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Trends and Issues in the Medicaid 1915(c) Waiver Program

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Over the past 15 years, Medicaid 1915(c) home and community-based waivers have made a substantial contribution to States' efforts to transform their long-term care (LTC) systems from largely institutional to community-based systems. By 1997, every State had implemented a waiver program for at least some subgroups of individuals with disabilities, and expenditures increased from $3.8 million in 1982 to more than $8.1 billion in 1997. Emerging, as well as long-standing, policy issues related to the waiver program include concerns with access, variation in availability by disability group, State decisions related to the provision of community-based LTC, and evidence on effectiveness.

INTRODUCTION

State efforts to transform their LTC systems from institutional to community based have been fueled by a variety of forces. Many consumers and their families and advocates view community-based care as essential to attaining LTC goals such as independence and social integration (Batavia, DeJong, and McKnew, 1991; Kaye and Longmore, 1998). These goals have been strengthened by legal remedies such as the Americans with Disabilities Act and made more viable by technological change. Against rising Medicaid expenditures, particularly those funding LTC, many view home and community-based services to be more cost effective (Wiener and Stevenson 1998). Cost effectiveness may be more likely for certain segments of the population experiencing disability (e.g., persons with acquired immunodeficiency syndrome [AIDS]; Master, et al. 1996), when targeted to those with serious impairments (Alecxih, Lutzky, and Corea, 1996), or when combined with State actions to decrease institutional capacity (Coleman, Kassner, and Pack, 1996; Ladd et al., 1995).

Six States participated in the 1915(c) waiver program in 1982, operating one program each. By 1997, every State had been approved for a 1915(c) waiver program for at least some subgroups of individuals who are disabled, reflected in a total of 221 approved waiver programs. (Arizona's program is operated under its 1115 demonstration waiver.) As the number of waiver programs has grown, expenditures have increased from $3.8 million in 1982 to more than $8.1 billion in 1997. In that same year, the waiver program comprised 14.4 percent of Medicaid LTC expenditures.

Despite the general trend in increased use and expenditures related to home and community-based waiver services, some States have more actively turned to this programmatic opportunity to reconfigure their LTC systems. In 1997, Oregon and Vermont targeted more than 40 percent of Medicaid LTC dollars to 1915(c) services. In contrast, Mississippi devoted only 2.1 percent of its LTC dollars to community-based care through a 1915(c) waiver program.

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The purpose of this article is threefold: (1) to update trends in State use of the 1915(c) waiver program; (2) to provide waiver-specific data related to the number of beneficiaries receiving services as well as the types and costs of services they receive; and (3) to highlight emerging as well as long standing issues related to the provision of home and community-based care.

BACKGROUND

The home and community-based services waiver program was established under section 2176 of the Omnibus Budget Reconciliation Act of 1981 (Public Law 97-35), which added section 1915(c) to the Social Security Act for the Medicaid program. This section authorized HCFA to waive certain Medicaid statutory limitations in order to allow States to cover home and community-based services that individuals might need to avoid institutionalization. Initially, coverage was limited to those who would otherwise require the level of care provided in a skilled nursing facility (SNF), intermediate care facility (ICF), or intermediate care facility for the mentally retarded (ICF/MR). The Consolidated Omnibus Budget Reconciliation Act of 1985 (Public Law 99-272) added section 9502, which permitted States to offer home and community-based services to ventilator-dependent individuals requiring a hospital level of care. The Omnibus Budget Reconciliation Act of 1986 (Public Law 99-509) added section 9411 to eliminate the requirement for being ventilator-dependent and expanded the waiver authority to any individual who would otherwise require Medicaid-funded long-term hospital care.

Under the 1915(c) waiver program, States may develop waivers that provide services to targeted subgroups of individuals with disabilities. Focused initially on the frail elderly or individuals with developmental disabilities, States have expanded target groups to include adults and children with AIDS, working-age adults primarily with physical disabilities, children experiencing a variety of disabling conditions, and persons with serious mental illness. These expansions relate in part to the legislative expansions previously discussed and in part to changes in the way cost neutrality is calculated (described later). As well, States have turned to community-based care as a cost-containment strategy (Wiener and Stevenson, 1998) and to be responsive to individuals with disabilities and their families, who often view community-based care as essential to attaining LTC goals.

States may provide a range of non-medical services, such as case management, homemaker services, personal care, and adult day care, as well as medical services, such as nursing, under their waiver programs. States maintain the flexibility to define specific services covered in each waiver program, as well to define the geographic area for the waiver program. In limiting the 1915(c) waiver program to one or more eligibility groups (e.g., the frail elderly, persons with AIDS), the State may also modify certain financial-eligibility requirements as well as functional requirements. For example, at the State's option, the financial-eligibility criteria used to determine eligibility for an institutional level of care (set higher, so that an individual may have a higher income and retain greater assets than for the general Medicaid program) can be used to determine eligibility for 1915(c) services. In 1997, 38 States used these more lenient standards in determining financial eligibility.

As a control for growth of the 1915(c) waiver program, States originally were required to document that for each person enrolled in a waiver program, a bed was

available for that person in an institution. This stipulation was known as the "cold bed policy," which meant that States had to demonstrate the capacity to institutionally serve both the current institutionalized population as well as the 1915(c) waiver beneficiaries. The need to provide this demonstration was replaced in 1994 with an assurance that, absent the waiver, participants would receive the appropriate type of Medicaid-funded institutional care, giving States increased flexibility to enroll participants in 1915(c) waivers.

In 1990, a survey was conducted regarding State plans for the waiver program. States were found to be supportive of the home and community-based waiver services but reported that changes were needed to reduce the administrative and reporting burdens of the States. In response, HCFA's Medicaid Bureau undertook a number of initiatives to improve administration and to encourage provision of home and community-based services under the waiver program. The Medicaid Bureau developed a streamlined application in 1992 for States to use in their waiver submissions. Additionally, several workgroups were formed to address various issues relevant to the 1915(c) waiver program.

More recently, HCFA has provided States with a prototype waiver application for individuals with AIDS, individuals with traumatic brain injury, and medically fragile children to expedite approval of these waivers. States may now establish a 1915(c) waiver program for these individuals by attaching State-specific information, signing, and submitting the prototype waiver application.

