

Trends & Milestones

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HCBS Recipients Are Increasingly Likely to Live With Parents or Other Relatives

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As of June 30, 2006, there were an estimated 224,264 individuals with intellectual and developmental disabilities (ID/DD) receiving Medicaid Home and Community Based Services (HCBS) while living with their parents or with other family members. This estimate is based on reports of the place of residence of HCBS recipients provided by 47 states representing 448,864 of 479,196 (93.7%) of all HCBS recipients with ID/DD on June 30,

2006. The steadily growing number and proportion of HCBS recipients living in their family homes have been evident for more than a decade but have been accelerating in recent years. As shown in Figure 1, on June 30, 1992, an estimated 13,200 of 62,462 HCBS recipients lived with family members. On June 30, 1999, 82,264 persons were receiving HCBS while living in the same home as other family members. By June 2006, the number of persons

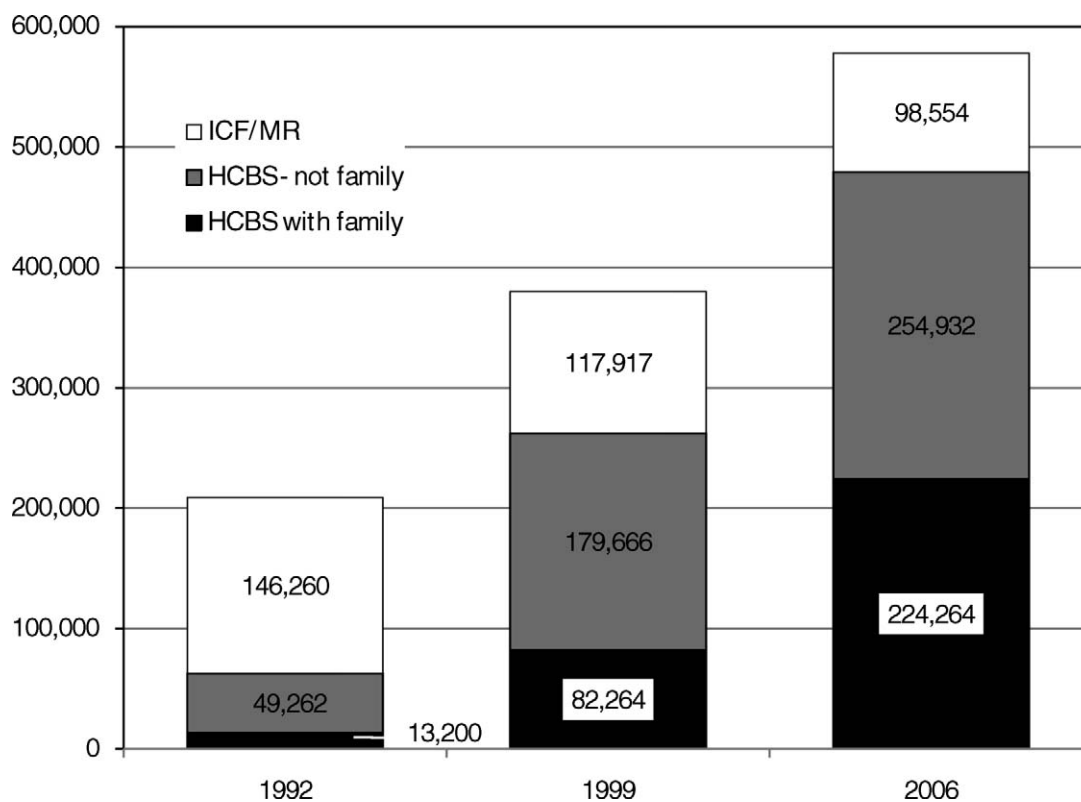


Figure 1 Persons with ID/DD receiving Medicaid HCBS and ICF/MR Services while living with versus away from family members.

Table 1 Number and Proportion of Medicaid HCBS and ICF/MR Recipients Living With Members of Their Own Families, June 30, 2006

