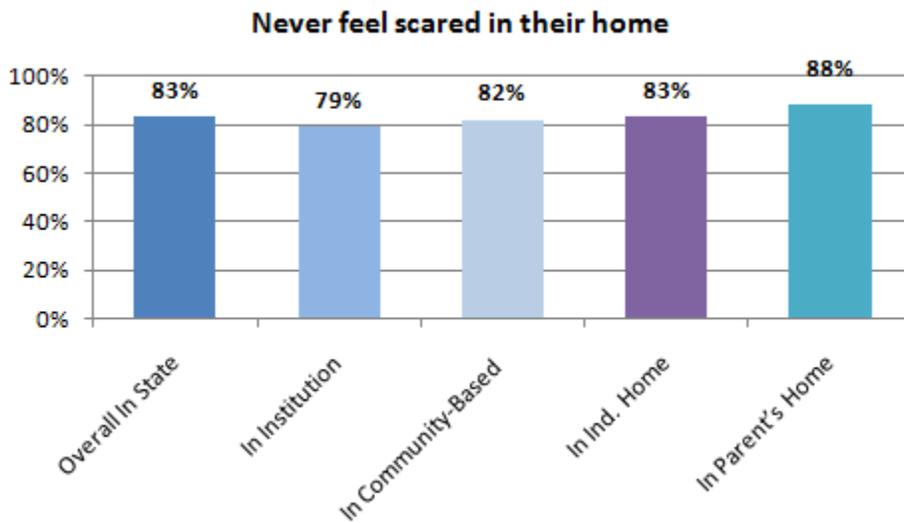
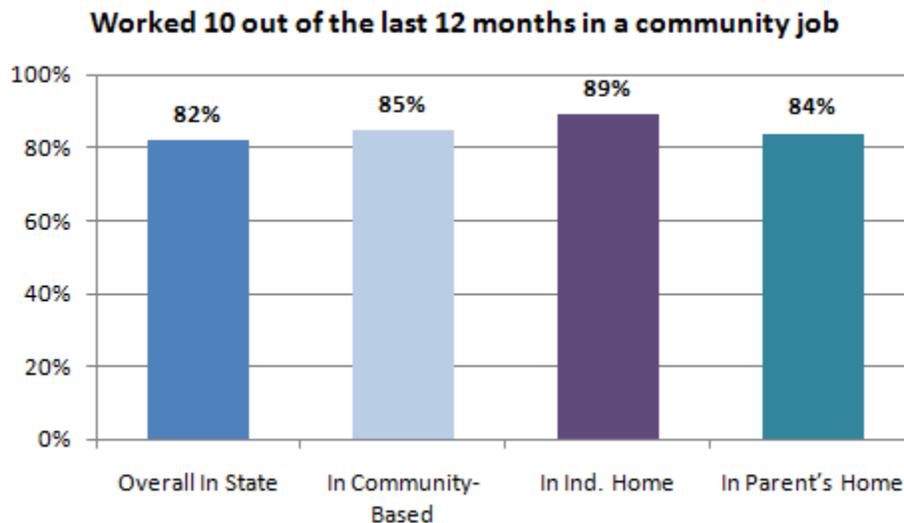




Figure 6. The Proportion of People Who Have a Job in the Community by Each Type of Community Employment*



*too few cases to report outcomes by people living in institutional settings

At least four well-regarded meta-analyses of institutional versus community care have been published since 2005. Together, the analyses review more than 150 articles that meet accepted criteria for quality research.

- Lakin et al. (2011) reviewed 38 studies related to changes in adaptive and challenging behavior associated with movement from institutional to community residences. They found that more than two-thirds of the studies showed improvements in adaptive behaviors of individuals in the community.
- Kozma et al. (2009) reviewed 68 studies published in English from different countries since 1997. The work focused on the following 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. They found that small-scale arrangements are superior to large, congregate options in most domains. Regarding quality of life, they reported that studies showed 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, people in the small community settings have



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more choice-making opportunities, have larger social networks and more friends, access more mainstream facilities, 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.

