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# Policy Research Brief

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## Family Support Services in the United States: 2008

*This Policy Research Brief provides a state-by-state summary of services supporting individuals living in the family home. Data presented are based on the State of the States in Developmental Disabilities project, a longitudinal study of public financial and programmatic trends in intellectual and developmental disabilities (ID/DD) services and supports in the states (Braddock, Hemp, & Rizzolo, 2008). This brief was authored by Mary C. Rizzolo, Associate Director, Institute on Disability and Human Development (IDHD), University of Illinois at Chicago; Richard Hemp, Senior Professional Research Assistant, University of Colorado; David Braddock, Executive Director, Coleman Institute for Cognitive Disabilities, University of Colorado and Professor Emeritus at IDHD, University of Illinois at Chicago; and Abigail Schindler, IDHD, University of Illinois at Chicago. The State of the States project is funded in part as a Data Collection Project of National Significance from the Administration on Developmental Disabilities, by the Department of Psychiatry of the University of Colorado School of Medicine, and by the Coleman Institute for Cognitive Disabilities, University of Colorado. The authors wish to acknowledge Sheryl A. Larson and Charlie Lakin for their contributions in the preparation of this brief. For further information, please contact Mary C. Rizzolo, PhD, at [mrizzo3@uic.edu](mailto:mrizzo3@uic.edu) or (312) 413-8879.*

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### ■ Introduction

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Support for children and adults with intellectual and developmental disabilities (ID/DD) 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 children and adults, will be eligible to receive the supports. States also vary in how they define “family” (Turnbull et al., 2007). Family members with ID/DD can receive instrumental support from siblings,

aunts and uncles, grandparents, and others in addition to the parents. Advocates, family members, policymakers, and researchers largely agree on the goals of family support, regardless of the variation in state definitions. A principal goal is keeping the family intact and building upon the family’s existing strengths and resources so the individual with a disability can continue living in the family home. Another important goal is helping to assure that a child supported in the family home has the best possible transition to adulthood (“Synthesis of discussion group perspectives,” 2006).

Services and supports that states offer to families with children or adults with ID/DD 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, specialized clothing, and dietary services. While family caregivers are the largest source of long-term care for individuals with ID/DD, family support did not emerge as a significant priority for ID/DD state agencies until the early 1980s (Agosta & Bradley, 1985; Fujiura, Garza, & Braddock, 1990; Turnbull & Turnbull, 2000).

Family support programs have historically been offered through public and private service agencies. However, in the late 1980s, a new means of providing support to families emerged in the form of financial subsidies, and in 2006, 24

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states provided cash subsidies to families (Braddock et al., 2008). Moreover, a growing number of consumer-directed services now take the form of individualized budgets, and individuals are often allowed to hire family members to provide support (Caldwell, 2007). The hiring of family members has been shown to be associated with increased community involvement for children or adults with developmental disabilities (Caldwell & Heller, 2003).

Increased family control over respite and personal care services can result in numerous benefits, including reduced stress (Herman, 1991; Meyers & Marcenko, 1989; Zimmerman, 1984), reduced financial worries (Herman, 1991), increased self-efficacy (perceived ability to provide care) (Heller, Miller, & Hsieh, 1999; Zimmerman, 1984), increased satisfaction with services (Caldwell & Heller, 2003), decreased need for out-of-home placement (Heller et al., 1999; Meyers & Marcenko, 1989), fewer placements into nursing homes and institutions (Caldwell, 2007; Caldwell & Heller, 2003; Heller & Caldwell, 2005), and increased maternal employment (Caldwell & Heller, 2003). Heller and Factor (2008), however, contend that much of the family support research has been unidirectional, strictly focusing on the benefits to family caregivers. They note that in many instances, the family member with ID/DD is also providing support, especially to elderly parents with increasing needs for support as they age (Heller & Factor, 2008).

Studies have also demonstrated the potential cost-effectiveness of family support programs in the states. One concern, however, is that savings are in fact due to a shifting of costs from taxpayers to unpaid family caregivers (Lewis & Johnson, 2005). This is compounded by the fact that families of individuals with ID/DD often experience higher rates of poverty than other families (Fujiura, 1998). Fujiura, Roccoforte, and Braddock (1994) estimated that families spent \$6,300 per year (in 1990 dollars) on out-of-pocket expenses for their adult child with a developmental disability that were not reimbursed by formal programs. Caldwell (2006) found that families in an Illinois sample who were recipients of the Illinois Home-Based Support Services Program had lower out-of-pocket expenses (\$3,462) than families on the State's waiting list for the program (\$5,358). The largest out-of-pocket expenses for Illinois families were the cost of respite/personal assistance services, transportation, medications, and related supplies. Greater out-of-pocket expenses for families contributed to lower access to health care for family caregivers (Caldwell, 2006). Ho, Collins, Davis, and Doty (2005), in their review of research, concluded that half of caregivers caring for elderly and non-elderly individuals with disabilities forego medical care due to financial constraints.

