

Trends & Milestones

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Family Support Services for Persons with Intellectual and Developmental Disabilities: Recent National Trends

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Family support data have been collected for the past 21 years by the *State of the States in Developmental Disabilities* project. New data were recently collected from the states for fiscal years (FYs) 2005 and 2006 (Braddock, Hemp, & Rizzolo, 2008). This article summarizes trends in family support services and spending nationally and in the individual states.

Support for children and adults with intellectual and developmental disabilities living in the family home, hereafter referred to as “family support,” varies greatly across the nation. States have great latitude in determining what services and supports will be included in their family support program as well as in determining whether children, adults, or both, will be eligible to receive the supports. Services and supports that states offer to families with children or adults with intellectual and developmental disabilities may include respite services; financial services, such as cash subsidies and vouchers; in-home supports, such as personal assistance or homemaker services; assistive technology and environmental modification; adaptive medical equipment; health and professional services; therapies; family counseling; family training; parent support groups; transportation; recreation activities; and specialized clothing and dietary services.

Family support has been a rapidly growing service model in recent years. As shown in Figure 1, between FYs 2000 and 2006, the number of individuals receiving family support services increased by over 108,000 (34%). Total adjusted expenditures for family support increased from \$1.3 billion to \$2.3 billion during that same period. In the 2 years between FYs 2004 and 2006, there was an increase of 43,000 families supported nation-

wide, from 385,579 to 428,803 families. Inflation-adjusted family support spending increased 7% from FYs 2004 to 2005, but the growth rate was only 2% from FYs 2005 to 2006.

Table 1 presents family support program expenditure, revenue, and participant data for the states in FY 2006. Family support spending nationwide in FY 2006 constituted only 5% of total intellectual and developmental disabilities spending (\$43.84 billion). Of particular note has been the dramatic increase in the percentage of total family support spending reimbursed by the Medicaid Home and Community Based Services (HCBS) waiver, increasing from 62% of total family support funding in FY 2004 to nearly 70% in FY 2006. Fifteen states financed 90% or more of their family support services with Medicaid HCBS; 11 states financed their family support activities solely through state funding.

In FY 2006, annual nationwide family support spending per family averaged \$5,376, ranging from \$232 per year per family in Alabama to over \$10,000 in 11 states. Spending per capita (spending divided by the state’s general population) varied widely, ranging from \$0.14 per state resident in Alabama to over \$35.00 in Arizona and Minnesota.

Financial subsidies refer to assistance that states provide families to offset the cost of supporting their child in the home. The subsidy may be in the form of a monthly stipend, reimbursement, or vouchers that enable families to purchase the services or supports they need. In FY 2006, financial subsidy programs constituted 5% of total family support spending and were almost exclusively financed with state funds. Families in 24 states received financial subsidy payments in FY 2006, an increase from the 22 states that reported providing

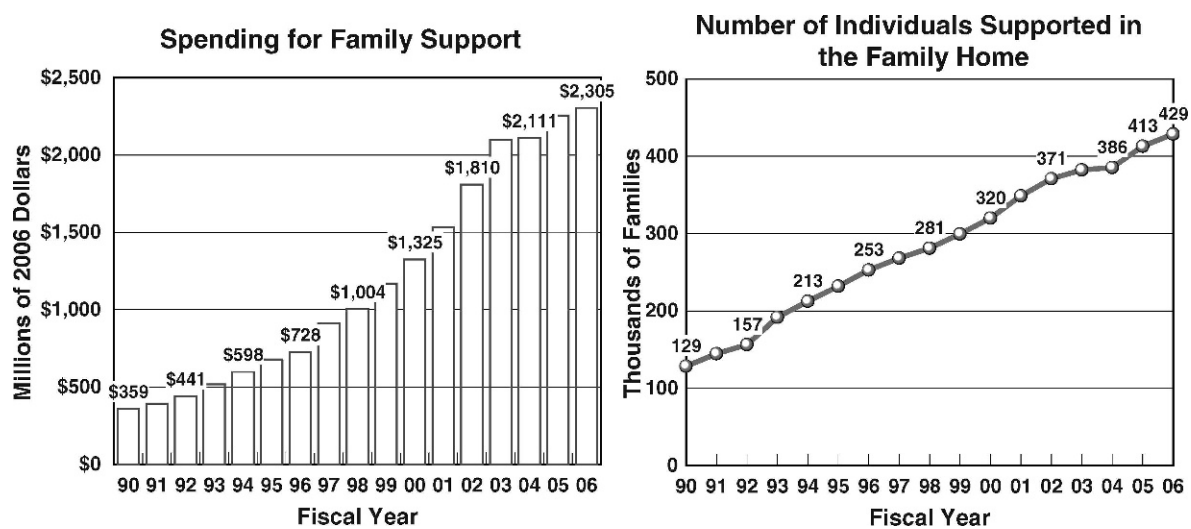


Figure 1 Family support spending and number of individuals supported in the family home, Fiscal Years 1990–2006.