- Walsh et al. (2010), in a meta-analysis of literature published between 1995 and 2005, found that the research showed consistent evidence that smaller settings provided for greater choice, self-determination, and participation in community-based activities. However, they found no evidence for better physical health or material well-being, and little evidence for a relationship between type of setting and employment.
- Stancliffe et al. (2009) used data from the NCI in six states to assess self-reported satisfaction and sense of well-being in a sample of 1,885 adults with ID/DD receiving Medicaid HCBS Waiver services and ICF/DD services. Questions dealt with such topics as loneliness, feeling afraid at home and in one's neighborhood, feeling happy, feeling staff are nice and polite, and liking one's home and work/day program. Loneliness was the most widespread problem, and small percentages of people also reported negative views in other areas. The research revealed consistent benefits of residential support provided in very small settings—with choices of where and with whom to live—and to individuals living with family.

The literature reviews indicate that community-based settings, services, and supports are superior to institutional settings in many areas, but certain key elements must be in place in order for the community living experiences to be optimum.

Community Based-Services—Quality 'Matters'

Community Integration and Participation Matters

Table 3 displays information from the NCI 2009–2010 survey. The chart depicts the number of times a person participated in an activity at a regular interval. The scores reveal that the consumers surveyed had a high level of participation in daily life activities reflecting community integration.



Table 3. Activity of People within a Time Period

- A** Number of times people went shopping in past month
- B** Number of times people went out on errands in past month
- C** Number of times people went out for entertainment in past month
- D** Number of times people went to exercise or play integrated sports in past month
- E** Number of times people went out to religious services in past month
- F** Number of times people went on vacation in past year

STATE	A		B		C		D		E		F	
	N	AVG	N	AVG	N	AVG	N	AVG	N	AVG	N	AVG
AL	325	2.9	298	1.84	321	2	389	2	355	2.5	381	0.3
AR	385	3.9	383	2.39	382	2.7	387	9.3	385	2.4	387	1
DC	351	2.9	346	2.64	344	2.9	342	7.1	343	2.3	342	1
GA	419	4.2	401	2.87	411	2.8	433	4.2	408	2.9	416	0.6
IL	358	2.6	351	2.03	349	1.9	359	6.1	349	1.7	348	0.4
KY	430	3.1	427	1.67	429	2.6	428	4.7	426	1.1	423	0.4
LA	324	3.7	325	2.18	324	2.1	326	4.5	322	2.4	320	0.7
ME	400	6.1	392	5.46	385	3	401	7.3	408	1	407	1
MO	408	3.3	408	2.82	404	2.6	410	4.9	403	1.7	402	0.4
NC	882	4.4	885	2.9	878	2.4	889	6.5	879	2.4	879	0.9
NJ	400	3.1	397	2.26	390	3.3	392	0.9	380	1.2	389	0.5
NY	1,136	4.4	1,126	3.04	1,129	2.3	1,156	4.9	1,132	1.4	1,120	0.8
OH	483	3.3	476	2.65	479	1.9	481	5.2	469	1.9	476	0.8
OK	401	3.8	402	4.09	400	4.4	402	2.5	402	1.5	397	0.6
PA	1,237	4.2	1,220	3.59			1,237	6.7			1,244	0.7
RCOC	593	3.7	591	2.2	593	2.4	593	7.2	599	1.7	593	0.7
TX	1,943	2.2	1,949	1.8	1,958	1.9	1,971	5.1	1,951	2.2	1,939	0.4
WY	390	4.7	386	4.15	385	4.1	388	9.9	385	1.1	381	0.7
Total	10,865	3.7*	10,763	2.81*	9,984	2.5*	10,984	5.5*	10,341	1.7*	10,844	0.7*

* average of averages

N=Number of Individuals

Source: Compiled from tables 1–7 of the NCI 2009–2010 survey.



