

Policy Research Brief

RESEARCH AND
TRAINING CENTER
ON COMMUNITY LIVING
UNIVERSITY OF MINNESOTA

Medicaid Home and Community-Based Services: The First 20 Years

This Policy Research Brief reports on the implementation of the Medicaid Home and Community-Based Services “waiver” program during its first 20 years, from Fiscal Year 1982 through Fiscal Year 2002. The review provides a description of the program, its initial purposes, patterns and trends in its use, its relationship to other services, and challenges in the years ahead. The review was written by K. Charlie Lakin and Robert Prouty of the Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota. Mr. Lakin may be reached at 612/624-5005 or lakin001@umn.edu, and Mr. Prouty at 612/626-2020 or prout004@umn.edu.

■ Introduction

“Official” federal involvement in the financing of long-term care for persons with intellectual and developmental disabilities (ID/DD) began in 1971. In 1971, Congress authorized federal financial participation (FFP) for “intermediate care” provided in facilities specifically for people with mental retardation (ICFs-MR). This new federal program provided substantial financial incentives for upgrading residential institutions to qualify for ICF-MR participation, it neutralized previously existing financial incentives for placing persons with ID/DD in Medicaid nursing homes to obtain FFP for their care, and it created the first federal involvement in long-term care that was specifically designed to respond to the needs of persons with ID/DD. States quickly began to participate in the ICF-MR program. By June 1977, 40 states had at least one ICF-MR certified state facility and a majority (28) states had both public and private ICFs-MR.

In the late 1970s, in the context of growing support for the development of community services, advocates expressed concern that the ICF-MR program had created

incentives for maintaining people in institutions through Medicaid cost-sharing; diverted funds that could have been spent on community service development to institution renovations to qualify for Medicaid certification; and promoted a single uniform standard of ICF-MR care at a time when there was growing advocacy for services that would respond to the unique needs and preferences of individuals. These concerns, the commitment to expand community services, and the need of states to maximize use of federal funding led 20 states to develop one or more community ICFs-MR by 1980. The interest in community ICF-MR development also caused the Health Care Financing Administration, now the Centers for Medicare and Medicaid Services (CMS), to issue in 1981 “Interpretive Guidelines” to support efforts to develop ICF-MR group homes in the community. Immediately following the issuance of the Interpretive Guidelines for community ICFs-MR in 1981, the number of such settings began to grow steadily (e.g., the number of community ICF-MR residents increased from 9,985 in June 1982 to 23,528 in June 1987). But a far more significant event in 1981 for Medicaid funding of services for persons with ID/DD was the authorization of the Medicaid Home and Community-Based Services (HCBS) “waiver” program (Lakin, Hill, & Bruininks, 1985; Prouty, Smith, & Lakin, 2003).

Within the Omnibus Budget Reconciliation Act of 1981 (P.L. 97-35), passed in August 1981, Section 2176 granted the Secretary of Health and Human Services the authority to waive certain existing statutory requirements of Medicaid to

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provide “non-institutional” services to Medicaid-eligible individuals. The HCBS authorization allowed states to apply to the Secretary for approval of a state plan to provide home and community-based services to people who are aged, blind, disabled, or who have ID/DD (“mental retardation or related conditions”), who, in the absence of the alternative home and community-based services, would remain in or would be at risk of being placed in a Medicaid facility (i.e., a Nursing Facility or an ICF-MR). Non-institutional services were authorized within HCBS programs including case management, personal care services, adult day health services, habilitation services, respite care, or any other service that a state can show will lead to decreased per beneficiary expenditures for Medicaid funded long-term care. Unlike the ICF-MR program, HCBS reimbursements cannot be used to pay for room and board. For most HCBS recipients, cash assistance from other Social Security Act programs are available for room and board costs.

■ HCBS and ICF-MR Service Recipients

Following the authorization of HCBS states quickly recognized it to be a significant resource in the financing of community alternatives to institutional care for persons with ID/DD (Greenberg, Schmitz & Lakin, 1983). Within five years of authorization (June 1986), 32 states were providing HCBS to persons with ID/DD, but in all but 6 states there were still fewer than 600 total HCBS recipients. Because initially the growth in state HCBS programs was limited to the amount of ICF-MR capacity and expenditures that states could convincingly argue would be replaced by the new HCBS to be offered, early HCBS growth was restrained.

HCBS recipients grew steadily but relatively slowly in the first decade of the program. By June 1987, the number of HCBS recipients reached 22,687 and by June 1992 there were 62,429 persons receiving HCBS.

In the early 1990s, the relaxing of the requirement of one-for-one reduction in projected ICF-MR residents for each new HCBS recipient, and then the rescission of the link between ICF-MR and HCBS utilization in the revised regulations of 1994, dramatically changed the dynamics of Medicaid programs for persons with ID/DD. Between June 30, 1992 and June 30, 2002, HCBS programs grew from 62,429 to 378,566 recipients (506%). During the same period the number of ICF-MR residents began to decline steadily for the first time. ICF-MR residents decreased by 20.4%, from 146,260 residents in June 1992 to 110,572 residents in June 2002. Figure 1 depicts graphically the number of HCBS recipients and ICF-MR residents at five year intervals and HCBS recipients between June 30, 1977 and June 30, 2002 with the data points supplied below it (Prouty, Smith, & Lakin, 2003).

Table 1 provides a summary of selected statistics on the June 2002 status and 1992-2002 trends in state HCBS utilization as well as on current status. It provides the number of HCBS recipients on June 30, 1992 and June 30, 2002 in each state and permits comparison of individual state growth in HCBS with growth in other states and in the nation as a whole. It also permits comparisons of the number of HCBS recipients per 100,000 of total state residents and HCBS recipients as a proportion of the combined total of ICF-MR and HCBS recipients.

States differ greatly in their overall use of HCBS, their rate of expansion of HCBS over the past decade, and in their relative commitment to HCBS as an alternative to ICF-MR.