DATA SOURCES

Two sources of administrative data are available from HCFA on the home and community-based services waiver program. HCFA Form 64 is a quarterly financial management report that States submit to the Federal Medicaid program in order to obtain Federal matching funds. This report divides home care data into three categories—home health care, personal care, and 1915(c) waiver services—and reports program expenditures. Second, States are required to report all beneficiaries and expenditures for the 1915(c) waiver program on HCFA waiver report Form 372. The first HCFA-372 report for each waiver must have data from the effective date of the waiver to the end of 1 full year. Six months after the end of each year, States are required to submit initial reports for the previous year's waiver services. One year later (18 months after the end of the waiver year), States are required to submit "lag (final) reports," which include all revisions, adjustments, refunds, recoupments, cost settlements, disallowances, and other changes in HCFA-372. Initial and lag reports are submitted for subsequent waiver years in the same manner. In addition, States must include an annual unduplicated count of all individuals who receive services. Individuals frequently receive several different services or receive them on multiple occasions during the year, so that all expenditures must be reported for the unduplicated beneficiaries in each waiver category.

The waiver data for this article were compiled using both Form 64 data and HCFA-372 reports. Because Form 64 data are the basis for claims by States for Federal matching funds, Form 64 is considered to be a more reliable source for expenditure data than HCFA-372 and is the data source for expenditure trends. HCFA-372 waiver reports, collected for 1992, were used to provide a detailed, although time-limited, description of the number of beneficiaries, types of services, and aver-

age cost per beneficiary participating in the waiver program[1] (Harrington and DuNah, 1994).

1915(c) WAIVER PROGRAM GROWTH

By 1997, all States and the District of Columbia had been approved for a 1915(c) waiver program. (Arizona's program is operated under its 1115 demonstration waiver.) The 221 approved waiver programs targeted six eligibility groups, including the frail elderly, working-age individuals with disabilities, people with developmental disabilities, persons with AIDS, children with a variety of disabling conditions, and individuals with serious mental illness. In 1997, States were approved for between 2 and 11 separate waiver programs, with multiple waivers sometimes operational for a selected target group (Table 1). Forty-nine States targeted a 1915(c) waiver program to people with developmental disabilities. Forty-eight States targeted waiver services to frail elderly individuals through separate or combined aged/disabled waiver programs. Forty-five States provided 1915(c) services to working-age individuals with disabilities under separate or combined aged/disabled waivers. Colorado covered every disability group under 11 separate waiver programs (although the waiver for individuals with serious mental illness was limited to children). Five States covered all eligibility groups in the waiver programs, with the exclusion of people with serious mental illness, and two States provided services to every group except persons with AIDS (again excluding adults with serious mental illness in their serious mental illness waiver).

As shown in Table 1, one-third (33.9 percent) of the waivers operational in 1997 were targeted to people with developmental disabilities, including 14 programs that provided services to children and adults. Most frail elderly waiver services were provided under a combined aged/disabled waiver program; although 19 (8.6 percent) waiver programs targeted only the frail elderly, 48 (21.7 percent) offered services to both the frail elderly and working-age persons with disabilities. Thirty-nine waiver programs (17.6 percent) were targeted specifically to working-age people with disabilities. Sixteen waiver programs (7.2 percent) served persons with AIDS, including four that served children. The fewest waiver programs (three) were targeted to children with serious mental illness.

Medicaid home and community-based waiver expenditures totaled $8.1 billion in 1997, up from $1.2 billion in 1990 (Table 2). This growth in expenditures can be contrasted with rates of growth for total Medicaid expenditures as well as Medicaid LTC expenditures. Between 1990 and 1997, 1915(c) waiver expenditures grew at an average annual rate of 30.9 percent, in contrast to 9.7 percent for Medicaid LTC expenditures and 13.0 percent for total Medicaid expenditures.

States vary in the proportion of LTC expenditures allocated to 1915(c) services. As shown in Tables 3 and 4, two States, Oregon and Vermont, targeted 40 percent or more of their Medicaid LTC dollars to waiver services, and New Mexico targeted 39 percent of LTC dollars to these services. Seven States devoted 10 percent or less of their LTC dollars to 1915(c) services, with Mississippi setting the low at 2.1 percent. (The District of Columbia had not yet reported 1997 expenditures for its two approved waivers.)

[1] HCFA-372 data provide a rich description of program trends over time, as they allow one to examine changes in services offered, expenditures by type of service, expenditures per participant, and similar data that are not seen in aggregate State data. These data are difficult to collect, as they reside in HCFA central and regional offices and in individual State Medicaid agencies. HCFA awarded a contract to the University of California San Francisco in 1997 to collect these data for the period 1993 through 1998, and they will be analyzed in subsequent work.

Table 1

1915(c) Waiver Programs, by State and Disability Group: Fiscal Year 1997

State	Total	Aged	Aged/ Disabled	Disabled	Develop- mentally Disabled	AIDS	Children	Chronic Mental Illness
Total	221	19	48	39	75	16	21	3
Alabama	3	—	1	1	1	—	—	—
Alaska	4	1	—	1	2	—	—	—
Arkansas	4	—	2	1	1	—	—	—
California	6	1	2	—	1	1	1	—
Colorado	11	—	1	1	6	1	1	1
Connecticut	5	—	1	2	2	—	—	—
Delaware	3	—	1	—	1	1	—	—
District of Columbia	2	—	—	—	1	1	—	—
Florida	8	2	2	1	2	1	—	—
Georgia	4	—	1	1	1	—	1	—
Hawaii	3	—	2	—	—	1	—	—
Idaho	3	—	1	—	2	—	—	—
Illinois	7	1	—	1	2	1	2	—
Indiana	4	—	1	1	1	—	1	—
Iowa	6	1	—	1	3	1	—	—
Kansas	6	1	—	2	1	—	1	1
Kentucky	4	—	1	1	1	—	1	—
Louisiana	4	—	2	1	1	—	—	—
Maine	4	1	—	2	1	—	—	—
Maryland	3	1	—	—	1	—	1	—
Massachusetts	2	1	—	—	1	—	—	—
Michigan	3	—	1	—	2	—	—	—
Minnesota	5	1	—	3	1	—	—	—
Mississippi	3	—	1	1	1	—	—	—
Missouri	4	1	—	—	2	1	—	—
Montana	2	—	1	—	1	—	—	—
Nebraska	5	—	1	—	3	—	1	—
Nevada	4	2	—	1	1	—	—	—
New Hampshire	3	1	1	—	1	—	—	—
New Jersey	9	—	4	2	1	1	1	—
New Mexico	3	—	—	—	1	1	1	—
New York	9	—	1	1	3	—	3	1
North Carolina	4	—	1	—	1	1	1	—
North Dakota	3	—	1	1	1	—	—	—
Ohio	4	—	1	1	1	—	1	—
Oklahoma	3	—	1	—	2	—	—	—
Oregon	2	—	—	1	1	—	—	—
Pennsylvania	8	1	1	2	2	1	1	—
Rhode Island	4	1	1	1	1	—	—	—
South Carolina	5	—	1	2	1	1	—	—
South Dakota	3	1	—	1	1	—	—	—
Tennessee	3	—	2	—	1	—	—	—
Texas	6	—	1	—	4	—	1	—
Utah	4	1	—	1	1	—	1	—
Vermont	4	—	2	1	1	—	—	—
Virginia	7	—	4	1	1	1	—	—
Washington	5	—	1	1	2	1	—	—
West Virginia	2	—	1	—	1	—	—	—
Wisconsin	5	—	1	1	2	—	1	—
Wyoming	3	—	1	—	2	—	—	—