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Additional Consumer Survey scores may be found at:

<http://www2.hsri.org/docs/NCI%20CS%2009-10%20FINAL%20Report.pdf>

The Quality of the Community Care Matters

Physical presence in the community is not the same as integration and inclusion. Moving people from an institution to the community does not automatically result in positive impacts. For example, Kozma et al. (2009) note that results vary even within service models of the same type, depending on service characteristics. This implies that the shift from institutional care to community living does not guarantee a better outcome for all residents. In addition to changing where people live, it is critical to have the skilled staff necessary to support individual service requirements and goals.

Individual and Personalized Supports Matter

Kozma et al. (2009) found that people with higher support needs—whether because of the nature of their intellectual and physical disabilities or their challenging behavior or social impairment—often experience outcomes that are not as good as people who are more independent and have less complex medical or behavioral needs. However, demonstration projects have shown that it is possible to greatly increase the level of outcomes for people with the most severe disabilities to a level higher than achieved in any institutional setting. 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, 2006).



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Table 4. The Proportion of People Who Report Going to a Day Program or Some Other Daily Activity

State	N	Overall In State	In Institution	In Community-Based	In Ind. Home	In Parent's Home
Significantly Above Average						
WY	202	97%	n/a	96%	n/a	95%
AL	327	95%	n/a	94%	n/a	98%
NJ	258	93%	n/a	93%	n/a	n/a
KY	275	91%	n/a	94%	n/a	79%
IL	237	84%	92%	91%	53%	85%
Within Average Range						
NY	859	73%	n/a	75%	48%	77%
DC	247	73%	n/a	75%	65%	66%
AR	244	72%	87%	76%	55%	72%
RCOC	422	71%	91%	84%	34%	55%
OH	368	69%	n/a	89%	52%	67%
ME	294	65%	n/a	67%	26%	n/a
NC	553	65%	n/a	77%	42%	64%
LA	213	62%	77%	80%	45%	51%
Significantly Below Average						
GA	328	61%	n/a	81%	44%	54%
TX	723	57%	74%	n/a	n/a	48%
PA	968	56%	87%	78%	29%	48%
MO	255	51%	79%	48%	48%	56%
OK	197	41%	n/a	51%	32%	n/a
Total	6,970	71%*	84%*	79%*	44%*	68%*

Source: Consumer Outcomes – Phase XII Final Report 2009-2010 Data.

Community-Based Consumer Choice Matters

One of the most important indicators of a quality life in the community is the extent to which the person with ID/DD is empowered to make decisions on the issues that his or her life.

Again, we look to the NCI 2009–2010 survey for the key indicators reflecting the extent to which community residents participate in decision-making activities, have a voice in their daily schedule, and are able to choose who will provide professional support and services.



Table 5. Proportion of People Who Indicate the Option of Choice in Activities

- A** Proportion of people who chose where they live
- B** Proportion of people who chose the staff who help them at home
- C** Proportion of people who chose their day activity
- D** Proportion of people who choose how to spend their free time
- E** Proportion of people who choose what to buy with their spending money
- F** Proportion of people who chose their roommates

STATE	A		B		C		D		E		F	
	N	%	N	%	N	%	N	%	N	%	N	%
AL	436	16%	171	15%	315	25%	444	91%	440	89%	429	7%
AR	385	41%	236	81%	181	71%	386	88%	387	90%	385	39%
DC	330	49%	211	64%	212	60%	357	78%	358	84%	312	48%
GA	423	64%	153	69%	196	77%	437	98%	436	96%	416	61%
IL	330	47%	160	71%	200	67%	360	87%	355	85%	333	40%
KY	425	65%	195	56%	252	88%	430	97%	427	96%	428	35%
LA	317	33%	184	75%	133	48%	321	88%	320	83%	323	37%
ME	391	55%	266	70%	195	85%	407	97%	406	95%	385	45%
MO	390	34%	265	63%	146	61%	411	94%	406	87%	380	27%
NC	864	42%	555	58%	459	62%	896	88%	895	88%	866	35%
NJ	400	33%	250	52%	250	30%	394	97%	393	94%	393	17%
NY	1,088	46%	632	70%	702	59%	1168	89%	1,157	89%	1097	36%
OH	487	49%	219	88%	246	80%	493	91%	493	89%	488	54%
OK	344	53%	401	68%	185	60%	402	93%	402	86%	375	52%
PA	1,205	44%	440	45%	444	57%	1324	94%	1,306	88%	1183	42%
RCOC	544	43%	455	80%	409	48%	600	92%	598	91%	562	32%
TX	1,814	15%	421	43%	450	59%	1981	79%	1,968	74%	1934	22%
WY	359	89%	171	81%	193	93%	388	97%	388	96%	384	84%
Total	10,532	45%*	5,385	64%*	5,168	63%*	11,199	91%*	11,135	89%*	10,673	40%*