Figure 1: Total HCBS and ICF-MR Service Recipients, June 30, 1977 – June 30, 2002

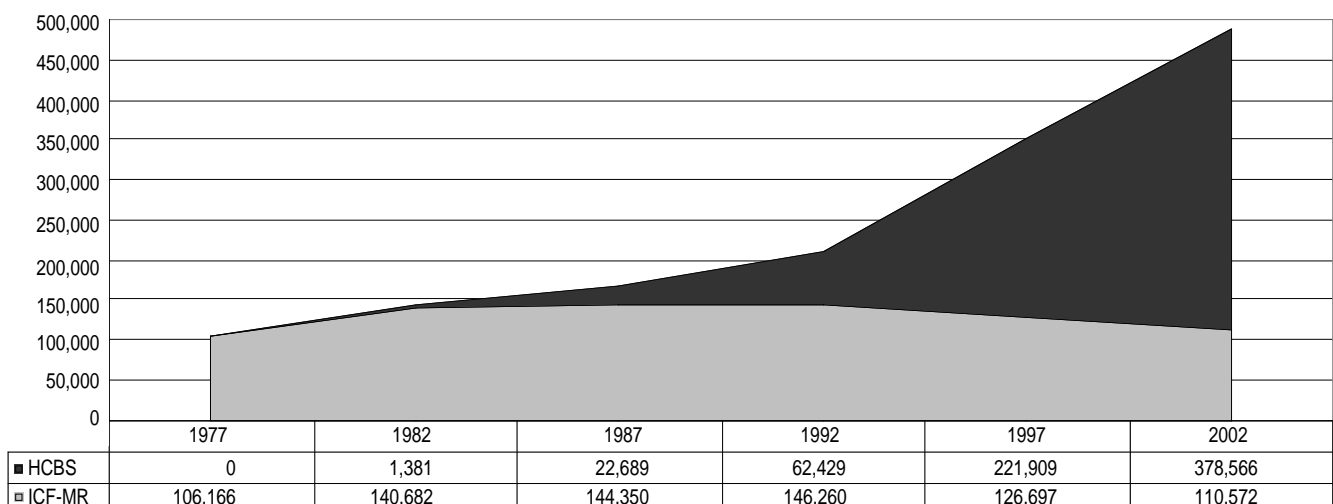


Table 1: Status and Trends in Medicaid HCBS, June 1992 – June 30, 2002

State	HCBS Recipients			HCBS Recipients per 100,000 State Residents	2002 ICF-MR Residents	HCBS Recipients as % of All HCBS & ICF-MR
	1992	2002	% Change			
AL	2,184	4,764 ^e	118.1	106.2	472	91.0
AK	35 ¹	884	2,425.7 ¹	137.3	0	100.0
AZ	4,832	13,471	178.8	246.9	207	98.5
AR	415	2,494 ^e	501.0	92.0	1,684	59.7
CA	3,360	44,205	1,215.6	125.9	10,839	80.3
CO	2,204	6,516 ^e	195.6	144.6	111	98.3
CT	1,693	5,890	247.9	170.2	1,192	83.2
DE	290	547	88.6	67.7	241	69.4
DC	67 ²	225	235.8 ²	39.4	734	23.5
FL	2,637	25,921	883.0	155.1	3,338	88.6
GA	359	9,826	2,637.0	114.8	1,475	86.9
HI	452	1,560	245.1	125.3	94	94.3
ID	225	1,139	406.2	84.9	576	66.4
IL	2,006 ³	6,787 [*]	238.3	53.9	9,923	40.6
IN	447	3,802	750.6 ³	61.7	4,981	43.3
IA	137	6,228 ^e	4,446.0	212.1	2,157	74.3
KS	555	6,239	1,024.1	229.7	688	90.1
KY	819	1,807	120.6	44.1	876	67.3
LA	939	4,232	350.7	94.4	5,539	43.3
ME	509	2,440	379.4	188.5	246	90.8
MD	1,972	6,768	243.2	124.0	502	93.1
MA	3,288	11,315	244.1	176.0	1,125	91.0
MI	2,741	8,550	211.9	85.1	173	98.0
MN	2,890	14,735	409.9	293.5	2,756	84.2
MS	65 ⁴	1,673	2,473.8 ⁴	58.3	2,534	39.8
MO	2,241	8,143	263.4	143.6	1,398	85.3
MT	444	1,452	227.0	159.7	119	92.4
NE	710	2,419	240.7	139.9	642	79.0
NV	136	1,083	696.3	49.8	242	81.7
NH	1,059	2,779	162.4	218.0	25	99.1
NJ	3,971	7,486	88.5	87.1	3,370	69.0
NM	334	2,794	736.5	150.6	284	90.8
NY	379	48,165	12,608.4 ⁵	251.4	9,815	83.1
NC	939	6,013	540.4	72.3	4,645	56.4
ND	1,334	2,011 [*]	50.7	317.1	629	76.2
OH	397	7,858	1,879.3	68.8	7,240	52.0
OK	949	4,100	332.0	117.4	2,243	64.6
OR	1,458	8,017	449.9	227.7	51	99.4
PA	2,705	24,969	823.1	202.4	4,280	85.4
RI	993	2,674	169.3	250.0	40	98.5
SC	471	4,793	917.6	116.7	1,992	70.6
SD	852	2,295	169.4	301.6	189	92.4
TN	704	4,340	516.5	74.9	1,460	74.8
TX	968	7,873	713.3	36.1	12,684	38.3
UT	1,367	3,589	162.5	154.9	783	82.1
VT	413	1,844	346.5	299.1	12	99.4
VA	537	5,491	922.5	75.3	1,885	74.4
WA	1,918	11,173	482.5	184.1	880	92.7
WV	513	2,796	445.0	155.2	515	84.4
WI	1,812	10,884	500.7	200.0	2,580	80.8
WY	318	1,507	373.9	302.2	106	93.4
U.S. Total	62,429	378,566	506.4	131.3	110,572	77.4

a=FY 2001 data e=estimate *from 4/1/01-3/31/02 HCBS began in: ¹1994, ²2000, ³1993, ⁴1996, ⁵1992

Source: State reports to the National Residential Information Systems Project, University of Minnesota (Prouty, Smith & Lakin, 2003)

While overall HCBS programs experienced a 506 percent expansion in recipients between June 1992 and June 2002, a few states accounted for disproportionate amounts of the overall growth. Increases of 47,786 HCBS recipients in New York and 40,845 in California together accounted for 28% of the national increase of 316,337 total HCBS recipients. But New York and California were by no means the only states rapidly increasing HCBS recipients during the 1992-2002 decade. During that period 10 states expanded HCBS programs by more than 900%, and only 3 states did not at least double their HCBS recipients. One of the three states with less than 100 percent growth in HCBS recipients was North Dakota, which committed early and substantially to HCBS. While North Dakota only increased HCBS recipients by 51% during the decade between 1992 and 2002, it remained in 2002 the state with the greatest number of HCBS recipients per 100,000 of total state population, (317 as compared to the national average of 131).