NOTES: AIDS is acquired immunodeficiency syndrome. Arizona provides home and community-based care services under its 1115 demonstration waiver; it is not included in these administrative data.

SOURCE: Health Care Financing Administration administrative data: home and community-based services waivers: regular waiver report and model waiver report, August 1, 1997.

Table 2

Medicaid Expenditures for Long-Term Care Services: 1990 and 1997

Type of Service	1990	1997	Average Annual Percent Change in Rate of Growth 1990-1997
	Thousands of Dollars		
Total Medicaid	$69,754,411	$160,256,207	13.0
Total Long-Term Care	29,549,822	56,124,582	9.7
Personal Care	1,864,565	3,207,381	8.3
1915(c) Waiver	1,246,722	8,107,233	30.9
Home Health Care	813,497	2,189,562	15.4
Frail Elderly	0	91,516	NA
Intermediate Care Facility	10,111,868	0	NA
Skilled Nursing Facility	7,874,013	32,532,667	8.9
Intermediate Care Facility for the Mentally Retarded	7,639,157	9,996,224	4.0

NOTE: NA is not applicable.

SOURCE: HCFA Form 64 data, Office of State Agency Financial Management.

Services and Expenditures by Target Group

To provide a more detailed picture of services and expenditures by target group, Tables 5 through 7 summarize waiver-specific data collected for 1992 from HCFA and States. Table 5 shows the number of waivers, dollars, and beneficiaries for different types of services for the 151 operational 1915(c) waivers in 1992 (data on services were unavailable for 12 States). The highest service expenditure category ($838 million) was for habilitation services (training in self-care), and this service also had the highest average expenditure per participant. (Habilitation services are for service costs and are not allowed to include room and board costs.) Personal care was the next-highest expenditure category ($287 million), followed by homemaker services ($217 million). However, the average expenditure per individual for these services was lower than for habilitation services. (The distinctions between homemaker and personal care services were not necessarily clear, because States were allowed to apply their own definitions to services, and the definitions varied across waivers and across States.) Personal care can be provided as a Medicaid State optional service, but almost one-half of the 1915(c) waiver programs also included personal care.

As demonstrated in Table 6, certain services dominated waiver programs, dependent on the particular population served. All waiver programs for people with developmental disabilities included habilitation; respite services and case management were provided in more than two-thirds of the waivers for these individuals. Day care (73.9 percent), respite care (71.7 percent), and case management (71.7 percent) were the most frequently provided service in waivers serving the frail elderly or combined aged/disabled populations, and more than one-half (54.3 percent) of these waiver programs also provided personal care. In 1915(c) waiver programs targeted solely to younger people with disabilities, virtually all (92.3 percent) provided case management; 53.8 percent also provided personal care. Nursing services were the dominant waiver service for persons with AIDS (86.7 percent) and waivers targeted toward children (75.0 percent). Case management was provided in at least one-half of the waiver programs, regardless of target group; it is most frequently provided in waivers serving non-elderly individuals who are disabled. (It should be noted that

Table 3
Medicaid Long-Term Care Spending, by Program: 1990

State	Total in Millions of Dollars	Skilled Nursing Facility	Intermediate Care Facility	Intermediate Care Facility for the Mentally Retarded	Home Health Care	Home and Community-Based Care 1915(c) Waivers	Personal Care	Support for Community-Based Care
					Percent			
Alabama	$276.1	8.2	52.6	23.3	5.1	10.8	0.0	15.9
Alaska	46.2	9.7	65.5	22.4	0.4	0.0	2.0	2.4
Arizona	85.0	44.9	15.5	39.6	0.0	0.0	0.0	0.0
Arkansas	280.0	49.3	14.6	26.3	1.6	0.2	8.0	9.8
California	1,776.0	73.7	1.7	21.8	0.8	2.0	[1]0.0	2.8
Colorado	268.1	42.7	16.2	19.5	1.7	19.9	0.0	21.6
Connecticut	821.1	9.7	57.3	20.2	4.3	8.5	0.0	12.8
Delaware	71.1	9.4	51.5	27.1	5.8	6.2	0.0	12.0
District of Columbia	136.8	8.5	63.5	20.4	2.9	0.0	4.6	7.5
Florida	854.5	14.7	61.1	18.4	2.0	3.8	0.0	5.8
Georgia	515.1	20.1	47.6	19.9	7.1	5.3	0.0	12.4
Hawaii	87.5	21.0	65.8	7.7	0.7	4.8	0.0	5.5
Idaho	79.6	17.3	37.8	35.7	1.4	7.8	0.0	9.2
Illinois	1,063.8	11.0	50.1	32.6	0.6	5.7	0.0	6.3
Indiana	651.1	17.5	54.1	26.2	2.2	0.0	0.0	2.2
Iowa	279.7	2.4	51.3	42.8	3.2	0.3	[1]0.0	3.5
Kansas	236.2	1.3	55.2	37.3	1.4	4.8	[1]0.0	6.2
Kentucky	341.3	13.7	53.8	14.8	10.5	7.2	0.0	17.7
Louisiana	486.6	2.6	52.9	42.6	1.7	0.2	0.0	1.9
Maine	241.1	3.4	62.1	23.2	2.5	7.8	1.0	11.3
Maryland	426.5	4.5	64.4	16.7	1.4	9.4	3.6	14.4
Massachusetts	1,655.4	32.5	32.8	24.2	0.2	3.0	7.3	10.5
Michigan	797.1	9.5	47.0	26.7	1.8	2.4	12.6	16.8
Minnesota	905.9	44.0	14.8	27.8	1.5	7.9	3.9	13.3
Mississippi	198.6	37.8	35.7	22.9	3.0	0.6	0.0	3.6
Missouri	421.6	3.0	65.8	21.1	0.7	6.4	3.0	10.1
Montana	80.2	2.3	67.0	13.7	0.6	12.7	3.7	17.
Nebraska	155.6	13.2	53.5	17.9	3.2	11.1	1.2	15.5
Nevada	57.0	10.3	56.6	23.9	2.0	5.6	1.6	9.2
New Hampshire	152.3	2.5	65.7	7.2	0.8	22.9	0.9	24.6
New Jersey	1,178.2	8.0	53.3	22.7	4.6	10.4	1.1	16.1
New Mexico	109.2	2.1	59.9	26.0	2.5	9.5	0.0	12.0
New York	6,114.9	41.5	6.7	24.9	5.0	0.1	21.8	26.9
North Carolina	653.3	28.2	24.4	34.1	5.6	5.0	2.7	13.3
North Dakota	122.3	31.4	22.9	30.2	2.0	13.5	0.0	15.5
Ohio	1,440.8	47.0	25.4	26.3	0.9	10.4	0.0	11.3
Oklahoma	313.4	0.6	56.1	31.8	0.0	1.7	9.8	11.5
Oregon	272.3	5.6	36.8	35.5	0.3	21.3	0.5	22.1
Pennsylvnia	1,545.9	6.4	56.8	29.0	1.7	6.1	0.0	7.8

