



NATIONAL CONFERENCE
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The Forum for America's Ideas

Deinstitutionalization of Persons with Developmental Disabilities: A Technical Assistance Report for Legislators

January 2000

Deinstitutionalization of Persons with Developmental Disabilities: A Technical Assistance Report for Legislators

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National Conference of State Legislatures
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Contents

Executive Summary	vii
1. Introduction.....	1
2. Numbers, Settings and Public Support Programs for the Developmentally Disabled	3
3. What Are States Doing?	13
4. Barriers to Deinstitutionalization	20
5. Opportunities for State Action.....	22
6. Conclusion.....	27
Notes	29



The Forum for State Health Policy Leadership

The Forum for State Health Policy Leadership (the Forum) is a unit within the National Conference of State Legislatures whose mission is to enhance the capacity for informed decision-making and legislative leadership regarding the financing, organization and delivery of health care services to low income and vulnerable populations. Established in 1995, the Forum carries out a variety of initiatives that serve targeted constituents within NCSL and responds to emerging issues and complex problems facing state legislatures.

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Executive Summary

In June 1999, the U.S. Supreme Court addressed the debate about appropriate care options for people with disabilities. In *L.C. & E.W. vs. Olmstead*, the court ruled that states are required to provide community-based services for people with mental disabilities if treatment professionals determine that it is appropriate and the affected individuals do not object to such placement. The Court further concluded that states are responsible for community-based placement if they have the available resources to provide community-based services. States that maintain waiting lists must make a good faith effort to move those on the list to community programs at a reasonable pace.

This report provides profiles of states that have made innovative changes in their service delivery systems to increase the number of community-based placements and reduced institutional placements. Using information from interviews from state disability service agency directors, academics, advocates and state policymakers, this report answers the following questions:

- How far along are states in deinstitutionalizing their disabled populations?
- What percent of disabled people live in community settings and in state hospitals?
- What kinds of medical and social services do these populations need, and what are the service gaps?
- Are there any models of care that could be considered "best practices" for states?
- What are the costs associated with care for this population, and how are services funded?

The report finds that states have great flexibility through traditional Medicaid and Medicaid Home- and Community-Based Waiver programs to redesign their disability service delivery systems to emphasize community-based placement for persons with mental retardation and other developmental disabilities (MR/DD) who are capable of living in the community. Increased communication and cooperation among those with MR/DD and their families, state agencies, providers, policymakers and advocates have been instrumental in transforming systems that have relied too heavily on institutions to serve disabled populations.

The report also finds great variation in state progress and approaches to de-institutionalization. Nine states and jurisdictions—Alaska, the District of Columbia, Hawaii, Maine, New Hampshire, New Mexico, Rhode Island, Vermont and West Virginia—have closed all their public institutions. These states are considered the successful models of deinstitutionalization and the pioneering examples of states that have created community-



based delivery systems for their developmentally disabled populations. In addition, states like Michigan, Minnesota, Colorado and West Virginia have taken progressive steps to decrease the number of persons with MR/DD who are housed in public institutions.

The report concludes that, although barriers exist in some states that keep them from moving completely to a community-based service delivery system, states can use a number of strategies and proposals to eliminate their reliance on institutional care. These strategies include:

- Building community resource networks and community crisis/emergency response systems to address the reason people initially are institutionalized;
- Creating systems of long-term care for people with disabilities that are more consumer-driven and include more home- and community-based services;
- Developing guidelines that reflect the state's individual MR/DD populations and regional variations;
- Emphasizing the search for better ways to treat disabled individuals both medically and socially;
- Experimenting with various payment models for personal assistance services, such as direct payment for services and vouchers;
- Convening a task force of legislators, state agencies, providers, and people with developmental disabilities and their families to discuss and report on the service needs of people with developmental disabilities;
- Establishing a statewide data-collection system that identifies people with developmental disabilities, their demographic and personal characteristics, and their service needs; and
- Appropriating money to operate both the institutional and community services until a community-based infrastructure can be developed.



1. Introduction

During the past two decades, parents of the disabled, disability advocacy groups and state policymakers have worked to serve more people with developmental disabilities in the community rather than in large, state-operated facilities. As a result, the number of people with developmental disabilities in public institutions declined from 149,892 in 1977 to 51,485 in 1999.¹ However, many states have not been able to move quickly enough to accommodate the demand for community placements.

On June 22, 1999, the U.S. Supreme Court addressed this contentious issue. A recent Supreme Court case, *L.C. & E.W. vs. Olmstead*, highlighted that, although states generally support the idea of a community-based delivery system and provide community services, many of them continue to rely heavily on their public institutions to provide services to those with developmental disabilities who are capable of living independently. As result, many states, including Georgia, continue to maintain waiting lists of people with developmental disabilities who are hoping to receive care in less restrictive settings.

In the case, two mentally retarded women, L.C. and E.W. (also diagnosed with schizophrenia and personality disorder, respectively) were voluntarily admitted to a psychiatric unit of a Georgia state hospital. Their treatment professionals eventually determined that the women were qualified to receive care in an appropriate community-based program, but the women were placed on a waiting list for the services and remained institutionalized. The women filed suit against Georgia officials, alleging a violation of the Americans with Disabilities Act for the state's failure to place them in a community-based program.

The Court ruled that states are required to provide community-based services for people with mental disabilities if treatment professionals determine that it is appropriate and the affected individuals do not object to such placement.² However, the Court concluded that states are responsible for community-based placement if they have the available resources to provide community-based services. The Court also requires that states demonstrate that they have a comprehensive, effective working plan, including timetables and progress reports, for placing qualified people in less restrictive settings. States that maintain waiting lists must make a good faith effort to move people on the list to community programs at a reasonable pace.

In light of this ruling, an assessment of the trends and models of care for the developmentally disabled is warranted. More important, there is a need to disseminate as much accurate and useful information as possible about the needs of people with disabilities, as well as the delivery and financing of services targeted toward them. State policymakers will want to be aware of the approaches and options available to them as they respond to the needs of their constituents with developmental disabilities. The recent trends in closures of public institutions and the increasing cost of institutional care require that lawmakers develop innovative alternatives to expensive, often unnecessary institutional care. Because legislators control the funding for these programs, it is important for them to understand the service gaps in their state system of care for individuals with disabilities, the number of people who are in need of services and the sources of funding streams. Thus, this report attempts to answer the following questions:



- How far along are states in deinstitutionalizing their disabled populations?
- What percent of disabled people live in community settings and in public or private institutions?
- What kinds of medical and social services do these populations need, and what are the service gaps?
- Are there any models of care that could be considered "best practices" for states?
- What are the costs associated with care for this population, and how are services funded?

The purpose of this report is to educate legislators and legislative staff about a vulnerable population—persons with MR/DD—that often is overlooked. The report describes models of care and state approaches to serving their disabled populations. It also gives legislators options for providing appropriate and necessary community services to those with mental retardation and developmental disabilities who are capable of living independently, while ensuring their safety and continued access to needed services.

Background

In the early part of this century, people with mental retardation and other developmental disabilities received services in large public institutions or were cared for by their families with very little financial and social support from the government. In the 1960s, due largely to a series of class action lawsuits and the scrutiny of institutions by an increasingly vocal advocacy movement, the appalling conditions and the poor treatment of patients in these institutions were revealed. Thus, the debate about care options for the disabled shifted to the idea of deinstitutionalizing those with developmental disabilities who are capable of living in the community and developing a more flexible service delivery system to serve them. However, the early wave of lawsuits resulted in decrees requiring states to improve conditions at public institutions without expanding the options of care provided.