* average of averages

N=Number of Individuals

Source: Compiled from tables 8–15 of the NCI 2009–2010 survey.



The NCI 2009–2010 survey results clearly show that people living in the community have increased autonomy and decision-making opportunities. Particularly meaningful are the questions in the survey indicating choice in relation to personal finance and staffing.

Myths and Realities

Myth 1: *Institutions are the best setting for some individuals with severe intellectual and developmental disabilities.*

Four groups of people are often cited as the most difficult to serve in the community.

- **Medically Fragile:** Some institution residents have complex medical conditions such as seizure disorder, aspiration risk, and dysphagia, requiring intensive medical support. If skilled nursing and medical planning are provided, successful community placement of people with complex medical issues can be ensured (Kozma et al., 2003).
- **Dual Diagnoses:** Half of institution residents have a condition requiring psychiatric attention (Lakin et al., 2009). Often people with dual diagnoses need high levels of services and supports that require integrated interventions from both ID/DD and mental health providers. Often ID/DD providers do not have the capacity to provide treatment for mental health issues, and mental health providers do not have the capacity to provide self-care supports to address ID/DD issues. Joint system planning can be difficult because the two types of services are available through different funding streams (Day, 2009).
- **Involved with the Criminal Justice System:** Developmental services agencies are expected to serve a public safety function for these individuals. This can be challenging in the context of developing a system designed to promote self-determination and community participation (Bascom, 2009).
- **Older People Who Have Spent Many Years in the Institution:** Older residents who have spent many years in an institution present several challenges; they (or their parents or guardians) may feel that the institution is their home and they do not want to be uprooted. Many have never had the experience of living in the community.



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Some states have developed specific strategies to meet the needs of challenging populations, including those with the most significant challenges. People with co-occurring developmental disabilities and mental illnesses and older adults with developmental disabilities are particularly vulnerable populations. They face barriers to services related to a lack of coordination and collaboration across service systems, as well as gaps in research, clinical expertise, and access to appropriate programs. This lack of coordination has many causes, including separate systems for financing services; a reluctance by mental health and developmental disabilities systems to allocate scarce resources for a high-needs population that could be served in another service system; established provider networks that are not cross-trained; and the evolution of advocacy movements emphasizing different priorities. In many cases, specific barriers to service may be both a cause and a result of the lack of coordination across systems.

In 2002, the Surgeon General addressed the needs of vulnerable populations in *A National Blueprint to Improve the Health of Persons with [Mental Retardation]*.

<http://www.nichd.nih.gov/publications/pubs/closingthegap/sub7.cfm>

States and advocates have implemented strategies and programs to address the needs of people with complex medical needs, dual diagnoses, and older adults with development disabilities. For example:

- To facilitate the closure of Agnews Developmental Center, California created 23 licensed homes in the community that provide sophisticated medical support (SB 962 homes). Although they are expensive (an average monthly cost of \$15,000 per person), they seem to be meeting the needs of a medically fragile population (California Health and Human Service Agency ,2010).
- In 2008, Tennessee opened a 16-bed ICF/DD with medical services including 24-hour nursing care.
- Missouri advocates founded the Association on Aging with Developmental Disabilities to increase awareness of the importance of providing community-based services and support focusing on older adults with developmental disabilities.