See footnotes at end of table.

Table 3—Continued
Medicaid Long-Term Care Spending, by Program: 1990

State	Total in Millions of Dollars	Skilled Nursing Facility	Intermediate Care Facility	Intermediate Care Facility for the Mentally Retarded	Home Health Care	Home and Community-Based Care 1915(c) Waivers	Personal Care	Support for Community-Based Care
					Percent			
Rhode Island	$242.4	5.4	54.3	32.3	0.6	7.4	0.0	8.0
South Carolina	304.7	20.2	22.7	45.5	2.0	9.6	0.0	11.6
South Dakota	92.2	1.9	55.9	27.4	1.1	12.4	1.3	14.8
Tennessee	381.0	8.2	63.7	22.1	3.5	2.5	0.0	6.0
Texas	1,226.1	6.4	48.8	34.4	0.2	0.6	9.6	10.4
Utah	103.6	5.0	41.2	37.8	0.7	15.3	1.0	17.0
Vermont	76.7	4.4	54.3	22.6	3.4	15.3	0.0	
Virginia	458.6	4.4	55.3	32.4	2.6	5.3	0.0	7.9
Washington	531.6	32.2	28.0	26.7	1.2	10.5	1.4	13.1
West Virginia	173.7	10.9	66.3	8.6	4.0	7.3	2.9	14.2
Wisconsin	738.8	49.6	19.1	16.6	6.9	5.8	2.0	14.7
Wyoming	23.3	10.1	87.8	0.0	2.0	0.0	0.0	2.0
Average	579.4	17.1	46.5	25.3	2.4	6.8	2.2	11.3

[1] Less than 0.1 percent.

SOURCE: Health Care Financing Administration financial management reports, 1990.

Table 4
Medicaid Long-Term Care Spending, by Program: 1997

State	Total in Millions of Dollars	Skilled Nursing Facility	Intermediate Care Facility for the Mentally Retarded	Home Health Care	Home and Community-Based Care 1915(c) Waivers	Personal Care	Support for Community-Based Care
				Percent			
Alabama	$705.0	74.3	8.3	3.1	14.3	0.0	17.4
Alaska	77.0	59.3	2.6	1.6	31.7	4.8	38.1
Arizona	17.6	93.5	0.0	5.6	0.0	0.9	6.5
Arkansas	523.1	58.1	20.3	3.4	6.8	11.4	21.6
California	3,100.8	67.4	12.3	1.7	9.8	8.7	20.2
Colorado	570.2	56.6	4.1	7.1	32.1	0.0	39.2
Connecticut	1,413.7	60.7	13.3	6.7	19.3	0.0	26.0
Delaware	139.2	55.6	22.4	5.0	17.0	0.0	22.0
District of Columbia	255.3	65.4	29.1	5.3	0.0	0.2	5.7
Florida	1,844.7	68.6	13.5	5.7	11.7	0.7	18.1
Georgia	906.0	67.9	14.1	4.9	13.2	0.0	18.1
Hawaii	169.9	80.3	6.8	1.3	11.6	0.0	12.9
Idaho	170.7	53.9	25.5	1.9	10.0	8.7	20.6
Illinois	2,147.9	61.7	27.0	5.4	10.7	0.0	16.1
Indiana	1,059.1	63.5	28.7	4.1	3.7	0.0	7.8
Iowa	568.8	50.8	31.1	5.9	11.2	0.8	17.9
Kansas	471.9	48.2	20.0	2.3	28.0	1.5	31.8
Kentucky	704.7	65.3	10.7	14.1	9.9	0.0	24.0
Louisiana	894.9	43.5	47.2	3.0	6.4	0.0	9.4
Maine	344.6	58.6	13.2	4.1	23.3	0.7	28.1
Maryland	817.8	63.9	7.8	7.4	17.9	3.0	28.3
Massachusetts	2,090.3	62.8	12.2	4.2	15.0	5.8	25.0
Michigan	1,817.6	44.7	28.6	2.0	12.7	12.0	26.7
Minnesota	1,559.2	55.0	15.3	3.3	20.6	5.8	29.7
Mississippi	448.9	68.9	26.6	2.4	2.1	0.0	4.5
Missouri	1,062.4	59.1	14.7	0.8	18.4	7.2	26.4
Montana	168.1	59.2	9.4	1.4	21.7	8.3	31.4
Nebraska	345.5	64.4	10.7	3.9	19.5	1.5	24.9
Nevada	108.9	62.2	21.0	7.1	8.4	1.4	16.9
New Hampshire	320.7	63.9	4.1	1.2	33.8	0.7	35.7
New Jersey	2,027.5	55.1	18.4	4.5	12.8	6.8	24.1
New Mexico	266.8	49.9	8.1	3.0	39.0	0.0	42.0
New York	10,857.3	49.2	18.5	7.3	10.6	14.3	32.2
North Carolina	1,581.1	49.3	23.0	4.3	15.0	8.4	27.7
North Dakota	187.8	58.6	23.2	1.0	17.1	0.0	18.1
Ohio	2,772.5	65.6	14.1	1.2	19.1	0.0	20.3
Oklahoma	508.6	57.0	19.8	2.2	19.6	3.4	25.2
Oregon	491.6	34.4	15.3	0.1	45.8	4.4	50.3
Pennsylvnia	3,880.8	73.9	13.6	1.8	10.7	0.0	12.5

See footnotes at end of table.