Despite the potential that individual and family hardships might be incurred, most individuals with disabilities wish to remain at home and their families also prefer this (Johnson, Kastner, & the Committee on Children with Disabilities, 2005). The availability of external supports has

been shown to increase families' willingness and ability to keep their children with ID/DD at home (Birenbaum, Guyot, & Cohen, 1990; Cole & Meyer, 1989; Fujiura, et al. 1994).

An effective family support program empowers families while maximizing self-determination by the individual with a disability. Dunst, Trivette, and Hamby (2007) have found that family support programs should "honor and respect [families'] values and choices" (p. 370). Cultural values will also impact the future demand for residential services in the states. "Cultural care-giving norms and language barriers reflecting our increasingly diverse society are creating a hidden need for services that typically do not surface until families are in a crisis situation" (Heller & Factor, 2008, p. 132).

Demand for services for people with developmental disabilities who reside with aging family caregivers is undoubtedly going to increase. In 2006, an estimated 4.7 million Americans had ID/DD (Larson et al., 2000), and approximately 60% of these individuals lived with family caregivers. An additional 15% of individuals with ID/DD lived with a spouse, and 13% lived in their own home. Twelve percent lived in "supervised residential settings" (Braddock et al., 2008; Fujiura, 1998); supervised residential settings include public and private institutions, nursing facilities, group homes, apartments, foster care placements, and supported living/personal assistance settings (Braddock et al., 2008). The "informal" system of residential care was five times greater than the formal out-of-home residential care system (536,476 individuals) (Braddock et al., 2008). An estimated 716,000 individuals receiving "informal" residential care in fact resided with caregivers aged 60 years or more – many of whom will soon require out-of-home residential support (Braddock, 1999; Braddock et al., 2008; Fujiura, 1998; U.S. Census Bureau, 2007). This increased demand for services will directly impact the finite capacities of state service delivery systems, which already are struggling to address the needs of 70,000 persons with ID/DD awaiting residential services (Prouty, Smith, & Lakin, 2006).

Clearly, family support is critically important to the sustainability of families and the viability of the nation's long-term support programs for persons with disabilities. The preceding summary illustrates the potential benefits of supporting individuals with disabilities in the family home for the individuals, family members, and the states. However, funding for these initiatives has lagged substantially behind funding levels for out-of-home residential care.

## Methodology

This brief describes results from a nationwide study of family support commitments in each of the states and the District of Columbia in FYs 2005 and 2006. Data were collected during the most recent 2005-06 extension of the ongoing State of the States in Developmental Disabilities study, and were obtained from one or more state budget/program staff identified by the state ID/DD agency director, from state budget documents, and from secondary analysis of federal and state data sources. A more detailed discussion of the study's methodology is provided in Braddock et al. (2008).

The data presented in this brief were collected for two categories of support, managed by state ID/DD agencies, for individuals with ID/DD living in the family home: a) financial subsidy or cash payments to families, and b) all other non-subsidy supports. Data are also presented on the amount of federal-state Home and Community Based Services (HCBS) Waiver funding used to support children and adults with ID/DD living at home, and the proportions of children and adults in families receiving family support.

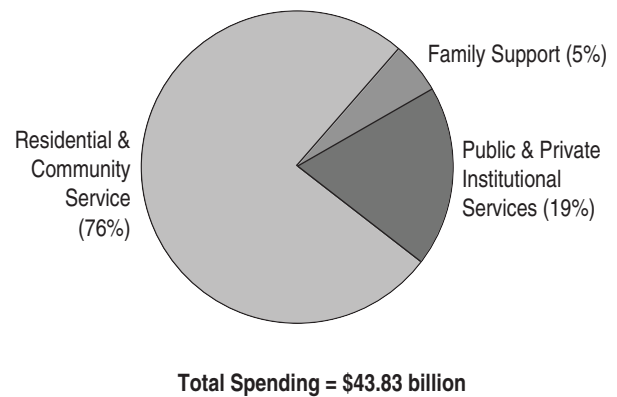
## Findings

### Family Support in the U.S., From 1990-2006

While the majority of long-term care for persons with ID/DD is provided in family homes, only a fraction of long-term care spending has been directed toward family support. In 2006, 5% of total ID/DD spending was allocated to support individuals living in the family home (see Figure 1). All 50 states reported a family support initiative for financial subsidy (including vouchers and individualized budgets), for other family support activity including respite care, in-home supports, and other services for families, or for both areas. The District of Columbia did not fund family support services in 2006.

