



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

February 7, 2020

The Honorable Lance Robertson
Administrator and Assistant Secretary for Aging
Administration for Community Living
Department of Health and Human Services
330 C Street, SW
Washington, D.C. 20201

Dear Administrator and Assistant Secretary for Aging Robertson:

We, the undersigned members of the Consortium for Citizens with Disabilities (CCD) Task Force on Developmental Disabilities, Autism, and Family Support appreciate the Administration for Community Living's (ACL) request for information as part of the implementation of the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act of 2018. We are grateful for ACL's request for input from family caregivers, organizations, and other individuals to help the Family Caregiving Advisory Council draft its initial report which will include recommendations to improve and better coordinate Federal programs and activities, including with state programs; and effectively deliver services based on performance, mission and purpose of the program while avoiding duplication/overlap.

Our organizations are committed to ensuring that family caregivers have the necessary tools and resources to be able to support family members with intellectual and/or developmental disabilities (I/DD) in achieving the goals of the Americans with Disabilities Act - equal opportunity, independent living, full participation, and economic self-sufficiency. The vast majority of people with I/DD live in the family home and families are overwhelmingly the primary source of support for their family member with I/DD. However, we also recognize that relying on families to provide lifelong care cannot be a substitute for creating a national solution to provide appropriate long term services and supports and for persons with I/DD. Efforts to support family caregivers must be addressed in conjunction with the Medicaid home and community services (HCBS) waiting list and direct support professional (DSP) crises for family members with I/DD.

In addition to our specific comments below, we believe that the national family caregiver strategy should address several overarching priorities for comprehensive family caregivers supports. They must be: 1) available to all families regardless of whether the person with I/DD resides in the family home or is presently receiving publicly funded services; 2) prioritized for when the need is most acute, such as when caregivers first receive a disability diagnosis for their child; during service system transitions or personal crises; and at the end of life; and 3) for family caregivers of minor children, serve to help families to stay intact, preventing any type of out-of-home placements for a minor child, particularly institutions or congregate settings.

We offer the following responses which we have submitted in the online form developed for this effort.

CCD Response #1:

**One Pressing Family Caregiving need/ concern I would to see addressed is:
Financial security and workplace issues**

Paid leave. Many caregivers are employed outside of the home and must sacrifice full time employment and opportunities for advancement in order to continue in their caregiving role. Currently, only 6% of part-time workers have access to paid leave. Paid family and medical leave would help ease the financial burden on family caregivers by allowing them to take time off for their own or a family member's serious and/or chronic health condition while receiving partial or full compensation. Therefore, the Family and Medical Leave Act should be amended to cover more workers by reaching smaller employers and part-time workers; expand the definition of covered family member to include, for example, siblings, grandparents, and domestic partners; and replace a sufficient percentage of wages to provide economic security.

There are currently two bills in Congress that would accomplish these goals:

1) The Family And Medical Insurance Leave (FAMILY) ACT (H.R. 1185/S. 463) would create a comprehensive national program that helps meet the needs of new parents and people with serious personal or family health issues through a shared fund that makes paid leave affordable for employers of all sizes and for workers and their families. It would provide workers with up to 12 weeks of partial income, enabling workers to earn 66 percent of their monthly wages, up to a capped amount.

2) The Family Medical Leave Modernization Act (H.R. 5456/S. 3071) acknowledges the broader nature of family caregiving relationships and expands the FMLA's unpaid job protection to cover siblings, domestic partners, adult children, and others. It also expands covered leave to include parental involvement and family wellness leave to attend school functions and other family care needs, such as attending a child's individualized education plan (IEP) meetings.

In addition, the Healthy Families Act (S. 840/H.R. 1784) would provide for coverage for shorter term health and family needs by setting a national paid sick days standard. It would apply to workers in businesses with 15 or more employees to earn up to seven job-protected paid sick days each year to be used to recover from their own illnesses, access preventive care, provide care to a sick family member, or attend school meetings related to a child's health condition or disability.

Tax credits. Family caregivers could benefit from a caregiver tax credit to assist families with out-of-pocket costs for disability-related expenses. For those caregivers with low incomes, the earned income tax credit (EITC) and child tax credit (CTC) should be expanded. Unfortunately, the EITC does not provide meaningful benefits for childless low-wage workers. Similarly, the CTC is unavailable to families with extremely low incomes and provides only a partial credit to families with very low incomes.

There are currently two tax credit bills in Congress that would help working family caregivers:

The Working Families Tax Relief Act (S. 1138, H.R. 3157) will boost the earned income tax credit (EITC) for families with children by roughly 25 percent. This would provide a meaningful increase in take home pay for low wage family caregivers. For instance, a parent with two young children making \$20,000 a year would gain about \$1,460 a year. The bill also would make the child tax credit (CTC) fully refundable so children in lower-income households could benefit fully from it. In addition, it would create a larger,

fully refundable Young Child Tax Credit (YCTC) for children under age 6, boosting the CTC to \$3,000 per child under age 6, from current \$2,000 per child.

The Credit for Caring Act (S. 1433/H.R. 2730) would provide working family caregivers with a new nonrefundable tax credit up to \$3,000 to assist with out-of-pocket expenses related to caregiving. This tax credit would ease the financial pressure on family caregivers, who, on average spend 20 percent of their income, or nearly \$7,000, on care-related expenses.