Table 4—Continued
Medicaid Long-Term Care Spending, by Program: 1997

State	Total in Millions of Dollars	Skilled Nursing Facility	Intermediate Care Facility for the Mentally Retarded	Home Health Care	Home and Community-Based Care 1915(c) Waivers	Personal Care	Support for Community-Based Care
				Percent			
Rhode Island	$354.3	61.7	2.9	1.2	34.2	0.0	35.4
South Carolina	579.9	48.9	30.1	3.0	17.7	0.2	20.9
South Dakota	162.5	61.2	12.4	1.5	24.5	0.4	26.4
Tennessee	963.1	68.6	22.1	[1]0.0	9.3	0.0	9.3
Texas	2,613.6	51.5	24.5	2.6	13.1	8.3	24.0
Utah	191.1	45.5	23.6	1.7	29.1	0.2	31.0
Vermont	134.5	52.4	1.1	3.4	42.5	0.6	46.5
Virginia	746.8	53.5	21.4	1.2	23.9	0.0	25.1
Washington	1,014.9	51.4	12.7	1.0	23.4	11.5	35.9
West Virginia	425.3	56.6	12.4	5.0	20.0	6.1	31.1
Wisconsin	1,342.8	56.7	15.0	3.8	20.8	3.7	28.3
Wyoming	105.9	44.6	16.8	3.6	35.0	2.5	38.6
Average	—	58.2	17.8	3.9	14.4	5.7	24.6

[1] Less than 0.1 percent.
SOURCE: Health Care Financing Administration financial management reports, 1997.

Table 5

Medicaid 1915(c) Waiver Program Participants, Expenditures, and Expenditures per Participant, by Service Category: United States, 1992

Service Category[1]	Waivers[2]		Waiver Expenditures		Number of Waiver Participants[3]	Amount of Waiver Expenditures per Participant
	Number	Percent	Dollars	Percent		
Total	—	—	$1,707,346,486	—	—	—
Case Management	104	68.9	101,533,616	5.9	107,145	$948
Day Care	53	35.1	58,123,053	3.4	14,027	4,144
Habilitation	71	47.0	837,622,940	49.1	55,317	15,142
Home Health Care	30	19.9	14,737,163	0.9	5,220	2,823
Homemaker	66	43.7	217,310,638	12.7	72,241	3,008
Home Modification/ Medical Supply	6	4.0	8,105,981	0.5	17,574	461
Nursing	71	47.0	85,581,634	5.0	12,568	6,809
Nutrition/Meals	26	17.2	9,345,584	0.5	15,403	607
Personal Care	70	46.4	286,604,575	16.8	65,906	4,349
Respite Care	91	60.3	31,569,929	1.8	17,573	1,797
Training	11	7.3	21,169,710	1.2	5,088	4,161
Transportation	37	24.5	14,763,602	0.9	15,277	966
Other	44	29.1	20,878,053	1.2	34,349	608

[1] Missing data by service for 12 waivers.

[2] *N* = 151.

[3] Participants are duplicated across services.

NOTE: Percents may not add to 100.0 because of rounding.

SOURCE: (Harrington and DuNah, 1994.)

Table 6

Composition of Medicaid 1915(c) Waivers,[1] by Waiver Targeting and Service Categories: United States, 1992

	MR/DD (*n* = 54)		Aged/Disabled[2] (*n* = 46)		Disabled (*n* = 13)		Children (*n* = 16)		AIDS/ARC (*n* = 15)		Other[3] (*n* = 7)	
Services	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Case Management	38	70.4	33	71.7	12	92.3	8	50.0	9	60.0	4	57.1
Day Care	12	22.2	34	73.9	3	23.1	0	0.0	0	0.0	4	57.1
Habilitation	54	100.0	9	19.6	2	15.4	1	6.3	1	6.7	4	57.1
Home Health Care	5	9.3	13	28.3	3	23.1	2	12.5	3	20.0	4	57.1
Homemaker	13	24.1	34	73.9	6	46.2	1	6.3	7	46.7	5	71.4
Home Modification/ Medical Supply	26	48.1	16	34.8	6	46.2	7	43.8	6	40.0	1	14.3
Nursing	21	38.9	16	34.8	5	38.5	12	75.0	13	86.7	4	57.1
Nutrition/Meals	4	7.4	15	32.6	3	23.1	0	0.0	4	26.7	0	0.0
Personal Care	25	46.3	25	54.3	7	53.8	2	12.5	10	66.7	1	14.3
Respite Care	40	74.1	33	71.7	4	30.8	5	31.3	4	26.7	5	71.4
Training	2	3.7	4	8.7	3	23.1	0	0.0	1	6.7	1	14.3
Transportation	21	38.9	11	23.9	1	7.8	0	0.0	3	20.0	1	14.3
Other	14	25.9	20	43.5	3	23.1	1	6.3	3	20.0	3	42.9

[1] *n* = 151 waivers; missing data by service for 12 waivers.

[2] Aged/Disabled includes waivers targeted solely to frail elderly and combined aged/disabled waivers.

[3] Other is generally some combination of target groups.

NOTES: MR/DD is mentally retarded/developmentally disabled. AIDS/ARC is acquired immunodeficiency syndrome/AIDS-related complex. Each waiver for a target group may allow for multiple services.

SOURCE: (Harrington and DuNah, 1994.)