Figure 2 depicts the growth in the number of families supported, and in the inflation-adjusted funding allocated for family support services in the states during 1990-2006. Total adjusted family support spending advanced from \$2.1 billion for 383,264 families in 2004 to \$2.3 billion for 426,782 families in 2006. This represented a 9% inflation-adjusted increase in spending and an 11% increase in the number of families supported (Braddock et al., 2008). The increased number of families supported during 2004-06 follows a period of slower growth during 2002-04 (Braddock et al., 2005). In fact, the 2002-04 period represented the smallest rate of increase in the number of families supported for any two-year period since the project began collecting family support data in 1988 (Braddock, Hemp, Fujiura, Bachelder, & Mitchell, 1990).

Figure 1. United States: Spending for ID/DD Services, 2006



Source: Braddock et al. (2008). Boulder, CO: University of Colorado, Department of Psychiatry and Coleman Institute for Cognitive Disabilities.

### Variability Across the States

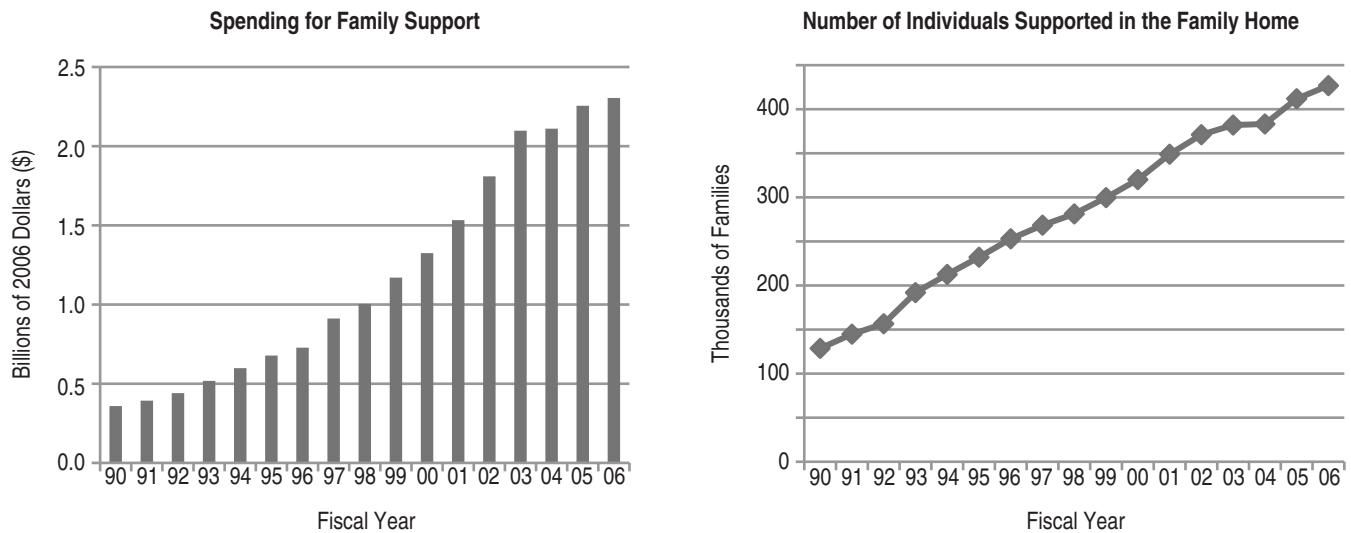
While all 50 states reported some form of family support initiative, there was tremendous variability across the states in family support spending levels. Twenty-four states increased both inflation-adjusted family support spending and the number of families supported during 2004-06 (Alaska, California, Delaware, Florida, Hawaii, Illinois, Iowa, Kansas, Louisiana, Michigan, Mississippi, Nevada, New Mexico, North Carolina, North Dakota, Oregon, Pennsylvania, South Carolina, Tennessee, Texas, Vermont, Virginia, West Virginia, and Wyoming). Five states increased family support spending yet decreased the number of families supported (Arizona, Arkansas, Colorado, Connecticut, and Idaho) and fourteen states reduced spending levels but increased the number of families supported (Alabama, Indiana, Kentucky, Missouri, Montana, Nebraska, New Hampshire, New Jersey, New York, Oklahoma, Rhode Island, South Dakota, Utah, and Wisconsin).

Six states reduced both family support spending and the number of families supported during 2004-06 (Georgia, Maine, Maryland, Minnesota, Ohio, and Washington). Maine reduced spending, while supporting the same number of families. In 2006, the nationwide average family support spending per family was \$5,400, ranging from \$232 per year per family in Alabama to over \$10,000 in 12 states. Spending per capita (spending divided by the state's population) ranged from \$0.14 in Alabama to \$36.00 in Arizona.

### Financial Subsidy

Financial subsidy payments were made to families in 24 states in 2006, an increase from 22 states that reported financing cash subsidies in 2004. Maine reported for the first time that it had provided cash subsidies during 1993-06 and

**Figure 2. Family Support Spending and Number of Families Supported in the Family Home: Fiscal Years 1990-2006**



Source: Braddock et al. (2008). Boulder, CO: University of Colorado, Department of Psychiatry and Coleman Institute for Cognitive Disabilities.