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- The Florida Department of Elder Affairs sponsored training for service providers on meeting the needs of aging people with developmental disabilities. (www.adrc-tae.org/tiki-download_file.php?fileId=30426)
- As part of a federal lawsuit settlement, the State of Hawaii is required to take specific steps to identify people with developmental disabilities within the mental health system and ensure that there are smooth discharges from the state psychiatric hospital.
- In 2008, the New Jersey Department of Human Services convened the Dual Diagnosis Task Force to examine and resolve the serious lack of services, unmet service needs, and other significant obstacles to receiving mental health and developmental disability services. The task force made recommendations on a framework for change that would enable the service system to effectively serve the needs of children and adults with developmental disabilities and co-occurring mental health and/or behavior disorders.
- Oregon and several other states use person-centered planning, coupled with individual budgeting, to adequately address complex individual needs.
- Maryland's Rosewood Center placed 17 of the 30 court-committed individuals in the community and 13 in a secure residential facility to ensure public safety. In the community, the individuals were placed in small residences with a range of supports, including one-to-one supervision and/or awake overnight supervision, or creative monitoring in a small (up to three individuals) residential setting with day, vocational, or supported employment services. Monitoring may include oversight by another agency (regular reporting to a probation officer through the Department of Corrections) or monitoring devices (alarmed windows and doors) (Maryland Developmental Disabilities Administration, 2008).

Myth 2: *The quality of care cannot be assured in a community-based residential setting.*

Opponents of institutional closure argue that it is easier to monitor the quality of a small number of large institutions rather than a large number of smaller facilities. Proponents of deinstitutionalization admit that “in the early phases of deinstitutionalization, efforts to develop quality assurance strategies suited to community services were sometimes subordinated in the rush to meet court-ordered deadlines” (Bradley and Kimmich, 2003).



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Most states have now developed mechanisms to monitor the quality of community-based services. However, no quality assurance mechanism is foolproof, and incidents of abuse, neglect, and even death occur in the community, just as they do in institutions. We have found no studies comparing the rate of adverse incidents in the community with the rate in institutional settings.

Family, friends, and neighbors play important roles in assuring safety and service quality for people in community-based settings. Several researchers found that family presence and participation in the person's life can be an important safeguard for security and service quality (Lemay, 2009) and should be regarded as the most important and dependable source of quality assurance.

Although there are few specific federal requirements as to how states must assure quality, states must persuade the Centers for Medicare and Medicaid Services (CMS) that the state can assure health and welfare. CMS has established a Quality Framework that addresses access, PCP and service delivery, provider capacity, participant safeguards, rights and responsibilities, outcomes and satisfaction, and system performance. Though it is not regulatory, it provides a framework for certain expectations of quality outcomes for HCBS Waiver program services.

In recent years, most states and communities have increased regulation or oversight of community-based services. Most states have multifaceted systems of quality assurance, including the participation of different stakeholders in and outside government and the service system. Systems of quality assurance include the following (from Bascom, 2009):

- **Licensure:** Group homes and other community residences where three or more unrelated people with disabilities live require licensure.
- **Quality Management Reviews:** Reviewers assess Medicaid-funded services to ensure compliance with state and federal Medicaid standards. In Vermont, for example, site visits are conducted every two years, with follow-up as appropriate.
- **Guardianship:** Public guardians who are provided to adults with developmental disabilities play distinct quality assurance functions. They are expected to have regular (in some states at least monthly) face-to-face contact with the people for



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whom they are guardians and to monitor their welfare and quality of life and advocate for appropriate services.