Table 7

Medicaid 1915(c) Expenditures, by Waiver Targeting and Service Categories: United States, 1992

Service	Total		Group Targeted					
	Thousands of Dollars	Percent	MR/DD	Aged/Disabled[1]	Disabled	Children	AIDS/ARC	Other[2]
			Percent Distribution					
All Services	—	100.00	62.8	29.6	3.5	2.6	0.4	1.0
			Amount for Target Group					
Total	$1,707,346	100.0	$1,072,866	$505,985	$60,577	$44,461	$6,970	$16,486
Case Management	101,534	5.9	34,787	59,136	4,341	1,775	995	498
Day Care	58,123	3.4	35,306	20,685	763	0	0	1,369
Habilitation	837,623	49.1	816,534	17,214	3,705	2	18	150
Home Health Care	14,737	0.9	310	6,523	2,038	353	123	5,391
Homemaker	217,311	12.7	63,718	140,290	10,359	153	1,329	1,461
Home Modification/ Medical Supply	8,106	0.5	2,210	2,673	238	2,905	32	48
Nursing	85,582	5.0	10,750	1,780	25,489	38,461	1,821	7,281
Nutrition/Meals	9,346	0.5	112	8,940	270	0	24	0
Personal Care	286,605	16.8	76,069	204,842	3,066	44	2,574	10
Respite Care	31,570	1.8	14,627	14,610	1,391	768	40	134
Training	14,764	0.9	6,769	4,778	1	0	10	1
Transportation	14,764	0.9	9,974	4,778	1	0	10	1
Other	20,878	1.2	1,701	10,431	8,602	0	2	142

[1] Aged/Disabled includes waivers targeted solely to frail elderly and combined aged/disabled waivers.

[2] Other is generally some combination of target groups.

NOTES: MR/DD is mentally retarded/developmentally disabled. AIDS/ARC is acquired immunodeficiency syndrome/AIDS-related complex. Data are missing for 12 waivers. Percents may not add to 100.0 because of rounding.

SOURCE: (Harrington and DuNah, 1994.)

where case management is not a waiver service, the State may provide it to individuals receiving waiver services either as targeted case management [a Medicaid optional service] or as an administrative activity of the Medicaid agency.)

Table 7 provides data on expenditures by eligibility category. Habilitation services represented 49.3 percent of total State 1915(c) expenditures in 1992, targeted almost entirely to people with developmental disabilities. Personal care services represented 16.7 percent of waiver expenditures, with these dollars associated most often with individuals who are aged and/or disabled. Homemaker services represented 12.7 percent of total expenditures, with expenditures most frequently associated with the aged/disabled or people with developmental disabilities.

Community-Based LTC Expenditures

In addition to 1915(c) waiver services, States can provide community-based services through the personal care program (at the State's option) and through the mandatory home health benefit. In 1997, 32 States offered personal care services as an optional Medicaid service. Across these States, more than $3.2 billion was expended for personal care, representing 5.7 percent of LTC dollars (Table 4). As with the 1915(c) waiver services, those States providing personal care as an optional benefit varied in the extent to which they targeted resources to this benefit, relative to other LTC services. Arkansas and New York targeted a greater proportion of LTC dollars to personal care than to 1915(c) waivers, with New York expending the greatest proportion on personal care services, at 14.3 percent. Home health care, at $2.2 billion in 1997, represented 3.9 percent of State LTC expenditures. Relative to 1915(c) expenditures, the rates of growth for personal care and home health care have been much more moderate. The average annual rate of growth over the period from 1990 to 1997 was 9.3 percent for personal care and 15.4 percent for home health care, in contrast to 30.9 percent for waiver services. Finally, Tables 3 and 4 demonstrate that, on average across States, the proportion of LTC dollars targeted to home health care and 1915(c) services increased between 1990 and 1997, but those for personal care decreased. The decrease in personal care is seen despite an increase in the number of States offering personal care as an optional benefit.

POLICY AND RESEARCH IMPLICATIONS

Access

These data suggest both the increasing availability of community-based LTC as well as the continuing disparities in access. All States now provide community-based care through 1915(c) waiver services (or 1115 demonstration waivers in the case of Arizona) to some subgroups of individuals with disabilities, increasing from six States in 1982. Yet within States, availability of community-based care through the waiver program is limited to certain individuals, based on the type of disability, and may be further limited to specific geographic areas of the State. As shown in Table 1, by 1997, most Medicaid-eligible individuals who are elderly and disabled, or who are developmentally disabled, had access to community-based care under a waiver program in at least some parts of their State. Access to 1915(c) waiver services is clearly more limited for persons with AIDS (where services were available in 16 States), for children with a variety of disabling conditions (who could elect services in 21 States), and for

children and adults with serious mental health problems (for whom only three States provided waiver services, limiting those to children).

When access to community-based LTC is viewed in the broader context of Medicaid services, including personal care and home health care, access increases. In 1997, 32 States offered personal care services, and all States provided at least skilled care-oriented home health services, reflected in the expenditures reported in Table 4. The proportion of Medicaid dollars that these combined services represents suggests, however, that access to community-based care may be limited in many States for individuals in need of LTC services. Community-based care on a per participant basis on average is less than institutional care (Alecxih, Lutzky, and Corea, 1996). Thus, for the expenditure associated with one person in an institutional setting, several people may receive services in community-based settings. It is difficult to examine the proportion of total dollars funding community-based care and assess what the appropriate split might be between institutional and community-based dollars. But in States where community-based expenditures represent a small fraction of total LTC dollars (refer to Tables 3 and 4), one might infer that availability of community-based care may be of concern. Other data support this contention. For example, Ladd and his colleagues (1995) assessed a variety of State-level data related to potential demand, institutional supply, and utilization, as well as expenditures. They report that in 1995, only 10 States had made substantial progress in developing community-based systems of care for elderly individuals.

Many argue that the Medicaid program is structured in a manner that creates a bias toward the use of institutional LTC services, such as services in a nursing facility. Although all Medicaid programs are required to provide nursing facility care, personal care and 1915(c) waiver services are provided at a State's option. Financial-eligibility criteria may also create a bias toward institutional services. Individuals are eligible for Medicaid services at a higher income and asset standard when they receive nursing facility care than when they receive personal care or home health care. Limitations set on benefits, such as the number of hours of personal care that can be provided on a daily or monthly basis, may effectively eliminate community-based services as an option for persons with more severe disabilities whose level of need may exceed the benefit level. Restrictive need criteria, as well as limited consumer information and choice of services, may also function to create an institutional bias in Medicaid services (Harrington et al., 1998).

Features such as these, combined with the continued allocation of the majority of Medicaid LTC dollars to institutional care in most States, have brought forth proposed legislation to foster access. House of Representatives 2020, the Medicaid Community Attendant Services Act, was introduced in 1997 to allow individuals, regardless of the State in which they reside, to have the choice of receiving Medicaid-funded personal assistance services. At a hearing of the House Subcommittee on Health and Environment on community-based care for Americans with disabilities in March 1998, then-Speaker Newt Gingrich and Minority Leader Richard Gephardt were the lead witnesses, speaking of their support of efforts to increase access to community- based care. Although acknowledging cost concerns, the legislation was viewed as a vehicle from which to begin a dialogue related to increased availability of community-based care.