Tennessee instituted a new financial subsidy program in 2005 (Braddock et al., 2008). Total financial subsidy payments to families in the U.S. increased from \$101.4 million in 2004 to \$124.5 million in 2006 (a 10% inflation-adjusted increase). There was a 19% increase in the number of families receiving subsidies, from 33,744 to 40,866. The average annual subsidy payment to a family in the U.S. in 2006 was \$3,046, ranging from \$931 in Connecticut to \$13,815 in Illinois (see Table 2). The combined financial subsidy programs in Alaska, Illinois, Louisiana, Michigan, Minnesota, New Jersey, Oklahoma, Texas, and Washington State accounted for 83% of all subsidy payments in the nation in 2006.

Nine states increased both financial subsidy spending and families supported during 2004-06 (Alaska, Delaware, Illinois, Minnesota, Nevada, New Jersey, New Mexico, Oklahoma, and Washington). Arkansas increased financial subsidy spending but reduced the number of families receiving subsidies. Six states reduced financial subsidy spending but increased the number of families supported (Arizona, Connecticut, Florida, Michigan, North Dakota, and South Carolina) and four states reduced both financial subsidy spending and number of families supported (Kansas, Louisiana, Rhode Island, and Utah). Iowa, Maine, and Texas decreased financial subsidy spending (in adjusted terms) but supported the same number of families.

### The HCBS Waiver

The federal government requires that all states provide certain “mandatory” services through their Medicaid plans, including inpatient hospital; outpatient hospital; Early and Periodic Screening, Diagnosis, and Treatment (EPSDT); and

some nursing facility services. In addition, there are numerous “optional” services that a state may choose to provide in its state plan, including six that are critically important to individuals with developmental disabilities – two health care services (clinic and rehabilitative services), one institutional long-term care service (ICF/MR), and three community-based long-term care services: the Medicaid Home and Community Based Services (HCBS) Waiver, personal assistance services, and targeted case management (Braddock, 2002; Hemp & Braddock, 2003). In 2006, federal and state Medicaid spending for these optional services constituted 78% of the \$43.83 billion in total ID/DD long-term care spending in the U.S. (Braddock et al., 2008).

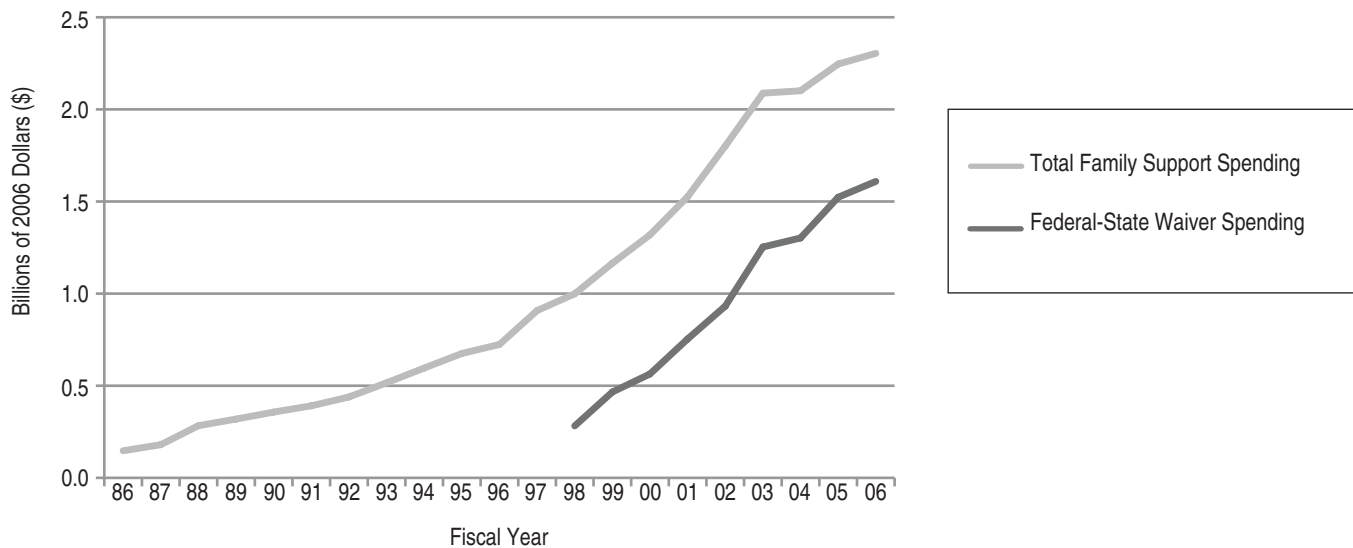
The HCBS waiver, enacted in 1981 (Pub. L. No. 97-35), has been instrumental in helping states reduce their reliance on institutional settings while developing community services programs, including family support. In fact, the HCBS waiver has emerged as the principal funding source for services that support individuals living in the family home (Rizzolo, Hemp, & Braddock, 2006). Lakin, Prouty, and Coucouvanis (2007) reported that over 45% of HCBS recipients in 2006 lived with their parents or other family members. The states offer a wide range of HCBS waiver services that benefit individuals with ID/DD, including those living in the family home. These waiver services include case management, homemaker assistance, home health aides, personal care, residential and day habilitation, transportation, supported employment, home modification, respite care, and therapies.