In June 2002, five states (Minnesota, North Dakota, South Dakota, Vermont, Wyoming) had more than twice the national average of HCBS recipients per 100,000 state residents. Six states (Illinois, Indiana, Kentucky, Mississippi, Nevada, Texas) and the District of Columbia had ratios of HCBS recipients per 100,000 total residents that were less than half the national average. Adjusted for national population growth, between 1992 and 2002 relative HCBS utilization increased by 433%.

By June 2002, more than three-quarters (77.4%) of combined HCBS and ICF-MR service recipients received HCBS, as compared with only 29.9% a decade earlier. In 19 states, more than 90% of the combined total received HCBS, with less than 50% in only 5 states (Illinois, Indiana, Louisiana, Mississippi, Texas) and in the District of Columbia. By comparison in 1992, 36 states and the District

of Columbia had more persons living in ICFs-MR than receiving HCBS.

HCBS and ICF-MR Expenditures

To fully appreciate the value of HCBS in financing services for persons with ID/DD, it must be recognized that most states already had substantial social and financial commitments to community services prior to the creation of the HCBS program. Furthermore, states continued to develop community services after the HCBS option was created even though through the early 1990s much of that development could not be financed as Medicaid HCBS. As Medicaid HCBS enrollments and financing were detached from commensurate reductions in existing or projected ICF-MR capacity in the early 1990s, the HCBS program was not only used to finance new services, but also to obtain federal cost-share for previously existing, state-financed community services. Figure 2 shows the growth in HCBS and ICF-MR expenditures between Fiscal Years (FY) 1977 and 2002. The most evident trends in Figure 2 are the rapid growth in the ICF-MR expenditures between 1977 and 1992 with relative stability thereafter, and the limited growth in HCBS expenditures from 1982 to 1992 with very rapid growth thereafter. In the five years between FYs 1997 and 2002, HCBS expenditures increased by \$7.4 billion or 124% (Prouty, Smith, & Lakin, 2003; also citing data supplied by Burwell for the MEDSTAT Group).

Table 2 provides summary statistics on HCBS expenditures during the decade between FYs 1992 and 2002. Nationally HCBS expenditures increased during the period by slightly more than 700%, from 1.655 billion dollars to 13.365 billion dollars. Eighteen states experienced more