In the 1970s, legal challenges sought not only to improve the conditions in public institutions, but also to eliminate the unnecessary institutionalization of people with developmental disabilities who are capable of living in their own communities. Many experts agree that most people in state hospitals could live in the community if they had the appropriate services, such as intense supervision, therapy and 24-hour medical care. Many communities, however, fall woefully short in providing these services.

More recently, states have responded to the desire of people with developmental disabilities and their families for a range of options for care and independent living by increasingly replacing institutional care with community-based services. However, there is wide variation in the rates of deinstitutionalization, funding for community-based services and social and political commitments to developing a community-based delivery system.

In 1991, New Hampshire and the District of Columbia became the first state and jurisdiction to close their only public institutions for people with developmental disabilities and develop a delivery system based entirely on community-based services. Since then, six states—Alaska, Maine, New Mexico, Rhode Island, Vermont and West Virginia—have followed suit, and other states are using waivers and other innovative ways to reduce their dependence on institutional care.³ Once dominated by large state-run institutions, systems of care for people with developmental disabilities are undergoing continued change, with community services increasingly replacing institutional care.



2. Numbers, Settings and Public Support Programs for the Developmentally Disabled

Numbers

More than 3.6 million non-institutionalized Americans have either mental retardation or developmental disabilities.⁴ Roughly one out of 10 of them lived in a residential setting in 1998 (348,394), not including natural or adoptive families or psychiatric facilities.⁵ The high number of non-institutionalized people with developmental disabilities highlights the need to develop a service delivery system that does not depend upon public institutions to provide care.

People with mental illnesses have not received services in a community-based mental health delivery system to the extent that those with MR/DD have. In fact, the public mental health facility sector is relatively small in relation to the total population of people with severe and persistent mental illness.⁶ Deinstitutionalization of people with mental retardation and related developmental disabilities has been far less problematic than for the mentally ill population because: a) the population of persons with mental retardation and developmental disabilities is a more stable, easily identifiable and definable population than the population of those with mental illness; and b) the nature of admissions to psychiatric facilities tends to be episodic and transitory, because people with mental illness may use psychotropic drugs or therapy to substantially improve their conditions.⁷ Consequently, psychiatric facilities often have incidents of reinstitutionalization of those with mental illness, whereas facilities serving the MR/DD population do not.⁸

Settings

Deinstitutionalization involves not only the discharge of patients from large residential facilities, but also the reduction in admissions into residential facilities. As a result, there has been wide variety in the choices of settings for those with developmental disabilities. The nature of those settings has changed, with those with developmental disabilities now living in either small community intermediate care facilities for mental retardation (ICFs/MR), in their own homes, with their families or in foster care settings. For instance, the number of people (240,321) with mental retardation and developmental disabilities who received services through the Home- and Community-Based Services (HCBS) waiver program was nearly twice the number living in ICFs/MR (124,248) in 1998 (see figure 1 and table 1).⁹

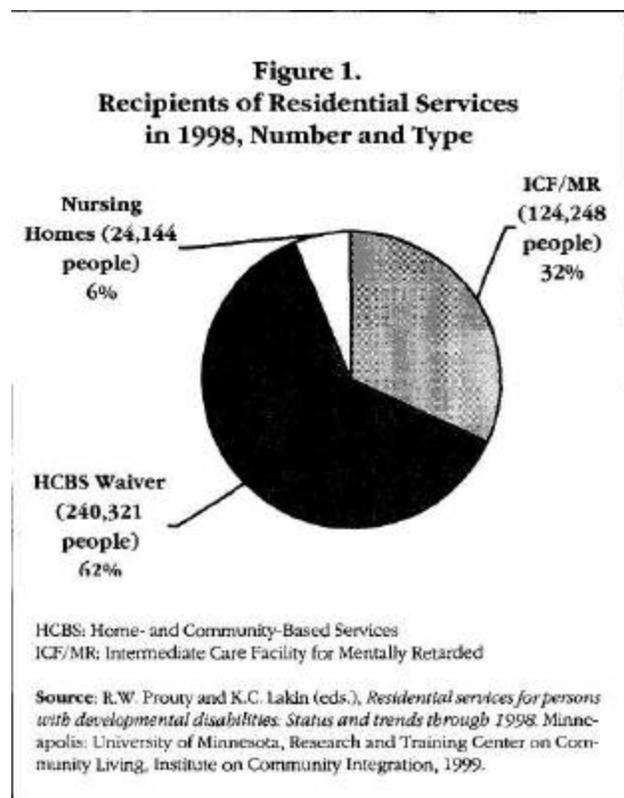


Table 1.
ICF-MR Residents and Medicaid Home- and Community-Based Service (HCBS)
Recipients with Mental Retardation and Related Developmental Disabilities by
State and Jurisdiction, 1998

State/ Jurisdiction	Total HCBS Recipients	HCBS Expenditures (in thousands)	Residents of All ICFs-MR	ICF-MR Expenditures (in thousands)
Alabama	3,713	\$77,000	734	\$56,664
Alaska	424	19,234	0	268
Arizona	9,248	211,971	215	0
Arkansas	646	16,815	1,749	109,175
California	33,202	436,829	10,835	391,152
Colorado	4,928	148,628	185	22,252
Connecticut	3,380	230,358	1,382	204,211
Delaware	382	17,679	285	32,558
District of Columbia	0	0	754	69,176
Florida	12,728	108,524	3,379	255,994
Georgia	2,400	83,000	1,732	106,845
Hawaii	759	17,100	120	10,027
Idaho	441	9,077	560	46,796
Illinois	6,037	151,000	10,789	610,073
Indiana	1,405	34,324	5,855	300,946
Iowa	4,058	51,737	2,154	177,480
Kansas	4,891	120,932	1,098	84,831
Kentucky	1,035	40,640	1,177	79,355
Louisiana	2,407	57,033	5,843	323,915
Maine	1,345	69,044	309	38,824
Maryland	3,353	140,673	593	55,636
Massachusetts	10,317	377,347	1,435	252,869
Michigan	5,708	237,666	2,830	242,896
Minnesota	6,710	311,248	3,419	223,835
Mississippi	413	1,526	2,351	131,471
Missouri	8,538	168,970	1,501	146,163
Montana	931	26,300	141	12,132
Nebraska	2,124	67,148	655	42,976
Nevada	392	8,353	286	25,449
New Hampshire	2,262	97,407	25	1,502
New Jersey	6,199	199,336	3,744	347,216



Table 1.
ICF-MR Residents and Medicaid Home- and Community-Based Service (HCBS)
Recipients with Mental Retardation and Related Developmental Disabilities by
State and Jurisdiction, 1998
(Continued)

State/ Jurisdiction	Total HCBS Recipients	HCBS Expenditures (in thousands)	Residents of All ICFs-MR	ICF-MR Expenditures (in thousands)
New Mexico	1,617	91,603	301	16,316
New York	30,610	1,343,414	11,083	2,047,529
North Carolina	3,986	134,167	4,705	380,157
North Dakota	1,819	33,850	609	44,306
Ohio	3,968	108,500	7,719	534,896
Oklahoma	2,586	119,328	2,705	106,414
Oregon	3,704	127,803	350	76,396
Pennsylvania	10,149	\$446,454	5,747	\$554,601
Rhode Island	2,296	125,265	0	5,893
South Carolina	3,701	70,200	2,439	172,453
South Dakota	1,619	40,462	263	20,469
Tennessee	3,823	96,593	1,709	243,620
Texas	5,666	210,317	12,832	646,618
Utah	2,647	58,316	811	43,955
Vermont	1,485	63,947	12	1,567
Virginia	3,138	88,557	2,109	160,217
Washington	7,125	115,511	1,081	127,047
West Virginia	1,679	57,751	454	48,656
Wisconsin	7,273	193,666	3,056	202,486
Wyoming	1,054	38,222	128	16,630
U.S. Total	240,321	\$7,100,826	124,248	\$9,852,914

Sources: R.W. Prouty and K.C. Lakin (eds.), *Residential services for persons with developmental disabilities: Status and trends through 1998*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, 1999; and B. Burwell, *Medicaid Long-Term Care Expenditures in FY1998*. Cambridge: The Medstat Group, 1999.