financial subsidies in FY 2004. Between FYs 2004 and 2006, there was a 19% increase in the number of families receiving financial subsidies nationally, from 34,212 families to 40,866. The average annual subsidy payment to a family in the United States in FY 2006 was \$3,046. Subsidy payments ranged from \$931 per family in Connecticut to \$13,815 in Illinois.

The proportion of adults with intellectual and developmental disabilities living in their families' home is growing. In FY 1998, according to the 35 states that reported data, 35% of support recipients with intellectual and developmental disabilities living in the family home were adults, generally aged 18 years and older. The proportion of adults increased to 41% in FY 2004, based on 34 reporting states. The increase in adults supported in the family home is especially evident in states using the Medicaid HCBS to finance respite care and other family support services (Rizzolo, Hemp, Braddock, & Schindler, 2008). A reported 44% of families supported in a 6-state, nonrandom sample in FY 2006 were families with adult children (Braddock & Hemp, 2008). These 6 states were Arizona, Connecticut, Georgia, New York, South Carolina, and South Dakota, which together accounted for approximately 20% of all families in the United States receiving family support services in FY 2006.

In FYs 2005–2006, the *State of the States in Developmental Disabilities* project content-analyzed data from 34 states on the types of family support

services they provided in FY 2004. The analysis yielded 10 major service categories, 11 subcategories, and 61 discrete family support services (Braddock & Hemp, 2008; Rizzolo et al., 2008). The resulting taxonomy will contribute to extending and expanding the *State of the States* project's longitudinal database on participants and spending in family support through FY 2009.

With growing waiting lists for out-of-home placements in most states, families increasingly serve the role of de facto service delivery systems (Davenport & Eidelman, 2008; Fujiura & Braddock, 1992; Fujiura, Roccoforte, & Braddock, 1994). The growing cohort of aging family members caring for persons with intellectual and developmental disabilities nationally only heightens the importance of enhancing family support services. Improving understanding of the nature and quality of family support through improved data collection is a necessary part of this process.

(Sources: Braddock, D., & Hemp, R. (2008). *A family support services taxonomy in intellectual and developmental disabilities*. Boulder: University of Colorado, Department of Psychiatry and Coleman Institute for Cognitive Disabilities; Braddock, D., Hemp, R., & Rizzolo, M. C. (2008). *The state of the states in developmental disabilities (Seventh edition)*. Washington, DC: American Association on Intellectual and Developmental Disabilities [see www.colemaninstitute.org for state-by-state spending and

Table 1 Family Support for Persons With Intellectual and Developmental Disabilities in the United States: 2004–2006