In 2006, the HCBS waiver financed 70% of all family support services in the U.S. (see Figure 3). States varied greatly in the extent to which they utilized HCBS waiver

**Table 1: Change in ID/DD Family Support Spending and Number of Families Supported, by State, 2004-2006**

| State      | Family Support Total 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 |
|------------|---|-----------------------------------|---------------------------------------|---|--|
| AL         | 648,389                                 | 2,800                             | 232                                   | -12   | 14                                       |
| AK         | 4,668,000                               | 1,516                             | 3,079                                 | 33  | 50                                       |
| AZ         | 213,935,759                             | 18,361                            | 11,652                                | 18  | 0  |
| AR         | 578,107                                 | 790                               | 732                                   | 25  | -9                                       |
| CA         | 437,010,818                             | 81,096                            | 5,389                                 | 4   | 0  |
| CO         | 6,235,187                               | 3,432                             | 1,817                                 | 74  | -4                                       |
| CT         | 45,121,284                              | 7,984                             | 5,651                                 | 14  | -9                                       |
| DE         | 1,657,775                               | 1,735                             | 955                                   | 8   | 15                                       |
| DC         | 0                                       | 0                                 | 0                                     | ---   | ---                                      |
| FL         | 321,925,659                             | 20,035                            | 16,068                                | 29  | 16                                       |
| GA         | 23,244,497                              | 6,801                             | 3,418                                 | -4  | -21                                      |
| HI         | 31,276,613                              | 2,739                             | 11,419                                | 21  | 28                                       |
| ID         | 302,722                                 | 709                               | 427                                   | 11  | -16                                      |
| IL         | 62,531,939                              | 11,114                            | 5,626                                 | 9   | 4  |
| IN         | 27,834,340                              | 2,109                             | 13,198                                | -5  | 32                                       |
| IA         | 30,565,329                              | 2,002                             | 15,267                                | 176   | 4  |
| KS         | 43,291,821                              | 3,549                             | 12,198                                | 4   | 5  |
| KY         | 3,324,247                               | 1,735                             | 1,916                                 | -8  | 20                                       |
| LA         | 118,768,849                             | 8,211                             | 14,465                                | 17  | 7  |
| ME         | 1,100,000                               | 545                               | 2,018                                 | -11   | 0  |
| MD         | 38,235,667                              | 7,846                             | 4,873                                 | -4  | -3                                       |
| MA         | 38,711,810                              | 14,114                            | 2,743                                 | -21   | -1                                       |
| MI         | 54,108,014                              | 11,539                            | 4,689                                 | 18  | 8  |
| MN         | 182,768,481                             | 8,183                             | 22,335                                | -5  | 0  |
| MS         | 20,645,970                              | 4,052                             | 5,095                                 | 30  | 30                                       |
| MO         | 13,534,785                              | 7,463                             | 1,814                                 | -11   | 75                                       |
| MT         | 11,066,188                              | 2,885                             | 3,836                                 | -6  | 4  |
| NE         | 4,634,959                               | 566                               | 8,189                                 | -2  | 34                                       |
| NV         | 6,640,537                               | 2,451                             | 2,709                                 | 133   | 34                                       |
| NH         | 6,881,345                               | 4,605                             | 1,494                                 | -4  | 27                                       |
| NJ         | 59,123,073                              | 20,013                            | 2,954                                 | -8  | 28                                       |
| NM         | 34,058,910                              | 10,262                            | 3,319                                 | 43  | 325                                      |
| NY         | 56,317,000                              | 41,571                            | 1,355                                 | -5  | 3  |
| NC         | 27,304,416                              | 4,255                             | 6,417                                 | 8   | 21                                       |
| ND         | 5,607,743                               | 604                               | 9,282                                 | 23  | 19                                       |
| OH         | 10,482,428                              | 12,067                            | 869                                   | -16   | -6                                       |
| OK         | 43,682,678                              | 4,615                             | 9,465                                 | -13   | 28                                       |
| OR         | 4,554,818                               | 1,275                             | 3,572                                 | 6   | 14                                       |
| PA         | 64,882,837                              | 22,990                            | 2,822                                 | 9   | 2  |
| RI         | 10,343,464                              | 753                               | 13,736                                | -10   | 0  |
| SC         | 34,606,072                              | 8,989                             | 3,850                                 | 5   | 5  |
| SD         | 3,161,365                               | 2,019                             | 1,566                                 | -7  | 14                                       |
| TN         | 11,563,100                              | 6,285                             | 1,840                                 | 59  | 69                                       |
| TX         | 50,174,833                              | 22,980                            | 2,183                                 | 37  | 140                                      |
| UT         | 14,548,828                              | 1,268                             | 11,474                                | 0   | 10                                       |
| VT         | 15,819,422                              | 1,354                             | 11,683                                | 2   | 8  |
| VA         | 2,480,413                               | 2,917                             | 850                                   | 0   | 32                                       |
| WA         | 48,177,202                              | 7,292                             | 6,607                                 | -18   | -10                                      |
| WV         | 20,057,784                              | 2,232                             | 8,986                                 | 142   | 15                                       |
| WI         | 23,235,497                              | 11,064                            | 2,100                                 | 0   | 12                                       |
| WY         | 13,037,112                              | 1,010                             | 12,908                                | 42  | 29                                       |
| U.S. Total | 2,304,468,087                           | 426,782                           | 5,400                                 | 9   | 11                                       |