Between 1990 and 1998, the number of persons with MR/DD who received services through the HCBS waiver program increased by more than 200,000, from 39,838 recipients in 1990 to 240,321 in 1998 (see table 2). In addition, all 50 states had waivers to provide services to their MR/DD populations by 1996. In contrast, the total number of ICF/MR residents remained relatively constant between 1982 and 1994 with a corresponding decrease in the Medicaid expenditures for the ICF/MR program.¹⁰ Since 1994, the number of public ICF/MR beds has declined, but they have not been replaced with



Table 2. Home - And Community-Based Services Recipients by State And Jurisdiction, 1990-1998

State/ Jurisdiction	1990	1994	1998	Net Change 1990-1998
Alabama	1,839	2,900	3,713	1,874
Alaska	0	32	424	424
Arizona	0	6,773	9,248	9,248
Arkansas	91	429	646	555
California	3,628	13,266	33,202	29,574
Colorado	1,841	2,684	4,928	3,087
Connecticut	1,555	2,361	3,380	1,825
Delaware	196	310	382	186
District of Columbia	0	0	0	0
Florida	2,615	6,430	12,728	10,113
Georgia	160	556	2,400	2,240
Hawaii	123	513	759	636
Idaho	346	333	441	95
Illinois	724	4,590	6,037	5,313
Indiana	0	529	1,405	1,405
Iowa	5	879	4,058	4,053
Kansas	361	1,339	4,891	4,530
Kentucky	743	887	1,035	292
Louisiana	0	1,543	2,407	2,407
Maine	454	742	1,345	891
Maryland	858	2,787	3,353	2,495
Massachusetts	1,539	5,130	10,317	8,778
Michigan	1,658	3,367	5,708	4,050
Minnesota	2,184	4,385	6,710	4,526
Mississippi	0	0	413	413
Missouri	989	3,057	8,538	7,549
Montana	276	546	931	655
Nebraska	658	1,257	2,124	1,466
Nevada	133	172	392	259
New Hampshire	822	1,303	2,262	1,440
New Jersey	3,270	4,729	6,199	2,929
New Mexico	160	402	1,617	1,457
New York	0	18,877	30,610	30,610
North Carolina	731	1,318	3,986	3,255
North Dakota	1,055	1,509	1,819	764
Ohio	245	2,399	3,968	3,723
Oklahoma	621	1,693	2,586	1,965

Table 2.
Home- And Community-Based Services Recipients
by State And Jurisdiction, 1990-1998
(Continued)

State	1990	1994	1998	Net Change 1990-1998
Oregon	1,282	2,136	3,704	2,422
Pennsylvania	2,221	4,303	10,149	7,928
Rhode Island	277	1,333	2,296	2,019
South Carolina	0	966	3,701	3,701
South Dakota	721	1,004	1,619	898
Tennessee	581	964	3,823	3,242
Texas	485	1,564	5,666	5,181
Utah	1,200	1,590	2,647	1,447
Vermont	323	722	1,485	1,162
Virginia	0	715	3,138	3,138
Washington	1,250	3,068	7,125	5,875
West Virginia	316	803	1,679	1,363
Wisconsin	1,302	2,315	7,273	5,971
Wyoming	0	565	1,054	1,054
U.S. Total	39,838	122,075	240,321	200,483
Number of States with HCBS	42	49	50	

Source: R.W. Prouty and K.C. Lakin (eds.), *Residential services for persons with developmental disabilities: Status and trends through 1998*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, 1999.

Note: Italicized bold typeface indicates estimate.

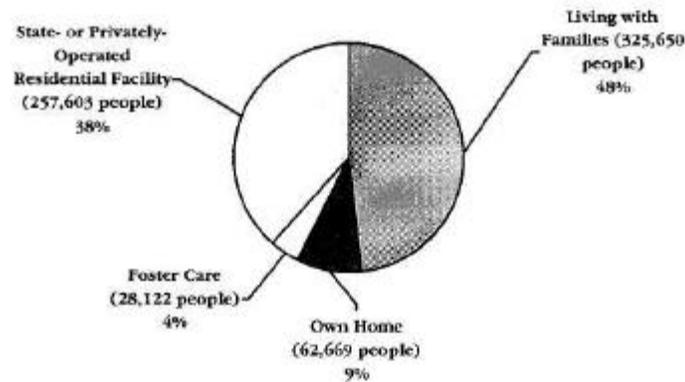
private ICF/MR beds. States have shifted to the HCBS waiver to fund services outside of public institutions.

More importantly, although 38 percent (257,603 people) of individuals with MR/DD reside in state-operated or privately-owned residential facilities, home settings continue to be a more typical option for those with mental retardation and developmental disabilities who need care. About 48 percent (325,650 people) of those receiving personal assistance, instruction, supervision and other support lived with their families, and another seven percent received those services in foster care settings (see figure 2).¹¹ About 14 percent (55,190 people) with mental retardation and related developmental disabilities receive services in their own homes.¹²

In addition, states have been moving toward an important care option for persons with mental retardation and developmental disabilities: smaller residential settings with bed



Figure 2.
Home Settings of People Receiving State Services, 1998



Source: R.W. Prouty and K.C. Lakin (eds.), *Residential services for persons with developmental disabilities: Status and trends through 1998*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, 1999.

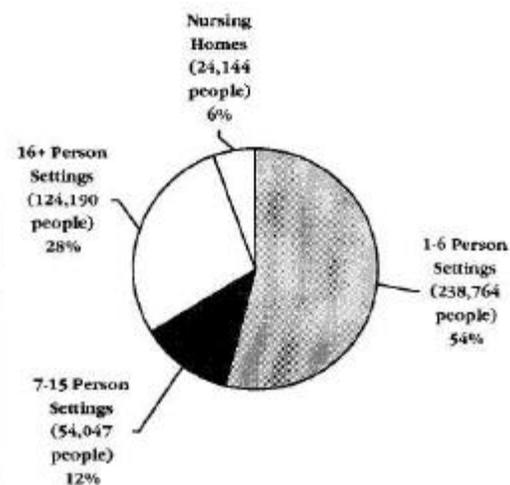
capacities of less than 15. As shown in figure 3, more than half (nearly 64 percent) of those with mental retardation and developmental disabilities who reside in residential settings live with 15 or fewer people. About half of all residential placements for those with MR/DD are in one-to-six person settings housing about 238,764 people, compared to 28 percent of the disabled who are placed in settings with 16 or more persons (124,190). The trend holds for both state and

non-state ICFs/MR. As seen in table 3, about 90 percent of all ICFs/MR accommodate one to 15 people, with the remaining 10 percent accommodating more than 16 people. In addition, the number of ICFs/MR that accommodate six or fewer people (4,006) is nearly twice the number that accommodates between seven to 15 people (2,379). In 1998, 19 states—Alaska, Arizona, California, Colorado, Connecticut, Hawaii, Kansas, Maine, Maryland, Michigan, Minnesota, New Hampshire, New Mexico, Oregon, Rhode Island, Vermont, Washington, West Virginia and Wyoming—provided 70 percent or more of residential services in settings for six or fewer persons.¹³

Public Support Programs

Several payment sources exist for medical care for the disabled—out-of-pocket; private health insurance; Medicare; Medicaid; and other programs, including veteran and military coverage and private pensions; and other sources such as workers' compensation and charities. About 31 percent of those with MR/DD who do not receive out-of-the-family home residential services are in households that have incomes at or below the federal poverty level, making the use of public support programs essential to receiving care.¹⁴ Medicaid and its related waiver programs are increasingly used to finance the services that people with mental retardation require whether they reside in public institutions, small group settings or their own homes.