	Total Family Support Spending 2006	Number of Families Supported 2006	Average Spending Per Family 2006	% Change in Inflation-Adjusted Spending 2004-2006	% Change in Families Supported 2004-2006	Spending Per Capita of State General Population 2006	% HCBS Waiver Funding 2006
Alabama	\$648,389	2,800	\$232	-12%	14%	\$0.14	0%
Alaska	\$4,668,000	1,516	\$3,079	33%	50%	\$7.03	0%
Arizona	\$213,935,759	18,361	\$11,652	18%	0%	\$36.00	92%
Arkansas	\$578,107	790	\$732	25%	-9%	\$0.21	16%
California	\$437,010,818	81,096	\$5,389	4%	0%	\$12.06	72%
Colorado	\$6,235,187	3,432	\$1,817	74%	-4%	\$1.34	0%
Connecticut	\$45,121,284	7,984	\$5,651	14%	-9%	\$12.85	1%
Delaware	\$1,657,775	1,735	\$955	8%	15%	\$1.97	0%
District of Columbia	\$0	0				\$0.00	
Florida	\$321,925,659	20,035	\$16,068	29%	16%	\$18.21	95%
Georgia	\$23,244,497	6,801	\$3,418	-4%	-21%	\$2.58	15%
Hawaii	\$31,276,613	2,739	\$11,419	21%	28%	\$24.36	95%
Idaho	\$302,722	709	\$427	11%	-16%	\$0.21	0%
Illinois	\$62,531,939	11,114	\$5,626	9%	4%	\$4.91	43%
Indiana	\$28,515,681	4,130	\$6,905	-5%	32%	\$4.55	98%
Iowa	\$30,565,329	2,002	\$15,267	176%	4%	\$10.26	95%
Kansas	\$43,291,821	3,549	\$12,198	4%	5%	\$15.70	100%
Kentucky	\$3,324,247	1,735	\$1,916	-8%	20%	\$0.80	0%
Louisiana	\$118,768,849	8,211	\$14,465	17%	7%	\$26.14	89%
Maine	\$1,100,000	545	\$2,018	-11%	0%	\$0.83	0%
Maryland	\$38,235,687	7,846	\$4,873	-4%	-3%	\$6.79	11%
Massachusetts	\$38,711,810	14,114	\$2,743	-21%	-1%	\$5.93	3%
Michigan	\$54,108,014	11,539	\$4,689	18%	8%	\$5.28	24%
Minnesota	\$182,768,481	8,183	\$22,335	-5%	0%	\$35.15	93%
Mississippi	\$20,645,970	4,052	\$5,095	30%	30%	\$7.07	56%
Missouri	\$13,534,785	7,463	\$1,814	-11%	75%	\$2.34	79%
Montana	\$11,066,188	2,885	\$3,836	-6%	4%	\$11.81	48%
Nebraska	\$4,634,959	566	\$8,189	-2%	34%	\$2.65	71%
Nevada	\$6,640,537	2,451	\$2,709	133%	34%	\$2.78	26%
New Hampshire	\$6,881,345	4,605	\$1,494	-4%	27%	\$5.21	100%
New Jersey	\$59,123,073	20,013	\$2,954	-8%	28%	\$6.74	0%
New Mexico	\$34,058,910	10,262	\$3,319	43%	325%	\$17.83	86%
New York	\$56,317,000	41,571	\$1,355	-5%	3%	\$2.92	0%
North Carolina	\$27,304,416	4,255	\$6,417	8%	21%	\$3.11	74%
North Dakota	\$5,607,743	604	\$9,282	23%	19%	\$8.82	89%
Ohio	\$10,482,428	12,067	\$869	-16%	-6%	\$0.91	0%
Oklahoma	\$43,682,678	4,615	\$9,465	-13%	28%	\$12.38	89%
Oregon	\$4,554,818	1,275	\$3,572	6%	14%	\$1.26	100%
Pennsylvania	\$64,882,837	22,990	\$2,822	9%	2%	\$5.21	64%
Rhode Island	\$10,343,464	753	\$13,736	-10%	0%	\$9.49	99%
South Carolina	\$34,606,072	8,989	\$3,850	5%	5%	\$8.12	91%
South Dakota	\$3,161,365	2,019	\$1,566	-7%	14%	\$4.09	42%
Tennessee	\$11,563,100	6,285	\$1,840	59%	69%	\$1.93	0%
Texas	\$50,174,833	22,980	\$2,183	37%	140%	\$2.18	55%
Utah	\$14,548,828	1,268	\$11,474	0%	10%	\$5.97	100%
Vermont	\$15,819,422	1,354	\$11,683	2%	8%	\$24.99	93%
Virginia	\$2,480,413	2,917	\$850	0%	32%	\$0.33	0%
Washington	\$48,177,202	7,292	\$6,607	-18%	-10%	\$7.73	53%
West Virginia	\$20,057,784	2,232	\$8,986	142%	15%	\$11.02	94%
Wisconsin	\$23,235,497	11,064	\$2,100	0%	12%	\$4.17	0%
Wyoming	\$13,037,112	1,010	\$12,908	42%	29%	\$25.63	99%
United States	\$2,305,149,428	428,803	\$5,376	9%	11%	\$7.76	70%

Note. From Braddock, D., Hemp, R., & Rizzolo, M.C. (2008). *The state of the states in developmental disabilities* (Seventh edition). Washington, DC: American Association on Intellectual and Developmental Disabilities. Reprinted with permission.

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