- **Safety and Accessibility Checks:** All residences of people with developmental disabilities are inspected for compliance with safety and accessibility standards.
- **Consumer and Family Surveys:** Annually, about 25 states participate in the National Association of State Directors of Developmental Disability Services and Human Services Research Institute NCI survey, which canvasses consumer and family members to measure the satisfaction of people receiving services and to measure what services people report receiving. (<http://www2.hsri.org/nci>)
- **Critical Incident Reporting Process:** Most states have a critical incident reporting process, whereby developmental disability service providers report to the state developmental disability agency when certain incidents take place, such as the death of someone receiving services; use of restrictive procedures; allegations of abuse, neglect, or exploitation; or criminal behavior by or against someone receiving services.
- **Grievance and Appeals:** The only formal federal requirement for developmental disability service providers is that they provide rights of appeal for eligibility decisions. However, many states require each developmental disability service provider to have written grievance and appeals procedures and to inform applicants and service recipients of that process.
- **Abuse Complaints:** Any human service provider is legally required to file an immediate report of any suspected abuse, neglect, or exploitation of a vulnerable adult.
- **Medicaid Fraud Unit:** The Medicaid Fraud Unit is a specially staffed unit within the Office of the Attorney General. It investigates allegations of criminal activity, including abuse, neglect, or exploitation, in any Medicaid-funded facility or involving a person receiving Medicaid-funded supports.
- **Service Coordination:** The role of service coordinator or case manager often includes the functions of monitoring and advocacy. In some states, the service coordinator is the focal point for individual-based quality assurance at the local level.



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- **Advocacy:** Empowered service users and families are powerful components in the quality assurance chain. Self-advocacy groups work to empower people with disabilities to learn about their rights, step forward, and speak for themselves. In addition, advocacy organizations such as The Arc provide information, support, and advocacy for people with disabilities and their families.
- **Other Organizations:** Other organizations develop the capacity to monitor specific groups of people. For example, the Guardianship Trust in Vermont provides regular, structured individually based citizen monitoring of residential services provided by the state. Brandon Training School Association is an alliance of parents and other people concerned with the well-being of former residents of Brandon Training School.

Myth 3: *Community-based settings do not offer the same level of safety as institutional settings.*

All states take measures to make sure that people, whether living in institutions or in the community, are healthy, safe, and protected from harm. However, if the state's safeguards are not rigorous, closely enforced, and monitored, people with developmental disabilities are not safe, regardless of where they live. Two significant factors increase the risk of abuse and neglect: isolation from family and a system that rewards compliant attitudes among people with developmental disabilities (Valenti-Hein and Schwartz, 1995).

The NCI 2009–2010 survey shows that the majority of people with ID/DD feel safe in their home, in their neighborhood, and their work/day program/daily activity. More than 90 percent of the individuals surveyed reported that they have someone to go to when they feel afraid. Nevertheless, some opponents of deinstitutionalization claim that the safeguards offered in the community are inadequate to ensure the physical safety of a very vulnerable population.

Based on newspaper reports, Protection and Advocacy investigations, and state investigations, it is clear that instances of abuse and neglect occur in community settings, and some of them result in unnecessary deaths. However, the same can be said about institutions. For example, the 2009 “fight club” incident, in which institution workers forced residents to fight one another while employees taped the incidents on



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their cell phones, made national news. In 2007, the *Atlanta Journal-Constitution* published an exposé on state mental health hospitals that revealed more than 100 suspicious deaths of patients during the previous five years (Judd, 2010). The 2002 death of Brian Kent in Kiley Center in Waukegan, Illinois, revealed a pattern of neglect caused by unprofessional attitudes, administrative indifference, lack of competence, and caregiver fatigue (Equip for Equality, 2008).

As systems of care become more sophisticated and mature, states are able to move toward increasing their quality assurance efforts to protect health and safety. Missouri, for example, has instituted a Health Identification Planning System, which represents the quality monitoring process for the discovery and remediation of health and safety concerns for individuals in Division of Developmental Disability community residential services. A Health Inventory tool is completed on all people when they enter a community placement and annually, as well as when there are significant health changes. Regional Office registered nurses complete Nursing Reviews on individuals with a defined score on their health inventory. These reviews evaluate the provider's health supports and services, evaluate the individual's response to treatment, and identify unmet health care needs.