Figure 2: Total ICF-MR and HCBS Expenditures from 1977 to 2002

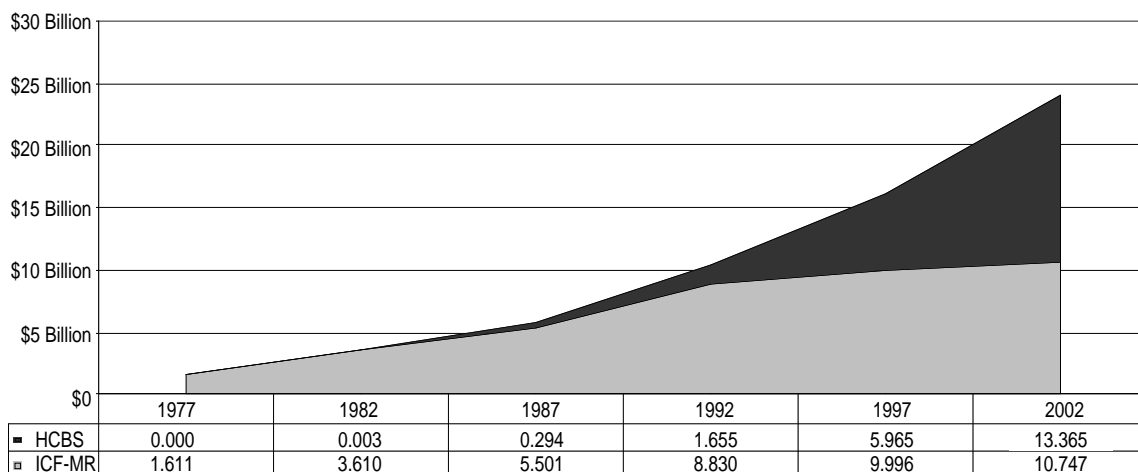


Table 2: Trends in Expenditures for HCBS Services, FY 1992 and FY 2002

State	HCBS Expenditures (in \$1,000s)			HCBS Expenditures Per Average Daily Recipient			HCBS Expenditures Per State Resident		
	1992	2002	% Change	1992	2002	% Change	1992	2002	% Change
AL	\$ 12,400.0	\$ 120,395.5 ^e	870.9	\$ 5,898	\$26,290	345.8	\$ 2.94	\$ 26.84	812.8
AK	666.6 ¹	51,865.8	7,680.6	20,831 ¹	60,030	188.2	1.24 ¹	80.56	6,390.1
AZ	98,716.4	386,529.1	291.6	22,888	29,977	31.0	23.17	70.84	205.7
AR	11,250.0	53,076.9	371.8	36,825	21,589	-41.4	2.67	19.59	633.4
CA	54,048.9	853,788.1 ^e	1,479.7	16,086	23,312	44.9	1.78	24.31	1,263.2
CO	60,191.5	205,028.1	240.6	28,683	31,640	10.3	16.77	45.50	171.3
CT	83,575.0	386,546.5	362.5	49,925	67,827	35.9	21.98	111.70	408.2
DE	5,105.1	34,181.4	569.6	19,084	64,190	236.3	6.96	42.34	508.5
DC	277.4 ²	1,647.8 [*]	494.0	4,140 ²	7,340	77.3	0.47 ²	2.89	520.1
FL	20,246.0	496,921.3	2,354.4	7,686	19,552	154.4	1.41	29.73	2,012.3
GA	10,250.0	286,389.8	2,694.0	28,792	41,275	43.4	1.11	33.46	2,901.4
HI	4,385.2	34,727.5	691.9	13,682	23,991	75.3	3.15	27.90	786.7
ID	1,188.0	27,804.3	2,240.4	6,092	25,626	320.6	1.64	20.73	1,165.3
IL	79,600.0	140,200.0 ^a	76.1	47,608	20,657	-56.6	4.11	11.13	170.5
IN	483.5 ³	198,630.0	40,981.7	1,082 ³	61,610	5,595.9	0.09 ³	32.25	37,632.9
IA	773.5	127,081.3	16,329.4	9,917	21,666	118.5	0.15	43.27	28,954.2
KS	13,737.3	189,358.1	1,278.4	26,117	31,366	20.1	5.01	69.72	1,293.0
KY	19,821.0	91,755.9	362.9	25,074	54,796	118.5	4.81	22.42	366.0
LA	1,785.0	129,015.1	7,127.7	3,588	31,314	772.8	0.23	28.78	12,443.9
ME	13,250.0	136,460.6	929.9	26,031	60,757	133.4	10.21	105.42	932.5
MD	72,326.5	404,949.7 ^e	459.9	47,365	63,367	33.8	11.68	74.19	534.9
MA	90,000.0	483,391.2	437.1	36,087	42,947	19.0	12.33	75.20	510.0
MI	81,039.0	538,108.5	564.0	33,329	62,937	88.8	7.48	53.54	615.4
MN	95,380.7	699,687.0	633.6	35,060	47,916	36.7	19.69	139.39	607.8
MS	25.8 ⁴	20,699.3	80,129.7	397 ⁴	12,201	2,973.9	0.01 ⁴	7.21	74,715.9
MO	65,792.0	235,897.0	258.5	35,631	28,487	-20.1	8.94	41.59	365.4
MT	10,826.7	42,005.4	288.0	27,101	31,266	15.4	11.74	46.19	293.6
NE	25,521.6	108,402.2	324.7	36,643	45,008	22.8	14.10	62.69	344.6
NV	2,400.0	24,367.3	915.3	17,712	22,427	26.6	1.94	11.21	478.5
NH	44,400.0	117,921.6	165.6	44,091	42,656	-3.3	35.01	92.48	164.2
NJ	108,600.7	402,988.0	271.1	28,482	55,723	95.6	12.63	46.91	271.4
NM	8,829.0	157,256.0	1,681.1	35,745	60,251	68.6	3.81	84.77	2,127.3
NY	34,496.2	2,125,806.3	6,062.4	182,038	48,133	-73.6	0.96	110.96	11,401.1
NC	13,833.4	254,336.7	1,738.6	16,095	41,852	160.0	1.93	30.57	1,480.2
ND	18,974.9	47,531.2	150.5	15,198	23,760	56.3	27.25	74.96	175.1
OH	12,824.0	245,009.4	1,810.6	39,888	36,247	-9.1	0.77	21.45	2,675.2
OK	39,375.3	222,356.1	464.7	43,921	57,717	31.4	8.14	63.64	682.2
OR	58,604.3	361,704.8	517.2	32,244	47,462	47.2	17.43	102.71	489.3
PA	133,681.0	977,487.2	631.2	53,069	43,950	-17.2	10.51	79.24	653.7
RI	14,366.8	160,859.5	1,019.7	16,088	61,385	281.6	14.25	150.37	955.1
SC	4,961.0	142,500.0	2,772.4	21,066	30,462	44.6	0.68	34.70	5,002.5
SD	16,256.6	58,935.2	262.5	19,825	26,411	33.2	20.61	77.44	275.8
TN	14,431.1	205,313.6	1,322.7	22,496	46,257	105.6	2.53	35.42	1,301.5
TX	39,754.6	321,670.6	709.1	40,963	42,389	3.5	1.57	14.77	843.4
UT	23,000.0	88,991.0	286.9	17,686	25,576	44.6	12.18	38.42	215.4
VT	14,154.2	74,856.2	428.9	31,524	41,130	30.5	20.97	121.40	478.9
VA	15,974.6	198,911.2	1,145.2	37,021	37,766	2.0	1.26	27.27	2,064.1
WA	39,973.5	214,490.5	436.6	21,879	20,838	-4.8	7.14	35.34	394.9
WV	13,200.0	120,217.7	810.7	28,510	46,309	62.4	6.43	66.72	936.9
WI	39,078.2	297,750.6	661.9	22,621	27,608	22.0	7.05	54.72	676.6
WY	12,508.0	56,956.5	355.4	56,470	39,816	-29.5	14.64	114.21	680.0
US Total	1,654,856.8	13,362,760.4	707.5	29,109	37,816	29.9	5.51	46.34	741.0

a=FY 2001 data e=estimate *from 4/1/01-3/31/02 **from 10/1/01-9/30/02 HCBS began in: ¹ 1994, ² 2000, ³ 1993, ⁴ 1996, ⁵ 1992

Note: Average daily recipients was calculated on the number at the beginning of the year, plus the number at the end of the year divided by 2.

Source: State reports to the National Residential Information Systems Project, University of Minnesota (Prouty, Smith & Lakin, 2003)

than 1000% increases. These increases were driven almost exclusively by increases in the number of persons covered under HCBS. Per recipient average expenditures increased modestly during the 10 year period from \$29,109 to \$37,816 (29.9%). However, caution must be exercised in making comparisons among or between FY 1992 and FY 2002. There are notable variations among states in their rates of increase in average expenditures. These variations often reflect different and evolving uses of HCBS within the states and not necessarily changing costs for comparable services.

Between 1992 and 2002 states took very different approaches to using the HCBS options, and the services and service recipients in FY 2002 were not only more numerous, but were often quite different than those in FY 1992. For example, based on reports for 62.5% of all HCBS recipients in 1992 and 70.8% in 2002, the estimated percentage of HCBS recipients living with parents or other family members increased from 21.1% in 1992 to 39.5% in 2002. Typically service costs for persons living with family members are reduced substantially by the value of support provided by family members that would be provided by paid staff in out-of-home placements. Also, states with new HCBS programs in 1992 (or beginning after 1992) had a small and generally unstable baseline for the comparison (notably Alaska, District of Columbia, Indiana, Louisiana, Mississippi, New York, South Carolina, Virginia, Wyoming).