Source: Braddock et al. (2008). Boulder, CO: University of Colorado, Department of Psychiatry and Coleman Institute for Cognitive Disabilities.

**Figure 3. Total Waiver Spending for Family Support Services, 1986-2006**

Source: Braddock et al. (2008). Boulder, CO: University of Colorado, Department of Psychiatry and Coleman Institute for Cognitive Disabilities.

funds to finance family support initiatives (see Table 3). Fourteen states funded 90% or more of their family support system with the Medicaid HCBS waiver. Conversely, 12 states opted to finance their family support initiatives solely through state funding.

### Supports for Children vs. Adults

States varied in the extent to which they provided family support services to children versus adults. The percentage of adult children living in the family home is growing. In 1998, 35% of recipients of family support services (in 35 reporting states) were families of adults aged 18 years and older. This figure increased to 41% by 2004 (in 34 reporting states) (Rizzolo et al., 2006). Analysis of changes from 1998 to 2004 revealed that the number of adult children supported in the family home was increasing in many states, while the number of younger children supported remained stable. The increase in adult children supported was especially evident in states that had HCBS waiver funding for respite care and other family support services in 2004.

In spring 2008, a six-state study was conducted by the State of the States in Developmental Disabilities project in collaboration with the Research Committee of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) (Braddock & Hemp, 2008). The six participating states (Arizona, Connecticut, Georgia, New York, South Carolina, and South Dakota) constituted 20% of all families receiving support in the U.S. that year. In these six states in 2006, 44% of families supported were caring for adults aged 18 years and older, while the remaining 56% supported children in the family home.

### Discussion

Despite these recent initiatives, state budget constraints now mean that funding for family support, especially funding for financial subsidy programs, often cannot compete with the financing of residential service programs. This was especially evident during 2003-2004, a period in which state general fund spending declined for the first time in more than 20 years. Challenging economic and fiscal constraints led state governments to reduce ID/DD spending growth in most states (Braddock et al., 2008). This was particularly true for family support spending which increased by only 1% in adjusted terms from 2003-2004. From 2004 to 2006, state general funds rebounded, increasing by 0.3% in 2005 and 1.7% in 2006 and family support spending increased modestly.

Family support spending, adjusted for inflation, increased 7% from 2004-05 and by 2% from 2005-06. Of particular note was the dramatic increase in the percentage of total family support spending reimbursed by Medicaid HCBS (from 57% of total family support funding in 2004 to nearly 70% in 2006). Many states are turning to the Waiver to leverage additional funds from the federal government to support families. From 2004 to 2006, an additional 30,000 families were supported nationwide (Braddock et al., 2008). However, many states are reluctant to “Medicaid” their family support programs (Human Services Research Institute, 2004) for fear of narrowing eligibility criteria and reducing program flexibility (Caldwell, 2007).