Recent court decisions, including *Helen L v. Didario,* 46 F.3d 325 (3rd Cir. (Pa.) 1995) and *Williams v. Wasserman,* 937 F. Supp. 524 (D. Md. 1996) have sought to establish States' obligations to provide community-based care (Harrington et al., 1998). This issue reached the Supreme Court, as it elected to review *Olmstead v. L.C.,* No. 98-536 (appealing *Zimring v. Olmstead,* 138 F.3d 893 [11th Cir. (Ga.) Apr. 8, 1998]). This case, from Georgia, pertains to two women with mental retardation, mental illness, and brain damage, who sued the State to receive care outside the State institution. In a 6-3 decision, the Supreme Court ruled that isolating people with disabilities in institutions, when there is no medical reason for such a placement, is a form of discrimination that violates the Americans with Disabilities Act. The Court affirmed, in most respects, a 1998 decision reached by the Federal appeals court in Atlanta, that held that States have a duty to provide care in community settings when medically appropriate (Greenhouse, 1999).

Variation by Type of Disability

All States provide 1915(c) waiver services to individuals with developmental disabilities (Table 1). A substantial share of 1915(c) dollars support services for people with developmental disabilities (Table 7) (Miller, 1992). Thus, the 1915(c) waiver program has proven to be a significant resource to States reconfiguring their systems serving people with developmental disabilities. The population living in large State ICFs/MR has declined markedly since the mid-1960s. Although many people with mental retardation and developmental disabilities continue to live in residential facilities, the facilities in which they now live are much smaller than they once were. And an increasing number of people are living in their own homes (Prouty and Lakin, 1998).

In contrast, over the 15-year period, only four States have ever drawn upon the 1915(c) waiver program to develop community options for individuals with serious mental illness. The three programs operational in 1997 were limited to children (Table 1). Yet serious mental illness is a significant source of disability in the Medicaid program. In 1997, 27.4 percent of working-age adults and 21.4 percent of children receiving Medicaid through SSI eligibility experienced a disability due to mental illness (Brooks, 1998). Furthermore, one of the stronger cases that community-based care can improve individuals' care outcomes and quality of life, at a cost at least no greater and sometimes less than institutional care, has been made for those with serious mental illness (Olfson, 1990). The lack of growth in 1915(c) waiver programs for adults may be attributed in part to some difficulty in meeting the waiver cost-effectiveness criterion, given that Medicaid does not cover services in institutions for mental disease for individuals under age 65. The demonstration of cost-effectiveness must be based on a comparison to services for adults with serious mental illness, which are received in general hospitals or nursing facilities, rather than in inpatient psychiatric hospitals. The lack of growth in 1915(c) waivers for children with serious mental health problems may be attributable to the availability of services under the Early and Periodic Screening, Diagnostic, and Testing benefit for children.

State Allocation Decisions

The Medicaid program is administered through a Federal-State partnership. Although the Federal Government sets broad programmatic parameters for State participation, much discretion is left to the States in their program design. Thus,

States are critical in determining service options regarding in what setting, from whom, and under what philosophy of care, people with disabilities can access LTC.

In designing their programs, States operate within certain constraints, as well as within particular political environments that shape the structure of public programs. Studies of fiscal effort related to a broad range of health services have found that factors such as State wealth, population need, State ideology, advocacy efforts, and civil rights activity influence funding effort (Barrilleaux and Miller, 1988; Braddock, 1992; Buchanan, Cappellini, and Ohsfeldt, 1991; Kane et al., 1998; Schneider and Jacoby, 1996). Devoting greater attention to identifying factors that influence States' resource-allocation decisions to programs such as Medicaid, as well as to services for people with different disabilities, would enhance our understanding of how State LTC systems are shaped.

Goals and Effectiveness

When Congress authorized the 1915(c) waiver program in 1982, there was a clear intent to provide services to individuals in need of an institutional level of care (nursing facility or ICF/MR) who, absent the waiver program, would be receiving institutional-based services. States were required to demonstrate the capacity to serve 1915(c) waiver participants in an institution and were further required to demonstrate that community-based services under the waiver were no more expensive than institutional care. Over time, the definition of "institution" has expanded, the "cold bed policy" has been eliminated, and the cost-neutrality test has been modified.

As a program, 1915(c) waivers have not been evaluated since shortly after program inception. The evaluations occurred at a time when waiver programs were limited in number, more restrictive in the populations served, and more firmly wed to a policy of institutional diversion. The actual studies frequently referenced regarding the cost-effectiveness of community-based care have not specifically focused on the 1915(c) waiver program. These studies most often evaluated community-based services for the frail elderly (Hughes, 1985; Weissert and Hedrick, 1994). Reviews of those studies tend to loosely define community-based care, comparing, for example, emergency response systems to medically oriented housing to in-home care provided by an interdisciplinary team. Goals of community-based care are not consistently identified across the studies. Outcomes examined have varied and have typically included some combination of effects on institutional use, participant health status and quality of life, caregiver burden, and program costs. Few of these reviews conducted a formal statistical analysis of individual study effect sizes (Hughes et al., 1997).

The 1915(c) waiver program provides a wide range of services for home and community-based LTC. When the patterns of data about the use of 1915(c) services by target group are examined (Tables 5-7), clear trends emerge. As previously noted, for example, all 1915(c) programs serving individuals with developmental disabilities include habilitation services, while nursing services dominate waiver programs for persons with AIDS and children with disabilities. Future research should focus on these patterns in order to more clearly define the program intervention in general and specifically within each target group, a recommendation echoed by Hughes and colleagues (1997) in a meta-analysis of the impact of home care on hospitalization.

Selection issues affect assessments of the cost-effectiveness of community-based care. Individuals with disabilities, in a decisionmaking process that typically involves

family members as well as a physician or other provider, voluntarily elect to receive services in a waiver program. A long-standing issue is the extent to which individuals who, although meeting the functional and financial criteria for nursing home placement, would not elect to receive institutional care, but would, given the opportunity, choose community-based care. Thus, it is argued that State LTC expenditures will increase, as community-based care complements, rather than substitutes for, institutional care. Actual evidence related to this concern is sparse and mixed. For example, take-up rates in a number of demonstrations that have provided community-based services (e.g., the Medicare Alzheimer's Disease Demon-stration) suggest that a significant segment of the population, when offered community-based services, chose not to receive these services. Thus, estimates of the number of people who would elect community-based care out of an eligible population and their impact on expenditures are difficult to determine.