Figure 3.
Residential Placements, 1998



Source: D. Braddock, R. Hemp, S. Parish, and M.C. Rizzolo, *The State of the States in Developmental Disabilities* (final report), Chicago: University of Illinois at Chicago, Department of Disability and Human Development, (in press).



Table 3. ICF-MR Certified Facilities and MR/DD Residents per 100,000 of Population by State and Jurisdiction, 1998

State/ Jurisdiction	1-6 Beds	7-15 Beds	1-15 Beds	16+ Beds	Total	Number of residents per 100,000
Alabama	0	3	3	4	7	16.3
Alaska	0	0	0	0	0	0.0
Arizona	0	4	4	2	6	5.5
Arkansas	0	30	30	10	40	49.1
California	970	49	1,019	31	1,050	12.1
Colorado	4	0	4	2	6	11.9
Connecticut	68	3	71	8	79	54.4
Delaware	1	1	2	1	3	36.4
District of Columbia	129	0	129	0	129	0.0
Florida	40	3	43	48	91	10.3
Georgia	0	0	0	6	6	21.2
Hawaii	20	1	21	1	22	2.0
Idaho	20	41	61	1	62	8.8
Illinois	42	218	260	63	323	27.9
Indiana	196	352	548	20	568	19.3
Iowa	57	37	94	28	122	30.0
Kansas	10	19	29	12	41	15.8
Kentucky	0	3	3	9	12	16.9
Louisiana	342	106	448	21	469	45.6
Maine	11	16	27	4	31	3.1
Maryland	0	0	0	4	4	11.5
Massachusetts	0	0	0	7	7	38.1
Michigan	436	0	436	2	438	2.9
Minnesota	141	118	259	37	296	10.6
Mississippi	0	34	34	5	39	75.1
Missouri	0	10	10	7	17	29.4
Montana	0	1	1	2	3	15.1
Nebraska	0	1	1	3	4	24.4
Nevada	15	2	17	2	19	10.7
New Hampshire	0	0	0	1	1	0.4
New Jersey	0	0	0	9	9	47.5
New Mexico	12	22	34	1	35	2.5
New York	122	624	746	86	832	56.0



**Table 3. ICF-MR Certified Facilities and MR/DD Residents
Per 100,000 of Population by State and Jurisdiction, 1998
(Continued)**

State/ Jurisdiction	1-6 Beds	7-15 Beds	1-15 Beds	16+ Beds	Total	Number of residents per 100,000
North Carolina	308	21	329	12	341	27.6
North Dakota	27	34	61	2	63	22.3
Ohio	53	229	282	97	379	18.0
Oklahoma	7	2	9	27	36	13.0
Oregon	0	0	0	2	2	12.4
Pennsylvania	134	80	214	33	247	24.2
Rhode Island	0	0	0	0	0	34.0
South Carolina	13	126	139	8	147	34.3
South Dakota	1	2	3	1	4	32.5
Tennessee	28	49	77	6	83	19.9
Texas	776	78	854	40	894	29.0
Utah	0	1	1	13	14	12.5
Vermont	2	0	2	0	2	0.0
Virginia	3	7	10	8	18	27.8
Washington	6	2	8	7	15	21.5
West Virginia	12	48	60	0	60	0.3
Wisconsin	0	2	2	37	39	19.3
Wyoming	0	0	0	1	1	26.6
U.S. Total	4,006	2,379	6,385	731	7,116	23.6
Percent of all ICFs-MR	56.3%	33.4%	89.7%	10.3%	100.0%	

Source: R.W. Prouty and K.C. Lakin (eds.), *Residential services for persons with developmental disabilities: Status and trends through 1998*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, 1999.

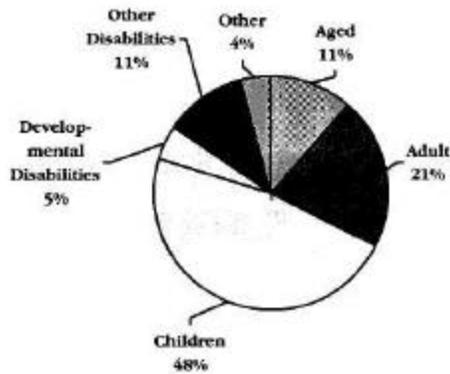
Medicaid

The federal- and state-funded program that provides health insurance to low income populations also is the largest single public funding source for services to people with developmental disabilities. In 1996, Medicaid funded nearly 71 percent of the total long-term care spending for MR/DD services.¹⁵ In 1995, about 1.8 million people with developmental disabilities received Medicaid.¹⁶ Of this population, roughly 1.4 million received only preventive and acute health care services paid through Medicaid, while ICF/MR and the Home and Community-Based Waiver Program provided long-term care services for about 330,000 people with mental retardation and other developmental disabilities.¹⁷

Although only five percent of Medicaid recipients have developmental disabilities, this population accounted for an estimated \$18.7 billion in Medicaid spending in 1995 (see figures 4 and 5). In fact, Medicaid spending for mental retardation and developmental



Figure 4.
Medicaid Recipients, 1995



Source: Health Care Financing Administration, 1996.

disabilities accounted for more than half of the total public spending (\$23 billion) on MR/DD services.¹⁸ In addition, as shown in figure 4, about 11 percent of Medicaid recipients have other physical or mental disabilities or are aged, making the MR/DD nearly the smallest population of Medicaid recipients (only the "other" category is smaller).

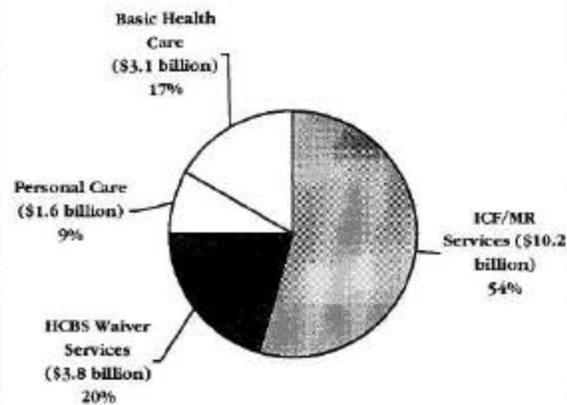
Of the \$18.7 billion in Medicaid spending for individuals with developmental disabilities in 1995, about half (54 percent) paid for ICF/MR services. Nearly one out of five dollars from Medicaid was spent on home- and community-based care provided through the HCBS waiver program, while only about 9 percent was spent on personal assistant care.