**Table 2: ID/DD Financial Subsidy Payments in the States, Fiscal Year 2006**

| State      | Financial Subsidy Spending 2006 (\$) | Families Receiving Financial Subsidy 2006 | Average Subsidy Per Family 2006 (\$) | % Change in Inflation-Adjusted Subsidy Spending 2004-2006 | % Change in Families Receiving Financial Subsidy 2004-2006 |
|------------|--------------------------------------|---|--------------------------------------|---|--|
| AL         |                                      |   |                                      |   |  |
| AK         | 4,548,000                            | 1,516                                     | 3,000                                | 34  | 51   |
| AZ         | 1,046,224                            | 573                                       | 1,826                                | -38   | 30   |
| AR         | 143,052                              | 92  | 1,555                                | 37  | -23  |
| CA         |                                      |   |                                      |   |  |
| CO         |                                      |   |                                      |   |  |
| CT         | 3,280,095                            | 3,525                                     | 931                                  | -11   | 11   |
| DE         | 233,854                              | 126                                       | 1,856                                | 18  | 70   |
| DC         |                                      |   |                                      |   |  |
| FL         | 473,600                              | 210                                       | 2,255                                | -21   | 53   |
| GA         |                                      |   |                                      |   |  |
| HI         |                                      |   |                                      |   |  |
| ID         |                                      |   |                                      |   |  |
| IL         | 36,071,886                           | 2,611                                     | 13,815                               | 16  | 11   |
| IN         |                                      |   |                                      |   |  |
| IA         | 1,602,523                            | 378                                       | 4,239                                | -11   | 0  |
| KS         | 3,415,962                            | 1,418                                     | 2,409                                | -7  | 0  |
| KY         |                                      |   |                                      |   |  |
| LA         | 4,634,670                            | 1,705                                     | 2,718                                | -16   | -5   |
| ME         | 600,000                              | 545                                       |                                      | -11   | 0  |
| MD         |                                      |   |                                      |   |  |
| MA         |                                      |   |                                      |   |  |
| MI         | 17,614,656                           | 6,722                                     | 2,620                                | -4  | 7  |
| MN         | 13,392,880                           | 2,346                                     | 5,709                                | 21  | 14   |
| MS         |                                      |   |                                      |   |  |
| MO         |                                      |   |                                      |   |  |
| MT         |                                      |   |                                      |   |  |
| NE         |                                      |   |                                      |   |  |
| NV         | 1,877,750                            | 454                                       | 4,136                                | 18  | 18   |
| NH         |                                      |   |                                      |   |  |
| NJ         | 12,005,157                           | 7,851                                     | 1,529                                | 17  | 21   |
| NM         | 568,752                              | 164                                       | 3,468                                | 143   | 105  |
| NY         |                                      |   |                                      |   |  |
| NC         |                                      |   |                                      |   |  |
| ND         | 607,599                              | 142                                       | 4,272                                | -9  | 51   |
| OH         |                                      |   |                                      |   |  |
| OK         | 4,972,075                            | 2,077                                     | 2,394                                | 5   | 20   |
| OR         |                                      |   |                                      |   |  |
| PA         |                                      |   |                                      |   |  |
| RI         | 170,116                              | 50  | 3,402                                | -13   | -6   |
| SC         | 3,233,432                            | 1,151                                     | 2,809                                | -15   | 57   |
| SD         |                                      |   |                                      |   |  |
| TN         | 3,897,900                            | 2,018                                     |                                      |   |  |
| TX         | 5,000,000                            | 2,674                                     | 1,870                                | -11   | 0  |
| UT         | 15,907                               | 5   | 3,181                                | -77   | -88  |
| VT         |                                      |   |                                      |   |  |
| VA         |                                      |   |                                      |   |  |
| WA         | 5,073,735                            | 2,513                                     | 2,019                                | 0   | 20   |
| WV         |                                      |   |                                      |   |  |
| WI         |                                      |   |                                      |   |  |
| WY         |                                      |   |                                      |   |  |
| U.S. Total | 124,479,825                          | 40,866                                    | 3,046                                | 9   | 19   |

Source: Braddock et al. (2008). Boulder, CO: University of Colorado, Department of Psychiatry and Coleman Institute for Cognitive Disabilities.