A second issue involved in the selection process is a concern that, overall, the less frail segment of a population with LTC needs will choose or be determined eligible to receive community-based services in lieu of institutional care. Whether the less frail of those in need of LTC are those most likely to receive community-based care is also unclear. One analysis of individuals receiving institutional care found a substantial number of nursing home residents who met clinical criteria appropriate to a lower level setting, suggesting that factors in addition to frailty level enter the decisionmaking process (Spector, Reschovsky, and Cohen, 1996). From a different perspective, some States have demonstrated that it is feasible to target community-based services to a seriously impaired elderly population. Targeting the most frail individuals, when combined with limits on institutional capacity, appears to contribute to cost-effectiveness (Alecxih, Lutzky, and Corea, 1996). And the developmental disabilities field has demonstrated the feasibility of serving substantially impaired individuals in non-institutional, supported home or community settings, when the appropriate mix of services and supports is provided (Prouty and Lakin, 1998).

A clearer specification of the 1915(c) program also requires that attention be given to identifying goals of the program beyond cost-effectiveness. Consumer-directed care research provides guidance about how to conduct research that will help identify broad goals of home and community-based LTC as well as specific goals for target groups. First, it is important to ask consumers what they want and to listen to their responses (Doty, Kasper, and Litvak, 1996; Meredith et al., 1997). In a conference on consumer-centered care sponsored by HCFA and The Brookings Institution, four consumer-panelists speaking for people with physical disabilities, developmental disabilities, serious mental illness, and elderly individuals provided answers to the question: What do consumers want? (Health Care Financing Administration, 1997). Similar answers emerged across all consumer-panelists. Each preferred home and community-based care because of its cost-effectiveness and enhanced quality of life. Other responses emphasized control over care in choosing specific services and in selecting the person delivering services. Panelists wanted an expanded range of services and greater flexibility in where they receive services, as well as the way in which service dollars are controlled. Taking into account these responses, broad goals of home and community-based care should facilitate consumer choice and control to the greatest extent feasible.

Second, measurement instruments and consumer LTC plans should incorporate consumer-identified needs and values.

Measuring quality-of-life outcomes, such as choice and control, is difficult because they can be conceptualized differently within each target group and among individuals within specific target groups (Gill and Feinstein, 1994; Dennis et al., 1993). However, several studies have demonstrated that one can reliably elicit consumers' values and preferences related to LTC goals, even for many with diminished cognitive capacity or multiple disabilities (Boswell, Dawson, and Heininger, 1998; Ju and Thomas, 1987; McCullough et al., 1993).

Recent research suggests that when the needs and preferences of consumers are identified and integrated into community-based LTC, consumer satisfaction increases (Beatty et al., 1998; Benjamin et al., 1998; Doty, Kasper, and Litvak, 1996). Beatty and colleagues conducted surveys of people with physical disabilities to determine if consumer-directed personal assistance services (PAS) were associated with higher levels of satisfaction than PAS that were not consumer-directed. They found that consumer-directed PAS are associated with higher levels of satisfaction, particularly with regard to personal control and flexibility of services. Consumer-directed PAS have also been found to enhance a sense of empowerment, improve quality of life, and increase productivity (Benjamin et al., 1998; Beatty et al., 1998).

LTC goals identified by consumers may not be the same as those identified by family members or other caregivers, providers, and/or researchers (Chadsey-Rusch, Linneman, and Rylance, 1997; Kane et al., 1994). For example, Kane and colleagues found differences among home care users, consumer representatives, professional and paraprofessional providers, insurers, and regulators in rating the importance of home care outcomes. Differences among groups appeared when they rated the importance of outcomes for case studies of people with various levels of need. For example, for a client with homemaking needs and minimal needs for personal care, home care users rated freedom from abuse the highest, in contrast to insurers, who rated affordability the highest. Research needs to attend more closely to these differences as well as to develop methods to negotiate the inevitable conflicts over goals that will arise.

State Medicaid agency goals have recently focused on controlling LTC expenditure growth. Strategies to effect this goal have included the increased use of community-based care, as well as the use of limits on the growth of institutional bed supply (Wiener and Stevenson, 1998). Some preliminary work suggests that use of a certificate of need and/or bed moratorium does not influence total LTC expenditures but does positively influence several measures of community-based expenditures. For example, States with both a nursing home bed certificate of need and moratorium were found to invest significantly greater dollars in 1915(c) waivers (Miller et al., 1999).

A third cost-containment strategy on the part of States is the use of managed care (Wiener and Stevenson, 1998). To date, Medicaid managed care initiatives have primarily been limited to the provision of acute care services. A few States, such as Texas, have recently implemented or been approved to implement programs under which access to community-based LTC services is tied to managed care arrangements. Operational experience has been largely limited to demonstration efforts, and findings related to individual health outcomes, quality of life, patterns of community and institutional use, and expenditures have been mixed (Chatterji and Burstein, 1998; Manton et al., 1993; Miller and Luft, 1997; Nelson et al., 1997; White, 1998). Wiener and Stevenson (1998) identify concerns raised by individuals with dis-

abilities related to these State managed care efforts. For instance, a lack of experience with LTC, fiscal pressures created by capitation that might impede access to LTC, and the potential for LTC to be overmedicalized and less consumer-focused were issues raised in Wisconsin's recent effort to redesign its public LTC system.

Further, those States that seek to expand community-based care may be constrained in their capacity to support such care. The most consistent empirical finding across a broad literature on State funding of Medicaid services, including LTC, is that State fiscal capacity serves as a constraint under which States operate (Braddock, 1992; Buchanan, Cappellini, and Ohsfeldt, 1991; Kane et al., 1998; Schneider and Jacoby, 1996). This may particularly be the case to the extent that a certain institutional capacity will need to be carried for a period of time as capacity is built on the community-based side.

To summarize the issues of goals and effectiveness, listening to consumers and others involved in long-term caregiving can better illuminate our understanding of the broad social goals of LTC. Thus, effectiveness can be more clearly defined and evaluated from a variety of perspectives. For some subgroups of people with disabilities, such as working-age individuals with disabilities, community-based care is viewed as essential to attaining LTC goals. In light of the constraints under which States often operate, greater attention should be given to developing ways to balance institutional and community-based capacity and expenditures. State actions to constrain institutional growth, combined with research on the effectiveness of features such as the use of new payment methods (e.g., vouchers or cash) for community-based care, will likely enhance the continued expansion of community-based LTC through the 1915(c) waiver program.

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