Home- and Community-Based Services Waivers

In 1981, Congress amended Title XIX of the Social Security Act to allow states to waive certain Medicaid requirements and permit payment of federal matching funds for an array of community services and supports—including case management, homemaker services, home health aid services, personal care services, adult day health, habilitation and respite care—for Medicaid-eligible people. Home- and Community-Based waiver (HCBS) services can be offered only to those who would otherwise be eligible for Medicaid and who are institutionalized.¹⁹ Those individuals who are found to require service in an ICF/MR, using the same or equivalent level of care criteria used in determining an individual's admissibility to an ICF/ MR, are eligible under the HCBS waiver.²⁰

Additionally, states must demonstrate the cost effectiveness of their waiver programs by assuring the Health Care Financing Administration (HCFA) that the average cost per person to provide HCBS care will not exceed the average cost per person of providing institutional services. By 1995, all states (except Arizona, which has an 1115 waiver) had at least one waiver serving people with developmental disabilities.²¹

Figure 5.
Medicaid Expenditures for Developmental Disabilities, 1995



Source: Health Care Financing Administration, 1996.

The HCBS waiver program has curbed the demand for ICF/MR services.²² Table 1 shows that the number of people (240,321) with mental retardation and developmental disabilities who received services through the HCBS waiver program was nearly twice the number (124,248) living in ICFs/MR in 1998. More important, the "Net Change 1990-



1998" column in table 2 reveals how quickly the HCBS waiver program has expanded to serve the MR/DD population since 1990.

Social Security and Supplemental Security Income

The Social Security Administration manages two programs that provide cash assistance to people with disabilities: Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). Beneficiaries in both programs are those who are determined to be "too disabled to work."²³ SSI provides low-income people with disabilities with an average monthly payment in 1999 of about \$500. SSDI, a social insurance program, is available to those who have worked and contributed to the Social Security trust fund.

SSI and SSDI are programs that do not specifically address community service needs for the disabled. They are mainly directed to addressing poverty due to unemployment. Such assistance, however, often is the basic building block for the financing of out-of-home living arrangements for people with developmental disabilities. As of 1997, 1,032,435 SSI recipients had a diagnosis of mental retardation (319,515 children and 712,920 adults).²⁴ Most people on SSI and SSDI rolls live at or below the poverty level and, therefore, are in no position to pay for institutional or home-based care unless they receive additional support. †



3. What Are States Doing?

Since the 1950s, the trend among state developmental disabilities agencies has been toward deinstitutionalization and community care. However, state approaches and progress vary considerably. Some states were spurred into action by a wave of class action litigation, while others have had few legal or legislative inducements to transform their delivery systems.

There is no dispute that the cost of institutional care is higher than the cost of services provided in community-based settings. The average cost of institutional care is more than six times the average cost of community-based care—\$94,348 for institutional care versus \$14,902 for community-based care.²⁵ This cost gap caused some states to increase spending on services provided through community-based programs (figure 6 contains a description of community-based services). By 1998, 45 states and the District of Columbia were spending more for community services for the developmentally disabled than for coverage for congregate residential services.²⁶ However, four states—Arkansas, Delaware, Kentucky and Mississippi—spent just as much or more for institutional care than for services provided in community-based settings.²⁷

Figure 6.

What Are Community-Based Services?

Community-based services are long-term support services for people who need help with activities of daily living (ADL) outside of large state institutions or nursing homes and in their own homes and communities. Community-based care originated as an outgrowth of the idea of meeting the needs of people with disabilities by emphasizing quality of life issues: presence in the community; health and safety; personal growth and opportunity; and self-determination. Community-based services include the following types of services, provided in community settings:

- Residential services and supported living facilities, including community-based residential placements in supervised apartments or group homes with case manager visits.
- Personal assistance services (PAS), including a range of human and mechanical assistance for those people of any age who require help with routine ADL and health maintenance.
- Care planning and case management, including a comprehensive assessment by a case manager and people with disabilities of their individual needs and the network of aid agencies and programs appropriate for providing care.
- Day programs, including placement in activity centers, habilitation and adult skills programs.
- Vocational services, including supported employment programs, vocational evaluations, job training and placement, and work adjustment programs.
- Other quality of life services, such as recreation and leisure activities, transportation and early intervention programs.

Trends

As noted earlier, there has been considerable variation in state progress and approaches to deinstitutionalization. Nine states and jurisdictions—Alaska, the District of Columbia, Hawaii, Maine, New Hampshire, New Mexico, Rhode Island, Vermont and West Virginia—have closed all their public institutions.²⁸ These states are considered to be successful

models of deinstitutionalization and the pioneering examples of states that have created community-based delivery systems for their developmentally disabled populations. In addition, states like Michigan, Minnesota, Colorado and West Virginia have taken progressive steps to decrease the number of those with MR/DD who are housed in public institutions.²⁹

However, some states continue to rely heavily on services provided in public facilities and have been slower to place people with disabilities in the community. Arkansas, Connecticut, Delaware, Louisiana, Mississippi, New Jersey, North Carolina, South Carolina, South Dakota, Texas and Virginia continue to rely heavily on their public institutions to provide services to their developmentally disabled population (see table 4). Most of these states have a comparatively high number of institutionalized people relative to the disabled population. More importantly, in these states 50 percent or more of those with MR/DD typically are committed to institutions for 16 or more people.³⁰ On a positive note, although some states lag behind others in reducing their institutional census, all states have reduced the number of people who receive service in large public facilities.

The trend toward closing institutions gained renewed momentum during the recession of the early 1980s. Successful litigation and more stringent federal enforcement of the ICF/MR regulations required more facility staff, which resulted in higher costs for facilities that were not downsized. There was new pressure to close institutions as average daily costs of institutional care began to increase and the number of those residing in institutions began to decrease. Because of declining numbers of residents in institutions, the average daily cost for living in an institution increased by 19 percent between 1988 and 1992.³¹ This increase occurred while the average daily institutionalized population decreased from 91,582 in 1988 to 75,477 in 1992, a difference of more than 15,000 residents.³² Today, the average daily cost for a stay in a public institution is \$258, compared to \$84 in an HCBS setting.³³

It is difficult for states to operate a completely community-based service delivery system when large public facilities are available as a "safety net." Moving large numbers of people from institutions to community settings requires that states provide a wide range of supports, including mental and physical health care, a crisis response system, housing assistance and income support. Some states have met the challenge.

*New Hampshire.*³⁴

New Hampshire was the first state to move to an exclusively community-based system. The state became an early innovator of a community-based system by enacting RSA-171-A in 1975, a law which mandated the development of individual service plans and created 12 area agencies designated to provide community-based services. Although New Hampshire had only one institution, a federal court decision in 1981 decreed that the state develop a community-based service system and eliminate unnecessary institutionalization. Thus, New Hampshire's Division of Developmental Services decided to pursue a plan that combined institutional reform and community placements.³⁵

In 1984, New Hampshire received a HCFA waiver to expand its community-based service system. Its use of HCBS waivers was more extensive than that of many other states, including case management, personal care and residential support, supported employment and environmental modifications such as home adaptations.³⁶ This use of the waiver was



**Table 4. State Progress in
Alternatives to Institutional Care**

States/Jurisdictions without Public Hospitals	States that Rely on Public and Private Institutions*		
	Very Limited Reliance (<20%)	Moderate Reliance (20% to 40%)	Extensive Reliance (more than 40%)
Alaska District of Columbia Maine Hawaii New Hampshire New Mexico Rhode Island Vermont West Virginia	Arizona California Colorado Kansas Massachusetts Michigan Minnesota Montana Oregon South Dakota Wyoming	Connecticut Florida Idaho Indiana Iowa Louisiana Maryland Missouri Nebraska Nevada New York North Carolina North Dakota Pennsylvania South Carolina Washington Wisconsin	Alabama Arkansas Delaware Georgia Illinois Kentucky Mississippi New Jersey Ohio Oklahoma Tennessee Texas Utah Virginia

Percentage of total out-of-home placements that are in public or private institutions serving 16 or more people.