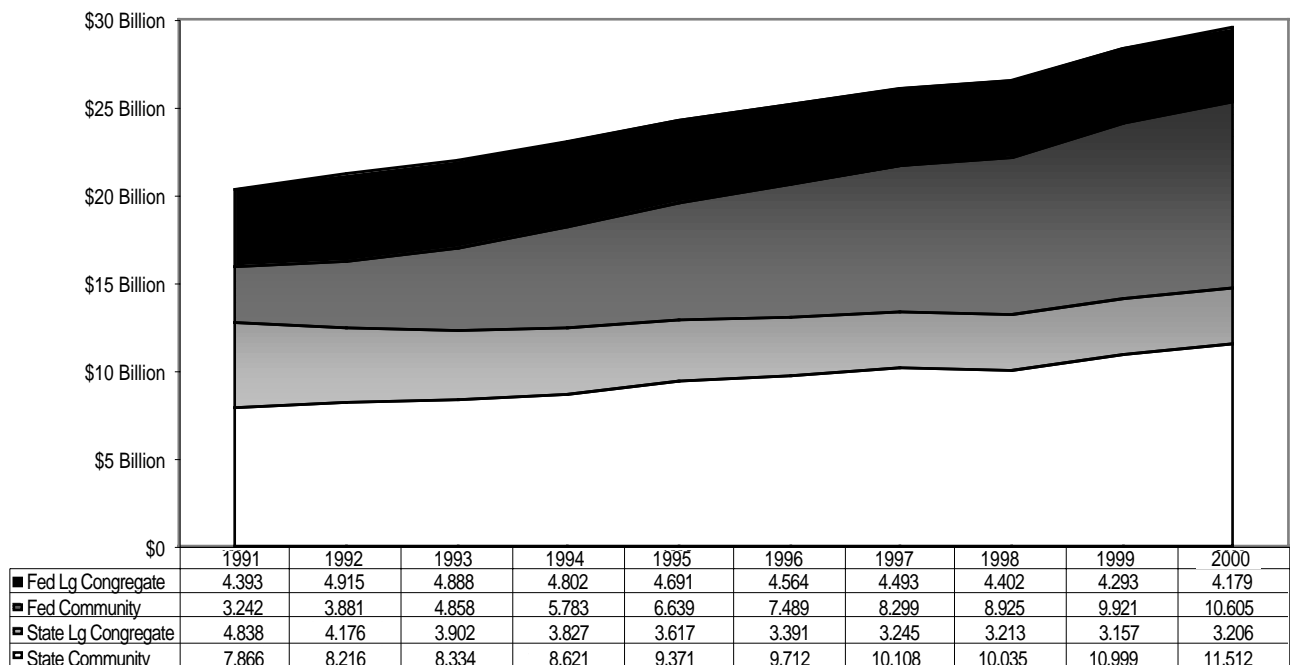
For a number of reasons related to the settings in which

HCBS recipients are served, the “case mix” of state’s HCBS population and, of course, state policy decisions about the amount of expenditures permitted for individuals, in FY 2002 there were 11 states with average per person HCBS expenditures below \$25,000 and 12 states with average expenditures greater than \$50,000. The majority of states fell within the \$25,000-\$50,000 range.

Between FY 1992 and FY 2002 HCBS expenditures per estimated July 1 U.S. resident increased from \$6.52 to \$46.34. With this indexing for population growth, HCBS expenditures increased by 610.7% (as compared with overall growth of 707.5%). In FY 2002, there were eight states with per resident expenditures of double the national average of \$46.34, and nine states with spending of less than half the national average.

Figure 3 shows graphically the substantial impact on overall federal and state expenditures that derived from the greater flexibility available to states to use HCBS in FY 1992 and after. The statistics used in Figure 3 were provided by the University of Colorado Coleman Institute’s *State of the States* longitudinal study of state expenditures for institutional and community services (Braddock et al., 1995, 1998, 2002). That study defines expenditures for “large congregate care” as those for people in programs with 16 or more participants, and “community” as those for people in programs serving 15 or fewer individuals. These statistics presented have been adjusted for inflation to 2000 dollars.

Figure 3: U.S. Total and Federal Inflation Adjusted (2000) Expenditures (in Billions) for Services for Persons with ID/DD, Fiscal Years 1990-2000



Source: Braddock, et al, *The State of the States in Developmental Disabilities* (1995, 1998, 2002).