**Table 3: HCBS Waiver Family Support Spending, 2006**

| State      | Total Family Support Spending 2006 (\$) | Federal-State HCBS Waiver Family Support Spending, 2006 (\$) | Waiver % of Total Family Support Spending, 2006 |
|------------|---|--|---|
| AL         | 648,389                                 | 0  | 0   |
| AK         | 4,668,000                               | 0  | 0   |
| AZ         | 213,935,759                             | 197,266,297  | 92  |
| AR         | 578,107                                 | 90,094   | 16  |
| CA         | 437,010,818                             | 315,349,600  | 72  |
| CO         | 6,235,187                               | 0  | 0   |
| CT         | 45,121,284                              | 260,004  | 1   |
| DE         | 1,657,775                               | 0  | 0   |
| DC         | 0                                       | 0  | 0   |
| FL         | 321,925,659                             | 306,573,390  | 95  |
| GA         | 23,244,497                              | 3,533,388  | 15  |
| HI         | 31,276,613                              | 29,636,925   | 95  |
| ID         | 302,722                                 | 0  | 0   |
| IL         | 62,531,939                              | 26,704,202   | 43  |
| IN         | 27,834,340                              | 27,147,257   | 98  |
| IA         | 30,565,329                              | 28,962,806   | 95  |
| KS         | 43,291,821                              | 43,291,821   | 100   |
| KY         | 3,324,247                               | 0  | 0   |
| LA         | 118,768,849                             | 106,219,850  | 89  |
| ME         | 1,100,000                               | 0  | 0   |
| MD         | 38,235,667                              | 4,017,280  | 11  |
| MA         | 38,711,810                              | 1,170,326  | 3   |
| MI         | 54,108,014                              | 12,965,920   | 24  |
| MN         | 182,768,481                             | 169,375,601  | 93  |
| MS         | 20,645,970                              | 11,590,552   | 56  |
| MO         | 13,534,785                              | 10,720,390   | 79  |
| MT         | 11,066,188                              | 5,308,481  | 48  |
| NE         | 4,634,959                               | 3,272,710  | 71  |
| NV         | 6,640,537                               | 1,739,544  | 26  |
| NH         | 6,881,345                               | 6,881,345  | 100   |
| NJ         | 59,123,073                              | 0  | 0   |
| NM         | 34,058,910                              | 29,218,855   | 86  |
| NY         | 56,317,000                              | 0  | 0   |
| NC         | 27,304,416                              | 20,264,119   | 74  |
| ND         | 5,607,743                               | 5,000,144  | 89  |
| OH         | 10,482,428                              | 0  | 0   |
| OK         | 43,682,678                              | 38,710,603   | 89  |
| OR         | 4,554,818                               | 4,554,818  | 100   |
| PA         | 64,882,837                              | 41,265,484   | 64  |
| RI         | 10,343,464                              | 10,275,000   | 99  |
| SC         | 34,606,072                              | 31,372,640   | 91  |
| SD         | 3,161,365                               | 1,322,318  | 42  |
| TN         | 11,563,100                              | 0  | 0   |
| TX         | 50,174,833                              | 27,737,788   | 55  |
| UT         | 14,548,828                              | 14,548,828   | 100   |
| VT         | 15,819,422                              | 14,733,132   | 93  |
| VA         | 2,480,413                               | 0  | 0   |
| WA         | 48,177,202                              | 25,684,289   | 53  |
| WV         | 20,057,784                              | 18,864,745   | 94  |
| WI         | 23,235,497                              | 0  | 0   |
| WY         | 13,037,112                              | 12,909,233   | 99  |
| U.S. Total | 2,304,468,087                           | 1,608,539,779  | 70  |

Source: Braddock et al. (2008). Boulder, CO: University of Colorado, Department of Psychiatry and Coleman Institute for Cognitive Disabilities.



Eighteen states now operate Medicaid “Support Waivers,” that have smaller authorized caps per beneficiary than regular HCBS Waivers, are flexible in the types of support offered, and encourage significant unpaid support from family caregivers and friends. States utilizing Support Waivers include Alabama, Colorado, Connecticut, Florida, Illinois, Indiana, Louisiana, Missouri, Montana, Nebraska, Ohio, Oklahoma, Oregon, Pennsylvania, South Dakota, Tennessee, Texas, and Washington (Smith, Agosta, & Fortune, 2007). States may increasingly use this more flexible option to expand family support services.

Funding for financial subsidy programs continues to constitute only a fraction of family support spending. In 2006, financial subsidy programs made up only 5% of total family support funding and were almost exclusively financed through state dollars. Only a handful of federal programs, such as the Cash and Counseling Demonstration grants, allow states to utilize federal funding to provide direct payments to individuals with developmental disabilities and their families. Some states may be financing cash subsidy programs at lower levels due to fears of abuse or misuse by consumers and families. However, “overly restrictive measures... negate the effect of the consumer-directed intervention” (Simon-Rusinowitz, Mahoney, Shoop, Squillace, & Sowers, 2001, p. 101).

One of the most requested family support services is respite care. However, the availability of qualified respite workers presents concerns for families. “Vacancies are causing families with members who have intellectual or developmental disabilities in the family home to do without basic family support services (e.g., personal assistance, respite care) as available staff are first allocated to residential and vocational programs for which there are no alternative care providers” (Larson, Hewitt, & Lakin, 2004, p. 482). States need to develop comprehensive respite programs that utilize family members, friends and neighbors, and untapped resources such as retirees to meet the rapidly-increasing need for in-home supports.

Families, mainly unpaid mothers, have historically assumed primary responsibility of caring for their elderly and/or disabled relatives. This reliance on family caregiving is likely to increase in the future as states try to contain the rising costs of out-of-home placements (Braddock, 2002), as individuals with ID/DD live longer, and as caregivers age beyond their caregiving capacity. Families continue to serve the role of a *de facto* service delivery system. Policymakers must be mindful of the changing demographics in the states and their potential impacts on demand for and provision of family support services. Policies adopted need to pay special attention to the needs of minority families, aging caregivers, and the increasing role of siblings. Family support is slowly emerging as a fundamental consideration in ID/DD long-term care policy. The pace of that emergence needs to be accelerated significantly by its adoption as a higher priority in state-federal legislative and administrative policy initiatives.

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