Source: D. Braddock, R. Hemp, S. Parish, and M.C. Rizzolo, *The State of the States in Developmental Disabilities* (final report), (Chicago: University of Illinois at Chicago, Department of Disability and Human Development, in press); Interview with Gary Smith, National Association of State Directors of Developmental Disabilities Services, July 5, 1999.

the centerpiece of the Division of Developmental Services' plan to create "individualized housing and regular work opportunities."¹³⁷

The state continued to pursue a more extensive community-based system of care when the New Hampshire legislature passed the Family Support Act of 1989. The act provided direct financial support for community services by providing public funds for the 12 area agencies, which previously were not appropriated any public funds. The area agencies consist of private, autonomous providers that contract with the state to provide services.

The 12 area agencies are responsible for submitting to the state detailed plans—as well as progress reports and proposed budgets—for placing the disabled in the community. The agencies usually emphasize enhanced family care and out-of-region placements.

- *Enhanced family care placement*—Case managers attempt to locate people's most significant familial and community ties, regardless of the region, as the first setting for



potential placement. If a patient's family no longer lives there, managers pursue placements in surrogate families in the region where MR/DD patients grew up.

- *Out-of-region placement*—Case managers place the disabled in the regions in which they grew up as opposed to the regions where they may have received services in an institution. Because some regions may have a more extensive network of community-based services, managers are more likely to seek placements in those regions. However, attempts to place those with MR/DD in regions that may not have the most extensive network of care—but in which the patient once lived—prevents the over-utilization of services in a particular region.

By 1991, all the developmentally disabled had been placed in community settings. The last state institution, Laconia, finally closed because the vast majority of residents had been placed in the community. The state legislature aided the further development of the community system by allowing institutional funds to be transferred directly into the community services system instead of into the state general fund. In 1998, total spending for developmental disabilities was \$123.5 million, with community spending accounting for 99 percent of the total (\$122 million).³⁸ The remaining spending included federal ICF/MR reimbursements and state matching funds.

Maine. 39

The conditions in Maine's only institution, Pineland, resulted in a 1978 consent decree that required Pineland to provide better living conditions and treatment for its disabled residents. Between 1978 to 1994, local providers of community services began to expand and to improve the community-based service delivery system. As the disabled moved into the community, the money was available for those who needed services outside the institution, further expanding the community system. Community spending—as well as spending to finance institutional reform—increased steadily until 1992, when institutional spending began to decline and Pineland faced closure.

In 1994, another consent decree declared that the original 1978 decree could be vacated if Pineland were closed. The momentum already had moved away from providing institutional care. The executive and legislative branches allowed the courts and the bureaucracy to determine the movement to community-based care. The 1994 consent decree further expanded the use of community-based care by proscribing the use of a crisis response system in which emergency beds are made available for those who need them until a longer-term community setting is found.

Michigan.

Michigan provides an example of a state's persistently innovative role in transforming its MR/DD services delivery system. In 1979, 80 cents of every dollar spent on mental retardation residential and community services was allocated to state institutions.⁴⁰ Several developments helped transform Michigan's delivery system into a model for other states that want to decrease reliance on their institutions.

- The Macomb-Oakland Regional Center, opened in 1973, focused on family support services, family preservation and permanency planning. The center helped avert unnecessary institutional placement when support and services could be found in a community setting.



- A lawsuit, *Michigan Association for Retarded Citizens vs. Smith*, focused on the conditions found in the Plymouth Center, a large state institution.
- The Community Mental Health Act, enacted by the Michigan Legislature, provided financial incentives to county boards of mental health and retardation to provide community services. Funds that were saved from closures were reallocated to finance community residential services and family support.⁴¹
- The Michigan cash subsidy program provides \$250 per month for families earning up to \$60,000 to pay for clothing, education aids, out-of-pocket medical expenses and transportation. The program allows people with developmental disabilities to combine their cash subsidy with the \$5,500 from SSI. The subsidy eliminates the routine practice of reducing benefits from public programs when persons with MR/DD receive additional benefits from other programs.

As a result of Michigan's determined efforts, nine state institutions were closed between 1981 and 1996. In 1998, only 283 residents remained in state institutions, down from 12,615 in 1965. Furthermore, the cash subsidy program provided support to 4,645 individuals with MR/DD and their families in 1996. Nearly 7,000 families received respite care, counseling and in-home services. Michigan allocated 95 percent of its total mental retardation resources for family support and community care, compared to a national figure of 72 percent.⁴²

Waiting Lists

As the trend of deinstitutionalization gained wider support throughout the disabilities services community, the demand for community-based services has outpaced the rate of state expansion of community services. As a result, waiting lists for community-based residential services have become a reality for state developmental disabilities services agencies. Researchers and advocates consider waiting lists to be a reflection of system failure because it indicates that a state has been unable to expand its supply of services fast enough to accommodate the increase in demand for community care.⁴³

As shown in table 5, 37 states report a total of 46,482 people on waiting lists for residential services or community-based residential placement. Four states—California, North Dakota, Rhode Island and Wyoming—and the District of Columbia report that they have no one on waiting lists for residential services. Some states—such as Vermont, South Dakota and Kansas—have small waiting lists that reflect short gaps in providing services to individuals; it does not indicate shortfalls in capacity.⁴⁴

However, the more troubling data in Table 5 is the percent by which states must expand their residential service programs to accommodate those in need. For example, Alaska would have to expand its residential programs by 82 percent to accommodate the 337 people on its waiting list for services. Georgia, the state at the center of the *Olmstead* case, would have to expand its programs by about 40 percent to accommodate the 1,900 MR/DD people on its waiting list. Nationwide, there is a need for an approximate 18 percent growth in residential services to accommodate those MR/DD people who are on waiting lists. †

Table 5: People with MR/DD Who Were on Waiting List for, But Were Not Receiving, Residential Services, 1998

State/ Jurisdiction	Total Number on Waiting List	Total Residential Service Recipients	% Growth Needed to Match Needs
Alabama	1,043*	3,208	33.7%
Alaska	337	412	81.8
Arizona	108	3,000	3.6
Arkansas	DNF	4,104	DNF
California	0	43,931	0.0
Colorado	1,924	4,011	48.0
Connecticut	1,434	5,539	25.9
Delaware	DNF	781	DNF
District of Columbia	0	978	0.0
Florida	716	10,620	6.7
Georgia	1,900	4,795	39.6
Hawaii	0	1,257	0.0
Idaho	100	2,468	4.1
Illinois	DNF	16,580	DNF
Indiana	DNF	8,750	DNF
Iowa	DNF	7,627	DNF
Kansas	113	4,493	2.5
Kentucky	1,160	2,519	46.1
Louisiana	DNF	6,713	DNF
Maine	DNF	2,680	DNF
Maryland	DNF	4,929	DNF
Massachusetts	2,583	9,851	26.2
Michigan	DNF	9,708	DNF
Minnesota	936	12,101	7.7
Mississippi	DNF	2,959	DNF
Missouri	553	9,237	6.0
Montana	260	1,518	17.1
NE	1,219	2,941	41.4
Nebraska	164	852	19.2
New Hampshire	234	1,728	13.5
New Jersey	4,608	9,527	DNF
New Mexico	DNF	1,701	DNF
New York	6,611	35,488	18.6



**Table 5: People with MR/DD Who Were on Waiting List for,
But Were Not Receiving, Residential Services, 1998
(Continued)**

State	Total Persons on Waiting List	Total Residential Service Recipients	% Growth Needed to Match Needs
North Carolina	2,450	7,485	32.7
North Dakota	0	1,977	0.0
Ohio	DNF	16,588	DNF
Oklahoma	2,500	4,745	52.7
Oregon	2,250	3,955	56.9
Pennsylvania	5,000	17,140	29.2
Rhode Island	0	1,339	0.0
South Carolina	1,492	4,433	33.7
South Dakota	13	2,056	0.6
Tennessee	DNF	4,441	DNF
Texas	172	17,363	1.0
Utah	1,172	2,364	49.6
Vermont	8	1,007	0.8
Virginia	<i>2,897</i>	4,863	59.6
Washington	DNF	6,678	DNF
West Virginia	270	1,637	16.5
Wisconsin	<i>2,255</i>	12,386	18.2
Wyoming	0	931	0.0
State Reported Waiting Lists	46,482	254,041	18.3
U.S. Est. Total	<i>63,735</i>	348,280	18.3

?1997 data.