Table 3: Trends in Combined HCBS and ICF-MR Expenditures

State	ICF-MR Expenditures Per Average Daily Resident			HCBS Expenditures Per Average Daily Recipient			Combined ICF-MR and HCBS Average Per Recipient Annual Expenditure		
	1992	2002	% Change	1992	2002	% Change	1992	2002	% Change
AL	\$ 61,888	\$127,773	106.5	\$ 5,898	\$26,290	345.8	\$26,692	\$34,512	29.3
AK	120,740	0	-100.0	20,831 ¹	60,030	188.2	91,324	58,672	-35.8
AZ	22,760	87,554	284.7	22,888	29,977	31.0	20,529	29,584	44.1
AR	50,689	70,957	40.0	36,825	21,589	-41.4	46,142	41,304	-10.5
CA	28,936	38,749 ^e	33.9	16,086	23,312	44.9	25,913	23,141	-10.7
CO	73,601	172,995	135.0	28,683	31,640	10.3	39,110	33,836	-13.5
CT	139,977	179,073	27.9	49,925	67,827	35.9	90,024	84,722	-5.9
DE	81,672	129,541	58.6	19,084	64,190	236.3	51,461	82,996	61.3
DC	68,034	108,283	59.2	4,140 ²	7,340	77.3	62,864	84,596	34.6
FL	58,307	92,988	59.5	7,686	19,552	154.4	35,108	27,592	-21.4
GA	59,634	75,023	25.8	28,792	41,275	43.4	54,769	35,134	-35.9
HI	55,527	91,373	64.6	13,682	23,991	75.3	21,347	26,189	22.7
ID	68,488	95,922	40.1	6,092	25,626	320.6	49,372	48,429	-1.9
IL	40,579	70,131	72.8	47,608	20,657	-56.6	40,454	50,037	23.7
IN	43,750	68,906	57.5	1,082 ³	61,610	5,595.9	40,895	61,693	50.9
IA	72,057	96,508	33.9	9,917	21,666	118.5	67,968	39,982	-41.2
KS	53,370	95,825	79.6	26,117	31,366	20.1	46,955	36,854	-21.5
KY	49,869 ^e	111,745	124.1	25,074	54,796	118.5	39,457	70,684	79.1
LA	46,222	64,883	40.4	3,588	31,314	772.8	39,901	49,985	25.3
ME	99,769	204,757	105.2	26,031	60,757	133.4	66,817	69,557	4.1
MD	68,158	107,694	58.0	47,365	63,367	33.8	46,941	63,138	34.5
MA	116,571	176,043	51.0	36,087	42,947	19.0	72,080	54,778	-24.0
MI	104,315	155,567	49.1	33,329	62,937	88.8	69,711	64,774	-7.1
MN	54,423	75,435	38.6	35,060	47,916	36.7	46,773	51,889	10.9
MS	26,614	70,262	164.0	397 ⁴	12,201	2,973.9	25,712	47,241	83.7
MO	61,032	81,690	33.8	35,631	28,487	-20.1	43,251	36,694	-15.2
MT	77,197	118,160	53.1	27,101	31,266	15.4	39,007	35,688	-8.5
NE	44,533	74,693	67.7	36,643	45,008	22.8	40,326	51,080	26.7
NV	114,180	125,902	10.3	17,712	22,427	26.6	67,625	41,385	-38.8
NH	75,645	78,113	3.3	44,091	42,656	-3.3	44,322	42,751	-3.5
NJ	70,102	137,379	96.0	28,482	55,723	95.6	48,647	79,768	64.0
NM	53,649 ^e	66,877	24.7	35,745	60,251	68.6	45,106	57,261	26.9
NY	92,723	224,342	141.9	182,038 ⁵	48,133	-73.6	92,689	74,642	-19.5
NC	61,858	89,650	44.9	16,095	41,852	160.0	53,725	62,935	17.1
ND	83,992	84,478	0.6	15,198	23,760	56.3	32,572	38,132	17.1
OH	52,281	128,031	144.9	39,888	36,247	-9.1	51,378	77,623	51.1
OK	40,264	48,516	20.5	43,921	57,717	31.4	40,577	52,212	28.7
OR	124,458	194,026	55.9	32,244	47,462	47.2	66,671	46,059	-30.9
PA	69,041	116,324	68.5	53,069	43,950	-17.2	63,726	50,441	-20.8
RI	110,146	181,111	64.4	16,088	61,385	281.6	50,580	61,940	22.5
SC	50,690	87,773	73.2	21,066	30,462	44.6	45,622	46,771	2.5
SD	52,937	97,607	84.4	19,825	26,411	33.2	32,392	31,153	-3.8
TN	46,567	173,879	273.4	22,496	46,257	105.6	40,653	79,168	94.7
TX	41,888	60,811	45.2	40,963	42,389	3.5	41,823	53,169	27.1
UT	42,644	70,093	64.4	17,686	25,576	44.6	27,279	32,908	20.6
VT	122,197	135,888	11.2	31,524	41,130	30.5	57,236	41,211	-28.0
VA	56,140 ^e	112,381	100.2	37,021	37,766	2.0	51,819	55,687	7.5
WA	107,401	146,956	36.8	21,879	20,838	-4.8	61,450	28,525	-53.6
WV	64,421	92,259	43.2	28,510	46,309	62.4	48,045	50,659	5.4
WI	47,004	87,720	86.6	22,621	27,608	22.0	39,220	38,924	-0.8
WY	60,959	110,020	80.5	56,470	39,816	-29.5	44,104	42,541	-3.5
US Total	60,370	97,190	61.0	29,109	37,816	29.9	50,240	49,289	-1.9

e=estimate *includes 1991 data HCBS began in: ¹1994, ²2000, ³1993, ⁴1996, ⁵1992

Note: Average daily recipients were estimated as the number at the beginning of the year, plus the number at the end of the year divided by 2.

Source: State reports to the National Residential Information Systems Project, University of Minnesota (Prouty, Smith & Lakin, 2003); report includes ICF-MR expenditure statistics provided by Brian Burwell of the MEDSTAT Group.

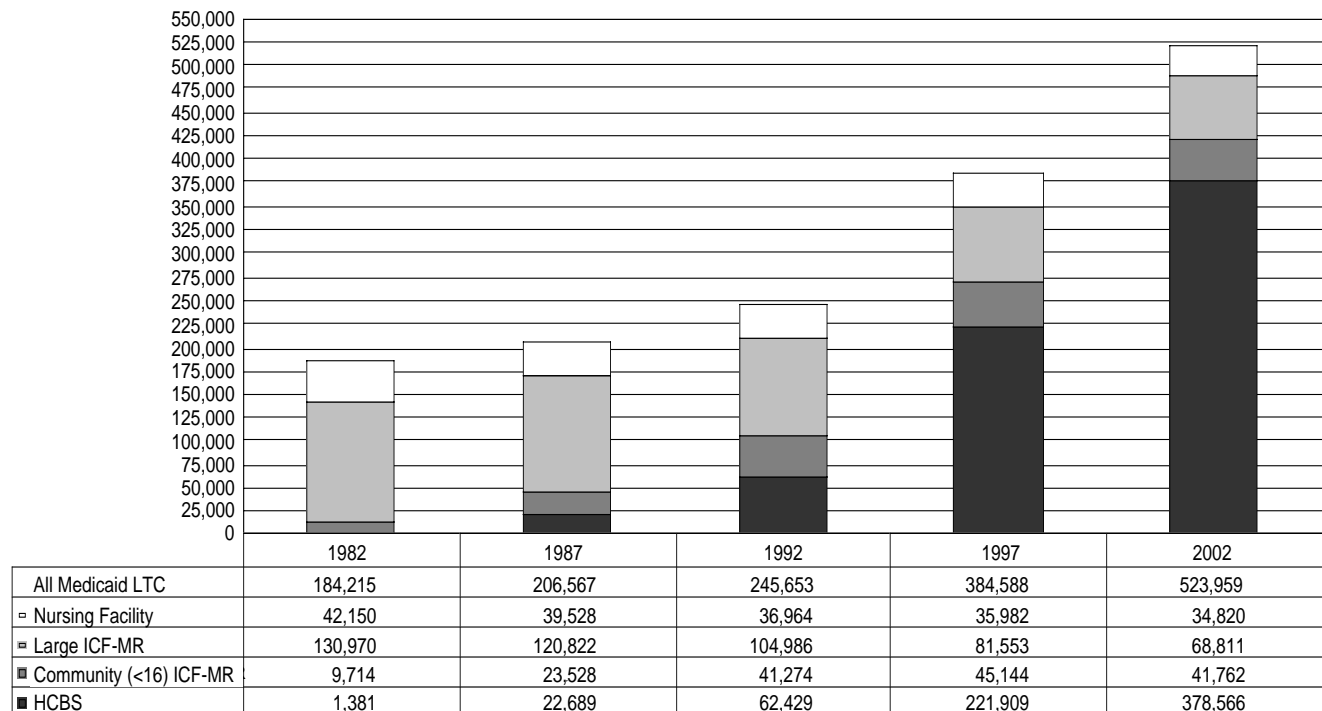
The top two darker bands in Figure 3 show federal expenditures for services for persons with ID/DD (congregate on top and community below). The bottom two lighter bands show state expenditures (again congregate on top, community below). As shown, between FY 1991 and FY 2000 federal contributions for community services increased 227.1% in real terms (an increase of about \$7.36 billion) as compared with substantial, but much lower real dollar increases of 46.4% in state expenditures for community services (an increase of about \$3.65 billion). Between FY 1991 and FY 2000 inflation-controlled state and federal services expenditures (Medicaid and non-Medicaid) for persons with ID/DD increased 45% from \$20.34 billion to about \$29.50 billion. Over this same period, total state expenditures (in 2000 dollars) increased from \$12.70 billion to \$14.72 billion (15.9%), while total federal expenditures increased from \$7.64 billion to \$14.78 billion (93.5%).

