

**Family Support**

Across the nation, the vast majority of people with I/DD live at home with their families. Families are broadly understood to include relationships of blood, marriage, or choice. These families often receive few services and lose jobs and income as they try to meet their family members’ needs. In addition, families of children and adults face the lack of necessary supports for their family member to meaningfully participate in appropriate programs and employment. Life-long caregiving for individuals with disabilities, without support or assistance, has long term negative economic, health, and social impacts on the well-being and quality of life of families. As people with disabilities are living longer, siblings and other family members are playing increasingly important roles across the lifespan and frequently assume primary caregiving responsibilities when aging parents are no longer able. The rapidly growing population of aging caregivers is in great need of supports and services. Given our nation’s fiscal challenges, it is likely that greater numbers of individuals with I/DD will be living with their families for longer periods.

To strengthen the ability of families and other caregivers to support their relatives or others with disabilities whom they support, during the 115th Congress, our public policy goals are to:

* Support federal initiatives that recognize the important role of families and the need for comprehensive family supports and ensure that any such initiatives explicitly recognize that they cannot be a substitute for creating a national solution to provide appropriate long term supports and services for persons with disabilities;
* Enact the recommendation of the Long Term Care Commission to adopt a national strategy to recognize and support families in their caregiving role;
* Significantly increase funding and establish a separate authorization level for the Family Support Program under Title II of the DD Act;
* Maintain full funding for a state capacity development program on family support;
* Ensure the Family and Medical Leave Act covers more workers by reaching smaller employers and part-time workers; provide paid leave; and ensure the definition of covered family member includes, for example, siblings, grandparents, and domestic partners;
* Fully fund the Lifespan Respite Care Act to help ensure the availability of respite care for families, regardless of age or disability;
* Fully implement and increase funding for the National Family Caregiver Support program;
* Reauthorize and increase funding for the Child Care and Development Block Grant (CCDBG) to expand child care services and provide technical assistance to child care providers so that they are better able to meet the needs of children with disabilities;
* Improve and expand adoption assistance and foster care programs to better address the multiple challenges facing children with disabilities and their adoptive or foster families;
* Amend the Adoption and Safe Families Act to extend the timelines for permanency for parents with disabilities as well as the “reasonable efforts” provision to keep children with their parents;
* Authorize Title IV-E of the Social Security Act waivers to encourage the use of in-home services to prevent the use of out of home placements;
* Address inequities in access to and funding for direct support caregiver services for all Medicaid-eligible developmental disability populations;
* Support initiatives that remove barriers to employment such as flex time, job sharing, and telecommuting, in order to prevent the descent of caregiving families into poverty;
* Provide incentives for businesses to offer employer-provided individual and family supports for employees that have a family member with I/DD as part of employee-assistance programs;
* Provide a caregiver tax credit to assist families with out-of-pocket costs for disability-related expenses;
* Ensure that programs providing personal assistance services include supports and services for parents with disabilities; and
* Continue funding of the Social Security Act Title V Maternal and Child Health Program.

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