<http://dmh.mo.gov/docs/dd/directives/3090.pdf>

Missouri also created an Office of Constituent Services to serve as an advocate for people with ID/DD.

Myth 4: *Mortality rates are higher in the community for individuals with ID/DD than in Institutions.*

Older adults or adults who are medically fragile have a higher mortality rate regardless of where they live (or their geographic location). As a result, mortality comparisons are not straightforward and require complex statistical approaches. For example, a Massachusetts study on deaths showed that the average age at death varied across residential settings. The study indicated generally that the average age of death for each residential setting reflects the relative age and health status of the residents in each of the residential settings. The study also showed that mortality rates are lowest



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among people living at home or with family. (Center for Developmental Disabilities Evaluation and Research (CDDER), 2010). The study showed that people with developmental disabilities generally died of the same causes as the general population. Heart disease remained the leading cause of death and Alzheimer's disease the second leading cause.

The Massachusetts Department of Developmental Services (DDS), in collaboration with the CDDER, has focused on the health status of people with developmental disabilities. Examples of projects they have taken on in Massachusetts include the following:

- Identification and customization of a health screening tool for use by direct supportive providers
- Development of *Preventive Health Guidelines for Individuals with Mental Retardation*
- Root Cause Analysis training and support
- Incident Management protocol development
- Mapping the community-based system of mental health and physical health supports
- Annual mortality reports
- Annual Quality Assurance reports and the development of web-based Quality Briefs
- Implementation of the DDS STOP Falls Pilot to identify patterns and risk factors for falls among people with ID/DD
- Implementation and evaluation of a pilot study of DDS's new Health Promotion and Coordination initiative
- Support in development of training modules for community providers
- Quantitative analysis of clinical service capacity within the residential provider system
- Analysis of Medicaid pharmacy utilization claims data

An increasing number of states conduct mortality studies, review each death, and have proactively begun programs and initiatives to improve the health status of people with developmental disabilities. However, adults with developmental disabilities are more



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likely to develop chronic health conditions at younger ages than other adults due to biological factors related to syndromes and associated developmental disabilities, limited access to adequate health care, and lifestyle and environmental issues. They have higher rates of obesity, sedentary behaviors, and poor nutritional habits than the general population (Yamaki, 2005).

Most studies find that the mortality rate is comparable across settings or is favorable in community settings. For example:

- Conroy and Adler (1998) found improved survival for people leaving the Pennhurst Institution for life in the community and no evidence of transfer trauma.
- Lerman, Apgar, and Jordan (2003) found the death ratio of 150 movers who left a New Jersey institution was quite comparable to a matched group of 150 stayers after controlling for critical high risk variables.
- Heller et al. (1998) found that, although transitions from institutions or nursing homes to community settings may result in short-term stress and risks that *may* affect mortality (transfer trauma), the long-term survival rates improve.
- Hsieh et al. (2009) found that, regardless of residential location, those who had a greater variation in the physical environment and greater involvement in social activities had a lower risk of mortality.

Despite such findings, opponents of deinstitutionalization continue to use the mortality argument. In its advocacy literature, one group continues to cite Strauss, Eyman, and Grossman (1996) and Strauss, Kastner, and Shavelle (1998), who suggest that people with developmental disabilities, particularly those with severe disabilities, have higher mortality rates in the community than in institutions.

Subsequent studies did not reproduce these results. O'Brien and Zaharia (1998) question the accuracy of the database used by Strauss and colleagues, Durkin (1996) critiques Strauss's methodology, and Lerman et al. (2003) review a number of unsuccessful attempts to reproduce the results.



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Additional Resources

Additional resources are available on the topic area of “community” in the Deinstitutionalization Toolkit. These are external documents that may be accessed for a more in**DEPTH** review of the topic area.

➤ COMMUNITY – in**DEPTH**

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