Table 3 presents statistics on change in the total, average per-recipient and average per-state resident expenditures for combined HCBS and ICF-MR programs. Between FY 1992 and FY 2002 the national average per-person expenditure for ICF-MR residents increased from \$60,370 to \$97,190 (61.0%). Increases were 100% or more in 10 states and 40% or less in 16 states. HCBS expenditures increased much less on average (only 29.9%), although with much smaller and often differently focused HCBS programs in 1992 than in 2002. Among the 46 states with HCBS programs that began before 1992, average HCBS expendi-

tures decreased in 8 and increased by more than 50% in 16.

The combined average annual expenditures for both HCBS and ICF-MR program participants present a much more stable picture of overall Medicaid than either HCBS or ICF-MR alone. Between 1992 and 2002, the combined average per recipient expenditure actually decreased. During this period as total HCBS and ICF-MR expenditures were increasing from \$10.485 billion to \$24.112 billion (130.0%), the average expenditure decreased by \$950 per person as total service recipients increased from 208,689 to 489,139 (134.4%). Altogether 24 states reduced per recipient Medicaid expenditures between 1992 to 2002 by shifting substantial portions of their long-term care supports for persons with ID/DD to HCBS programs, and another 17 kept overall per person increases under 30% (half the average rate of ICF-MR increase). There were seven states with increases of more than 50% in combined average HCBS and ICF-MR expenditures. While there were numerous factors involved in the increase, all seven of these states were below the national average in proportions of HCBS recipients among the combined HCBS and ICF-MR total. Conversely of the 24 states that reduced average expenditures for their combined HCBS and ICF-MR recipients, all but 3 were above the national average in the proportion of HCBS recipients among the combined HCBS and ICF-MR total.

Figure 4: Recipients with ID/DD in All Medicaid Long-Term Care Services, June 1982 to June 2002



■ HCBS and Other Medicaid Programs

Driven by growth in the Medicaid HCBS program, the number of persons with ID/DD in programs supported by Medicaid has increased dramatically in the past 20 years. Figure 4 shows this growth, including in addition to HCBS and ICF-MR recipients, the estimated number of individuals with ID/DD in Medicaid nursing facilities. Total Medicaid long-term care beneficiaries with ID/DD nearly tripled during the period. Equally impressive is the number of beneficiaries indicated by the two lightest shaded segments of the bars for each year. These are the segments showing nursing facility and large (16+ resident) ICFs-MR. In the bar showing the distribution of Medicaid long-term care beneficiaries in 1982 virtually all are included in the institutional segments. By 2002 these segments were a relatively small part of the total Medicaid long-term care beneficiaries.

■ Future Challenges for Medicaid HCBS

Medicaid HCBS programs have grown at remarkable rate in the first two decades of since their authorization, and especially in the most recent decade. They have truly transformed the focus of Medicaid long-term care supports for persons with ID/DD from an overwhelmingly institutional service program to a predominantly community service program. HCBS growth, the changing demand and expectations for services, and the socio-economic realities facing the nation and individual states will all contribute to notable challenges to future development and maintenance of HCBS programs. The four challenges described below stand out.

State Budget Crises

In budgeting for FYs 2003 and 2004 states have faced deficits that have been estimated at \$100 billion, with most of the deficits pushed into and responded to in FY 2004 budgets. These deficits are largely the result of sharply decreased state revenues, an estimated 13% reduction in just the one year between April-June 2001 and April-June 2002 (McNichol, 2003). While most state budgets for FY 2004 contain some new sources of revenues, the primary means of states dealing with their deficits have been budget cuts enacted for FY 2004. These budget reductions are affecting all aspects of access, expenditures, and quality improvement initiatives in HCBS programs for persons with ID/DD in virtually every state. In FY 2004, states also find themselves with substantially fewer alternatives for dealing with reduced state revenues for HCBS. Most have already brought the vast majority of long-term care services and expenditures under the Medicaid umbrella and thereby have

less opportunity to “refinance” state-only expenditures with federal Medicaid cost-share to use the resulting federal reimbursements to develop new services. Even those states that have significant opportunities to increase federal Medicaid participation and cost-share have found most of the potential revenue gains earmarked for general state deficit reduction efforts. In short, the combination of state revenue shortfalls and diminishing opportunities to claim new federal cost-share without the commitment of new state money has created enormous challenges for states in securing any growth in HCBS programs, much less maintaining the rates of growth rate evident in the previous decade.

