

Family Support Services for Persons with Intellectual and Developmental Disabilities

Mary Rizzolo, Richard Hemp, David Braddock, & Abigail Schindler

While the majority of long-term care for persons with I/DD is provided in family homes, only a fraction of such spending has been directed toward family support.

Support for children and adults with intellectual and developmental disabilities (I/DD) living in the family home -- “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”. Family members with I/DD can receive instrumental support from siblings, aunts and uncles, grandparents, and others in addition to 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.

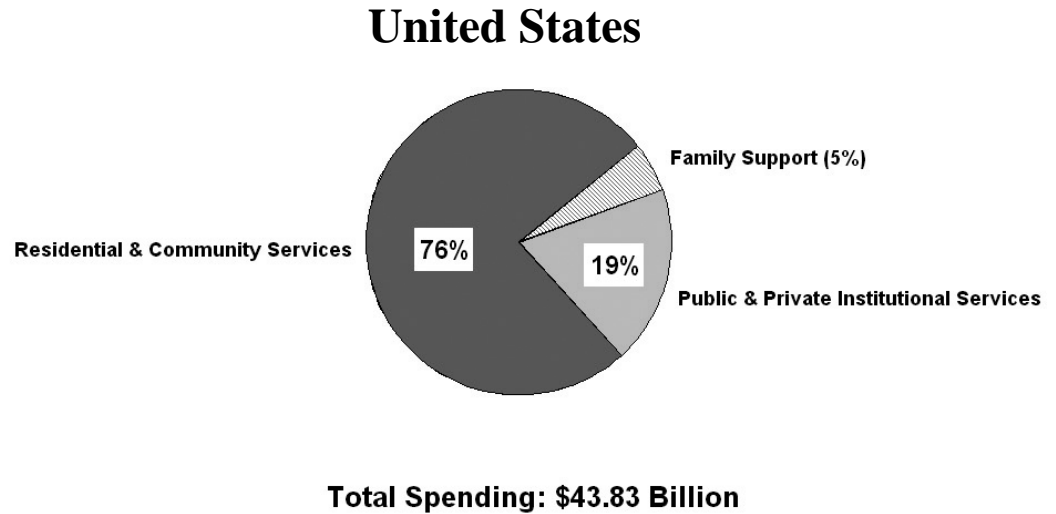
Services and supports that states offer to families with children or adults with I/DD include:

- respite services
- financial services such as cash subsidies and vouchers
- in-home supports such as personal assistance or home-maker services
- assistive technology and environmental modification
- adaptive medical equipment
- health and professional services
- therapies (PT, OT, behavioral)
- family counseling
- family training
- parent support groups
- transportation
- recreation activities
- specialized clothing
- dietary services

For more details on family support spending in each of the states, see Rizzolo, M. C., Hemp, R., Braddock, D. & Schindler, A. (2009). Family support services for persons with intellectual and developmental disabilities: Recent national trends. *Intellectual and Developmental Disabilities*, 47(2), 152-155.

Reliance on family caregiving is likely to increase in the future as states try to contain the rising costs of out-of-home placements, as individuals with I/DD live longer, and as caregivers age beyond their caregiving capacity. Families continue to serve the role of a de facto service delivery system.

While the majority of long-term care for persons with I/DD is provided in family homes, only a fraction of such spending has been directed toward family support. In 2006, 5% of total I/DD spending across the nation was allocated to support individuals living in the family home (see Figure below). All 50 states reported a family support initiative for financial subsidy (including vouchers and individualized budgets), for other family support activities 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.



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. In 2006, the HCBS waiver financed 70% of all family support services in the U.S. While all 50 states reported some form of family support initiative, there was tremendous variability across the states in family support spending levels.

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, as individuals with I/DD live longer, and as caregivers age beyond their caregiving capacity. Families continue to serve the role of a de facto service delivery system.

The State of the States in Developmental Disabilities Project is funded in part by The Administration on Developmental Disabilities, the Department of Psychiatry of the University of Colorado School of Medicine, and the Coleman Institute for Cognitive Disabilities. Two of the authors of this brief, Mary C. Rizzolo & Abigail Schindler are affiliated with the University of Illinois at Chicago University Center for Excellence in Developmental Disabilities, one of the University of Colorado's partners in The State of the States in Developmental Disabilities Project.