State	HCBS with family	HCBS non-family	ICF/MR (non-family)	Total HCBS & ICF/MR	HCBS with family (%)	Total with family (%)	Change with family 1999–2006
AL	2,152	3,012	235	5,399	41.7	39.9	2,080
AK	111	897	0	1,008	11.0	11.0	–19
AZ	14,481	3,364	190	18,035	81.1	80.3	6,869
AR	1,749	1,607	1,575	4,931	52.1	35.5	1,749
CA	41,359	28,423	9,864	79,646	59.3	51.9	28,739
CO	2,508	4,342	135	6,985	36.6	35.9	538
CT	2,385	4,847	1,199	8,431	33.0	28.3	1,658
DE	0	744	154	898	0.0	0.0	0
DC	452	438	677	1,567	50.8	28.8	452
FL	18,995 ^a	12,329	3,268	34,592	60.6	54.9	12,003
GA	4,163	4,454	1,085	9,702	48.3	42.9	4,133
HI	1,172	1,191	79	2,442	49.6	48.0	900
ID	413	1,400	542	2,355	22.8	17.5	413
IL	4,162	8,247	9,402	21,811	33.5	19.1	4,162
IN	3,391	6,040	4,207	13,638	36.0	24.9	3,391
IA	4,632	7,191	2,318	14,141	39.2	32.8	DNF ^a
KS	DNF	DNF	624	7,493	DNF	DNF	DNF
KY	0	2,768	656	3,424	0.0	0.0	–125
LA	3,758	1,726	5,603	11,087	68.5	33.9	DNF
ME	183 ^a	2,483	211	2,877	6.9	6.4	183
MD	DNF	DNF	365	10,336	DNF	DNF	DNF
MA	DNF	DNF	1,012	12,472	DNF	DNF	DNF
MI	923	7,360	127	8,410	11.1	11.0	DNF
MN	4,800	9,491	2,519	16,810	33.6	28.6	3,687
MS	1,541	297	2,630	4,468	83.8	34.5	1,046
MO	3,104 ^a	5,079	1,054	9,237	37.9	33.6	DNF
MT	11 ^a	2,047	72	2,130	0.5	0.5	–232
NE	220	3,018	602	3,840	6.8	5.7	107
NV	384	989	130	1,503	28.0	25.5	DNF
NH	647 ^a	2,558	25	3,230	20.2	20.0	5
NJ	3,046	6,565	3,020	12,631	31.7	24.1	1,137
NM	1,539 ^a	2,146	181	3,866	41.8	39.8	1,256
NY	27,239	27,012	8,124	62,375	50.2	43.7	DNF
NC	5,424	2,407	4,091	11,922	69.3	45.5	1,811
ND	995 ^a	2,302	592	3,889	30.2	25.6	700
OH	4,289 ^a	10,081	6,656	21,026	29.8	20.4	3,484
OK	2,570	2,473	1,588	6,631	51.0	38.8	1,632
OR	3,884 ^a	5,532	41	9,457	41.2	41.1	1,835
PA	13,807	11,836	3,743	29,386	53.8	47.0	13,007
RI	724	2,349	40	3,113	23.6	23.3	145
SC	2,066	2,829	1,610	6,505	42.2	31.8	–45
SD	631	1,891	162	2,684	25.0	23.5	444
TN	3,212	3,750	1,287	8,249	46.1	38.9	2,545
TX	3,895	10,104	11,616	25,615	27.8	15.2	2,101
UT	1,670	2,316	794	4,780	41.9	34.9	704
VT	508	1,594	6	2,108	24.2	24.1	234
VA	1,643 ^a	5,348	1,742	8,733	23.5	18.8	304
WA	4,704	4,771	779	10,254	49.6	45.9	1,880
WV	2,414	1,322	477	4,213	64.6	57.3	1,542
WI	1,849	12,089	1,346	15,284	13.3	12.1	1,030
WY	DNF	DNF	89	2,121	DNF	DNF	DNF
Estimated U.S. total	224,264	254,932	98,544	577,740	46.8	38.8	142,000

Note. Medicaid Home and Community Based Services. ICFs/MR = Intermediate Care Facilities/Mentally Retarded.

^aEstimate based on reported place of residence of 60% to 99% of all HCBS recipients. ^bData not furnished.

living with family members while receiving Medicaid HCBS had increased to 224,264 persons. Not only was the 2006 total number of persons with ID/DD receiving HCBS while living with family members 17 times greater than it was just 14 years earlier, their proportion among all HCBS recipients also grew steadily, from 21.1% in 1992 to 31.4% in 1999 to 46.8% in 2006. Between 1999 and 2006, 65.4% of the increase of 217,266 in total HCBS recipients (from 261,930 to 479,196 persons) was accounted for by the increase of 142,000 people living with family members. As a proportion of all participants in the Medicaid HCBS and ICF/MR programs for persons with ID/DD, persons living with family members increased from 6.3% in 1992 to 21.7% in 1999 to 38.8% in 2006.

Table 1 presents state-by-state statistics on participants in Medicaid HCBS and ICF/MR programs with ID/DD who were living with family members on June 30, 2006. It shows general consistency in direction with national trends, but to different degrees in different states. Although 46.8% of all HCBS recipients in June 2006 were living with family members, 8 states reported less than 15% living with family members, and 6 states reported more than 60%. Including both HCBS and ICF/MR service recipients with ID/DD showed the same general tendencies, although a somewhat lower total proportion (38.8%) living with family members. Only 12 states reported less than 20% of their total Medicaid HCBS and ICF/MR recipients living with family members. Between June 1999 and June 2006, all but 4 states reported increases in the number of HCBS recipients living with family members, with the largest numerical increase being in California (an increase of 28,731 persons). In 2006, California was among only 4 states with a majority of the com-

bined total of HCBS and ICF/MR recipients living with family members. Its 41,359 HCBS recipients living with family members made up 18.4% of the estimated national total of 224,264.

A notable policy trend in the provision of Medicaid HCBS to people with ID/DD living with family members is the growth of Medicaid “Supports Waiver” programs. Although HCBS Supports Waivers limit total expenditures to amounts that are typically considerably less, on average, than is provided in the regular HCBS program, it also provides greater flexibility to the individuals and families enrolled. The cost savings associated with the Supports Waivers derive primarily from the unpaid services and supports provided by the family members with whom people with ID/DD live. A recent comprehensive study of Supports Waivers was conducted by the Human Services Research Institute (Smith, Agosta, & Fortune, 2007). Smith et al. found that 17 states with Supports Waivers in 2006 served 27.6% of all their HCBS recipients in Supports Waiver programs with 9.3% of their HCBS expenditures. Clearly, the increasing reliance on family-based living in the support for Medicaid service recipients demands much more attention to the characteristics and needs of the individuals and families supported, the adequacy of the supports received, and the short- and long-term outcomes for individuals, families, and HCBS programs.

Sources: Prouty, R., Smith, G., & Lakin, K. C. (Eds.). (2007). *Residential services for persons with developmental disabilities: Status and trends through 2006*. Minneapolis: University of Minnesota Research and Training Center on Community Living; and Smith, G., Agosta, J., & Fortune, J. (2007). *Gauging the use of HCBS supports waivers for people with intellectual and developmental disabilities*. Research Triangle Park, NC: RTI International.