Key:

Italicized bold type face = estimate.

DNF = data not furnished.

Source: R.W. Prouty and K.C. Lakin (eds.) *Residential services for persons with developmental disabilities: Status and trends through 1998*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, 1999.

4. Barriers to Deinstitutionalization

Several barriers have precluded some states from expending the fiscal and political capital needed to successfully transform their delivery systems. First, there are major disincentives to move disabled people into community-based settings when states have inadequate budgets to cover community care. In the preliminary stages of reducing hospital admissions and developing community-based treatment options, states have to operate dual systems of care that may require higher appropriations.

Dual funding is usually the result of the states' reluctance to scale down institutional staffing in response to the reduction in the institutional population.⁴⁵ Costs could be minimized when appropriate cutbacks in facility operations are made, followed by the fairly rapid closure of an institution. States that operate dual systems of care maintain funding for an institutional care system while simultaneously supporting community living. As long as states continue to operate large public facilities, state funds will be used to support those facilities, per capita costs of operating facilities will continue to increase and expansion of community services will decline. Massachusetts, Illinois and Texas operate dual systems.

Second, even if states make a definite commitment to move those with MR/DD into community-based settings, they may encounter resistance from community residents who consider the placement of small group homes in their neighborhoods a social and financial blight. There is often local community resistance to locating MR/DD people in neighborhoods, as well as concerns about land use and economic development. This sentiment, "not in my back yard" (NIMBY), has been a source of major conflict in those areas where agencies are attempting to open small group homes to return those with developmental disabilities to the community and, in some cases, has resulted in state action to halt the purchase of small group homes. For instance, New Jersey's "fair share" law allows the state to reject the establishment of group homes in towns that have their fair share of group homes for the disabled.⁴⁶ The law was enacted in response to the criticism by some residents that too many group homes were located in their neighborhoods.

Third, some states that have implemented policies that emphasize community placement often have inadequate community medical care and services and also may lack formal training for physicians and medical providers in serving disabled populations. Inadequate systems of care can lead to a failure to provide quality care.

A fourth concern for states that are seeking to move to a community-based delivery system is high staff turnover due to such problems as inferior wages and benefits for support personnel in community settings and the lack of professional incentives and training for community-based medical personnel. These professionals and support staff often find it more professionally and financially rewarding to work in hospitals and institutions that can provide employee benefits and professional advancement. Moreover, many of these workers have been trained and apprenticed to provide treatment in large institutions that focus on uniform standards for a large population, not to respond to the individual needs of a single patient.

Fifth, some states have dispersed locations of treatment centers and personnel that are located near a state's large public institutions. Treatment centers and other supporting



institutions are likely to close or move in response to the closure of a public facility, leading to problems with service availability and accessibility of care. Without the anchor provided by institutions, it is difficult to anticipate where community-based services will be needed and where community settings are likely to be built. Additionally, rural areas often lack the necessary care infrastructure and information to adequately serve a deinstitutionalized population.

Sixth, there are institutional barriers to the development of a community-based delivery system. Private institutions have a vested interest in insurance policies that cover institutional care and increase their patient census counts, thus sustaining revenue and profits. Institutional facilities that are linked to for-profit corporations need high census counts to maximize profits.⁴⁷

Seventh, attempts to move to a community-based delivery system sometimes are hampered by the priorities and biases of government. The federal government's public finance programs are biased toward institutional care because such care is uniform for all residents. It also is easier for government to oversee monitoring and reporting of accounting and operations management. In addition, there is no incentive for states to use savings from closed institutions to pay for community-based programs. States typically find it more politically feasible to respond to what are considered more pressing issues such as building more prisons or increasing funding for education, for example.

Finally, although it is rare, clients and families sometimes oppose receiving services outside an institution. Some states have family group associations and trade unions that advocate better institutional care instead of institution closures. Some small but vocal parent groups consider public institutions the safest, most secure form of public assistance. In Illinois, for example, a parent group called Voice of the Retarded defends the use of public institutions and the care provided to their children.⁴⁸ |



5. Opportunities for State Action

Examples of State Success

States that have either closed all their public institutions for those with MR/DD or have substantially reduced their institutionalized populations have used a variety of methods to respond to their disabled populations and develop community-based service delivery systems. States can:

- 1. Build community resource networks and community crisis/emergency response systems to address the reasons people initially are institutionalized.⁴⁹**

Maine's three disability administrative regions each have a crisis response team and resource coordinators available to place those who need immediate care. The state has emergency beds in small settings and foster homes available as options for those in crisis. The crisis response team places these individuals for the short-term while resource coordinators look for appropriate long-term settings, such as family networks or foster care.⁵⁰

- 2. Develop new systems of long-term care for people with disabilities that are more consumer-driven, contain more home - and community-based services and are financed through local or regional networks.**

The legislature in New Hampshire passed legislation that created area agencies that are responsible for determining how much money will be distributed to families and individuals with disabilities who will make the financial and personal decisions about the types of care they require. Other than distributing the funds, the state bureaucracy does not mandate any specific services to the disabled.

Kansas has been so successful at expanding home- and community-based services that its state-operated facilities are shrinking due to lack of business.⁵¹ Those with disabilities stop seeking admission to state-operated hospitals to take advantage of Kansas' new network of community services. As a result, Kansas has closed its facility at Winfield and has shrunk to other facilities.

- 3. Develop guidelines that reflect the state's individual MR/DD populations and regional variations.⁵²**

In New Hampshire, 12 area agency boards are funded by the state to develop progress reports and proposed budgets for placing people in the community. The reports and proposed budgets are submitted to the state legislature, which uses them to assess the funding levels to provide to the area agencies in appropriations legislation. The agency board outlines the mix of case management, family support services and respite care that each region will provide, as well as how they will allocate funding within their region. Because the regions are not equally distributed by disabled population or budget, these regions often include in their plans ways in which they can work with other regions to place people with MR/DD in the community. For instance, most regions depend heavily on out-of-region placements; case managers determine if disabled individuals can be placed in a region of the state where the person's most significant familial relationships are found. Such placements redistribute and equalize the resource burdens among the regions.



4. Emphasize the search for better methods—both medical and social—to treat disabled individuals.

In Maine and New Hampshire, no announcements were made that public institutions would be closed. Both states had court orders and consent decrees to improve treatment of the MR/DD. To respond to the call for new treatment options, a community-based service system became the focus in these states. Consequently, public institutions were closed because few patients remained in those institutions. Announcement of hospital closures should be immediately accompanied by detailed information about how closure will proceed and how those with disabilities will be affected. Additionally, Kansas has responded to the need for better medical and social services for those with disabilities by allowing some people to choose the services they require. People with disabilities can now "self-direct" the services they need, including personal attendant services and medical treatment from nurses and doctors.⁵³

5. Experiment with various payment models for personal assistance services, such as vouchers and direct payment for services.