People Waiting for Services

States greatly expanded their services for persons with ID/DD between FY 1992 and FY 2002. The total number of out-of-home residential service recipients grew by more than one-third. The total number of persons receiving Medicaid financed services more than doubled. Total HCBS recipients grew by 316,000 during the period. Ironically the number of people reported to be waiting for services changed very little during the decade (based on the reports of 36 states, an estimated 59,800 in June 2002). The number of people still waiting for service reflects that some of the growth in HCBS was people already “in the system” in ICFs-MR or in state financed services. It also reflects the expanded coverage of services and service settings during the decade. For example, between 1990 and 2002, the number of people receiving HCBS while living in the home of parents or other family members increased by an estimated 120,000 persons (Prouty & Lakin, 1991; Prouty, Smith & Lakin, 2003). Many factors have pushed the demand for HCBS within the states. Demand for services has been growing as the settings in which people can receive services has expanded (from specialized facilities to almost anywhere people live). Demand has grown as the variety and flexibility of services has increased and what is offered is more and more likely to be what people want and need. Demand has increased as greater numbers of persons with ID/DD (especially “baby boomers”) have matured into adulthood with Medicaid services replacing educational services and paid service providers taking the place of parents as primary caregivers. Demand has increased as persons with ID/DD have lived to older ages and need greater average number of “service years” in their lifespan. All of these pressures can be expected to be exacerbated by the near-term state budget crises and resulting plans to limit the expansion of services to include those currently waiting. The unknown in this waiting list crisis is the eventual outcome of more than a dozen active court cases in which courts are asked to force state compliance with Medicaid law requiring states that choose to participate in Medicaid to provide the needed Medicaid services to eligible persons

with “reasonable promptness” (see Smith, 2003 for a summary).

Staffing of Community Services

There is a well-recognized national crisis in the recruitment, retention, and training of direct support personnel (DSPs) for community services. In September 2002, Secretary of Labor Elaine Chao, speaking at a national conference of the American Network of Community Options and Resources noted that, “The paraprofessional long-term care workforce ... is the cornerstone of America’s long-term care system,” that there are substantial challenges in recruiting the direct support workers needed, but that, “The solution is not simply one of supply. The fundamental, long-term challenge is how to develop a committed, stable pool of workers who are willing, able, and skilled to provide quality care” (Chao, 2002). Such an observation recognizes that, although the number of DSPs needed over the next decade is expected to increase by 58% (Bureau of Labor Statistics, 1999), the vast majority of DSPs hired during the next decade will be replacing workers who leave, not people providing newly created services for new service recipients. A joint House/Senate resolution was introduced in April 2003, “Expressing the sense of the Congress that community inclusion and enhanced lives for individuals with mental retardation and developmental disabilities is at serious risk because of the crisis in recruiting and retaining direct support professionals, which impedes the availability of a stable, quality direct support workforce” (S. Con. Res. 21/H. Con. Res. 94). This resolution mirrors the Congressional findings in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (PL 106-402; 42 USC 15001; Section 101 (a) (14)). Such attention reflects a growing awareness that the foundation of community services is jeopardized by high turnover, from 40% to 75% in most states studies; high rates of vacancy, from 6% to 14%; and inadequate training for the specific demands of the job (Braddock & Mitchell, 1992; Larson, Lakin, & Hewitt, 2002; Polister, Lakin & Prouty, 2003). These realities are substantially affected by wages for community DSPs that average only \$8.68 (\$7.33 for starting wages). This was 74.4% of average state institution DSP wages and only 55.4% of the average wage for all persons insured for unemployment benefits (Polister, Lakin & Prouty, 2003). In the late 1990s through 2001, there were efforts in most states to address the inadequate pay and other compensation of DSPs. Few such efforts have survived the state budget crises of FYs 2003 and 2004.

Quality Assurance

HCBS and other community services for persons with ID/DD have grown at an extremely rapid rate during the past decade. This growth and the nature and flexibility of HCBS have brought enormous challenges in monitoring of service quality and protecting persons receiving them. HCBS has

fueled dramatic increases in the number of different places that people receive services. In 1982, there were about 15,000 residential settings for persons with ID/DD. In 1992, there were about 46,000 places in which people received residential services (other than family homes). By 2002, the estimated number had grown to an estimated 125,000 (estimated because there are states that have simply lost count; see Prouty, Smith & Lakin, 2003). States have not been able to expand quality assurance (QA) systems commensurate with this growth. But even if they had, they would have had to adjust to new expectations. What was considered “quality” in community services in 1982 or even in 1992 no longer satisfies contemporary values. Today, definitions of quality in human services require attention to dimensions of quality of life in addition to protection of health and safety. A few states have established systems for quality review that attend to the new concepts of quality (see Bradley & Kimmich, 2003; www.qualitymall.org) and over the past decade there have been persistent concerns about whether they attend sufficiently even to the basics of health and safety. A March 19, 1993, House hearing called by Rep. (now Senator) Wyden examined the quality of community services and concluded, “State public officials charged with their oversight had little or no knowledge of the conditions within their homes... or at best found out only after terrible events had occurred.” The Wyden hearing was followed by newspaper stories of the inadequate, life-threatening, sometimes life-ending quality in community services published in several major newspapers in the late 1990s and early 2000s (e.g., Washington Post, San Francisco Chronicle, Minnesota Star Tribune, Hartford Courant). They stimulated emotional reactions, defensive responses, and promises to do better. But, in June 2003 the General Accounting Office (GAO) issued a new report critical of QA in Medicaid HCBS. Although focused primarily on HCBS for elderly people, it recommended that the federal government: “1) establish more detailed criteria regarding necessary components of HCBS QA systems; 2) require states to submit more specific information about QA approaches prior to approval; 3) ensure that states provide sufficient and timely information in their annual reports on efforts to monitor quality; 4) develop guidance on the scope and methodology for federal reviews of state programs; 5) ensure allocation of sufficient resources for conducting thorough and timely reviews of quality in HCBS and hold regional offices accountable for such reviews” (GAO, 2003, p. 5). Clearly, addressing challenges of creating effective quality assurance systems will require leaders that believe that the safety, well-being and quality of life of people with ID/DD deserves public investment in a time when other substantial needs are competing for that investment.

■ Conclusion

These and other challenges will surely affect future directions and patterns of growth of HCBS within the states. These challenges are likely to support the emergence and growth of options such as consumer-directed services in which individuals and families (typically families) manage their own service budgets and service providers with support from “intermediary organizations.” Responding to the demands facing HCBS in an era of reduced growth in expenditures will surely use the flexibility afforded in HCBS to accommodate new developments and innovations in the design, management, and implementation of HCBS. The creativity exhibited in this era of relative scarcity may well be instructive to cost-effective applications of HCBS as individual state economies improve. But, in the interim, addressing the needs of present and potential HCBS recipients, their families and the persons paid to support them will create enormous difficulties in most states.

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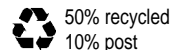
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