In 1984, Michigan instituted a cash subsidy program in which \$250 per month is provided for families that earn up to \$60,000 to pay for clothing, education aids, out-of-pocket medical expenses and transportation. Combined with the approximately \$5,500 that the mentally retarded receive in SSI payments, the costs for supporting families was one-tenth the annual cost of institutional care. Again, such a subsidy directly allows those with MR/DD to receive additional financial support without being penalized with reductions in financial support from the federal government.

In addition, the Robert Wood Johnson Foundation launched a cash subsidy program, *Putting People First: Initiative in Self-Determination for Persons with Developmental Disabilities*, in 1997. The initiative distributed more than \$5 million to states that implement pilot projects to reallocate state resources to assist those with MR/DD and the families gain control over their own personal care needs.⁵⁴ Nineteen states are participating in the program (see table 6).

Table 6.
States Participating in the Self-Determination Initiative

Arizona	Kansas	New Hampshire	Utah
Connecticut	Maryland	Ohio	Vermont
Florida	Massachusetts	Oregon	Washington
Hawaii	Michigan	Pennsylvania	Wisconsin
Iowa	Minnesota	Texas	

Oregon provides a good example of how state self-determination initiatives are designed to help those with MR/DD. Oregon's developmental disabilities agency received \$200,000 for two and one-half years to finance the Oregon Self-Determination Project to help reduce the number of patients admitted to the state institution and limit access to the state's system of congregate care.⁵⁵ The project created a brokerage to dispense service funds to



identify and pay for personalized care and support for 60 people with MR/DD. Those receiving services in the community, individuals on waiting lists and families with family support funding all are entitled to help from the service brokerage. The brokerage helps those with MR/DD find and gain access to community supports and develop personalized support plans and individual budgets, and serves as an intermediary for financial and personnel contracts between beneficiaries and support personnel.⁵⁶

What Can State Legislators Do?

There are a number of actions states can take should they choose to pursue the development of a disabled service delivery system that is based in the community. Legislators can:

- 1. Convene a task force of legislators, state agencies, providers and people with developmental disabilities and their families to discuss and report on the service needs of people with developmental disabilities.**

In 1989, before the closure of Vermont's only state institution, the director of the state Division of Mental Retardation issued a report, *The Unification Plan*, which included a collaborative statement from various state agencies and providers that outlined the problems, solutions, budgets and timelines for converting to a community-based system.⁵⁷ Likewise, New Hampshire's Division of Developmental Services collaborated with advocates and parents to create a multi-year community service development plan, *Action for Independence*. The plan recommended community spending options and the gradual transformation of the state's care system into a community-based system.⁵⁸ This development served as the blueprint for the state's benchmark legislative initiative that created the community-based delivery system.

- 2. Develop a statewide data-collection system that identifies people with developmental disabilities, their demographic and personal characteristics, and their service needs.**

Such data collection would provide state departments of developmental health services with information needed to help design community-based service systems that can efficiently and appropriately meet the needs of the MR/DD population. Such a system also would help to eliminate waiting lists because services can be developed in response to actual requirements of those in need. Oregon had developed an official community wait list, a detailed database of Oregon citizens who are eligible for developmental disability services but who are not offered such services because of lack of funding.⁵⁹ The list divides and categorizes those with developmental disabilities based upon the level of assistance needed ranging from minimal assistance with daily activities to 24-hour care and supervision, and attention to specialized medical needs.

- 3. Direct state departments of developmental health services to develop state wide systems of community-based services.**

The Vermont legislature passed the Developmental Disabilities Act of 1996, mandating that the state Department of Developmental and Mental Health Services consult with people with developmental disabilities to determine the services needed, operate a com-



munity-based system, adopt timelines and budgets for providing services and evaluate the success of its services.⁶⁰ As a result, state administrators and directors of community health centers were committed to developing individualized approaches to providing services by reducing the number of agency-operated facilities and deciding funding levels on an individual basis.

4. Appropriate money to operate both the institutional and community services until a community-based infrastructure can be developed.

Massachusetts continues to appropriate financial resources to mental retardation services in state institutions, while simultaneously expanding its use of the HCBS waiver. Massachusetts is gradually and responsibly phasing out its reliance on institutional care with recent closures of two state institutions and an additional closure planned by the year 2000.⁶¹

5. Help provide financial support for the families of persons with MR/DD.

New Hampshire established a statewide family support network in which families that are caring for people with developmental disabilities are provided with financial support. The state legislature passed the Family Support Act of 1989, in which money was appropriated to the state's 12 area agencies for family support services.⁶² The area agencies determine how much and to whom the money is distributed. This act shifted the balance of power for care from the bureaucracy to families and individuals with disabilities.

Legislatures also can help by exempting from state taxation payments in support of people with developmental disabilities. Vermont's legislature included in its Developmental Disabilities Act a provision that exempts payments to families who care for people with developmental disabilities from taxation by not classifying the payments as income.⁶³

6. Audit and monitor plans for community-based services.

As suggested by the *Olmstead* decision, states may want to devise plans to develop and to assess the progress of moving toward community-based service systems under the Americans with Disabilities Act. The New Hampshire legislature already requires that its 12 area agencies submit budgets and progress reports before they can be redesignated as area agencies that are qualified for continued financial support. For instance, the area agency community boards of directors must show that all decisions are made with direct consumer input and that agencies and providers cooperate to efficiently administer services.

7. Provide training to employees to ensure a smoother transition from institutions to community-based programs.

Some states have worked with employees' unions to redeploy institutional staff to community programs. In Vermont, the state Department of Employment and Training opened an office on the campus of its only public institution—Brandon Training School—before it was closed to provide computer banks and resume books for job searches. The Agency of Human Services gave Brandon workers special priority for state job openings.⁶⁴

In addition, New Hampshire provides training in a program called PASSING (Program Analysis of Service Systems' Implementation of Normalization Goals), which seeks to develop within its disabilities services staff and professionals a strong commitment to community placements and to offer job opportunities within the state for former institutional staff.⁶⁵ New Hampshire also has the Institute on Disability, which provides training and internships to graduate and undergraduate students in the state's higher education system. |



6. Conclusion

The environment is ripe for those states that want to expand the care options for their MR/DD populations. New perspectives and a clearer understanding of the lives of people with disabilities have demonstrated the capacity of persons with MR/DD to live independently and safely. As a result, all states have expanded their community-based delivery service systems to offer many services that, in the past, could be received only in an institutional setting.

More importantly, states have found the federal government far more willing to defer to state government and their developmental disabilities services agencies in the administration of their disabled service delivery systems. Consequently, states have been more innovative and proactive as they expand community services through the Home- and Community-Based Services waiver program. Also, states with highly developed community-based programs have shown that, with open communication with persons with MR/DD, their families, advocates, providers and state agencies, a service delivery system based on uniformity can be transformed into a community-based system where individual needs and independence of the disabled are essential components.

Finally, states like New Hampshire, Michigan and Vermont have shown that there is no uncharted territory for other states that are seeking to expand community-based services. States have implemented a range of policies from closure of their large state institutions and the elimination of unnecessary institutionalization to the distribution of direct cash subsidies to allow those with MR/DD to make their own purchasing decisions to support their needs. Although some states may be less likely to move as quickly as others in expanding service options for disabled populations, it is important that state policymakers understand what is possible and the options that are available to meet the needs of their disabled citizens. |



Notes

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This report was prepared by The Forum for State Health Policy Leadership. The Forum works to enhance the capacity for informed decision making and leadership among legislators on critical health policy issues.

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