Flexible work options. Barriers to employment should be removed, such as through flex time, job sharing, and telecommuting, in order to prevent the descent into poverty of caregiving families. Employee assistance programs -ACL should convene a roundtable with businesses to discuss incentives to offer employer-provided individual and family supports for employees who have a family member with disabilities or special health care needs as part of employee assistance programs.

Paid family caregivers. The option to compensate family caregivers should be available throughout the lifetime of a person with I/DD and subject to change as the person's and family's needs change. Therefore, we believe ACL should examine state Medicaid programs that allow for payment of family caretakers and consider recommending incentives for all state Medicaid programs to adopt such programs.

CCD Response #2:

One Pressing Family Caregiving need/ concern I would to see addressed is: Respite Options

Family caregivers consistently rate respite as their greatest service need. The Lifespan Respite Care program should serve as a model for a national respite strategy to meet the needs of family caregivers caring for anyone of any age or condition. The program helps states build coordinated statewide systems of respite services; provides critical gap-filling respite assistance for family caregivers who don't qualify for public funding sources or are on waiting lists; addresses the workforce shortage through provider recruitment and training; and increases respite options through partnerships with other state respite programs, community-based agencies and volunteer and faith-based initiatives.

In the private sector, employers should be educated and encouraged to offer respite services and information to the more than 60% of family caregivers who are working and incentives should be provided for private insurers to offer respite as a covered benefit. Therefore, we recommend that ACL convene a roundtable of business and health insurance leaders to explore opportunities for and barriers for achieving these policy changes.

The Lifespan Respite Care Act is woefully underfunded to meet current demands. The Administration should recommend full funding for the Lifespan Respite Care Act.

CCD Response #3:

One Pressing Family Caregiving need/concern I would to see addressed is: Assessment and service planning, care transitions, and coordination

The Department of Health and Human Services (HHS) should develop and include indicators on the family caregiver health and well-being in Healthy People 2030. In addition, several agencies under HHS have the authority to undertake a number of efforts that could help improve assessment and service planning, care transitions, and coordination across the country. These include:

The Centers for Medicare and Medicaid Services (CMS):

- Expand the requirement for caregiver assessments in Medicaid 1915(i) HCBS State Plan Option programs to all Medicaid HCBS authorities; issuing guidance on family caregiver assessments; and providing training and technical assistance to assist states with implementation;
- Invest in the development of HCBS quality measures on family caregiver support, including family caregiver identification, assessment, involvement in planning, and experience of care and supports;
- Annually track and report data from the Transformed Medicaid Statistical Information System (T-MSIS) on the extent to which family caregiver supports are provided within Medicaid HCBS programs by state and type of disability;
- Issue guidance and provide technical assistance to states on the inclusion of family caregiver supports within Medicaid HCBS authorities, such as respite and caregiver counseling/training;.
- In collaboration with the Centers for Medicare & Medicaid Innovation (CMMI), develop and test a pilot program that provides a limited respite and flexible caregiver support benefit within traditional Medicare to assess the impact on cost savings and improved health and community living outcomes for beneficiaries.

The Administration for Community Living:

- Report annually on the number of older relative caregivers of adults with disabilities served by the National Family Caregiver Support Programs and provide training and technical assistance to the aging network to improve supports and services for older caregivers of adults with developmental and other disabilities;
- Form an interagency workgroup of federal partners, researchers, and advocates to develop a core set of family caregiver questions (similar to the six disability questions in the American Community Survey); Federal partners should add the common set of caregiver questions to federal surveys, such as the National Health Interview Survey and American Community Survey, to improve data collection and comparability across surveys.

Centers for Disease Control and Prevention

- Update the Behavioral Risk Factor Surveillance System (BRFSS) optional caregiver module with public input;

CCD Response #4:

**One Pressing Family Caregiving need/concern I would to see addressed is:
Information, education, training supports, referral, and care coordination**

The National Family Caregiver Support Program is the only national program focusing on family caregiver needs. It provides: 1) information to caregivers about available services, 2) assistance to caregivers in gaining access to the services, 3) individual counseling, 4) organization of support groups and caregiver training, 5) respite care, and 6) supplemental services, on a limited basis. Funding for this program, which only received \$186 million for FY 2020, should be greatly expanded. Congress should also expand eligibility for the National Family Caregiver Support Program to all caregivers, regardless of age or disability category.

The Family to Family Health Information Centers (F2F) programs provide information and training to help families of children and youth with special health care needs learn how to navigate the complex health care system (e.g. find appropriate providers and sources of health care financing, including Medicaid and private health insurance), and to advocate for their children. Currently, there is one F2F in each state and territory, and three serving Native American families. Federal funding for Family-to-Family Health Information Centers (F2Fs) should be increased. The F2F program is funded at only \$6 million per year, providing less than \$100,000 per center.

Other Opportunities for Education and Training. There are approximately 10 million Americans with disabilities, including many with I/DD, who are covered by both Medicaid and Medicare (known as dual eligible beneficiaries). These “duals” utilize Medicare for medical services such as hospital care, post-acute care, physician services, durable medical equipment, and prescription drugs. Family caregivers of duals could greatly benefit from family caregiver education and training as part of post hospital or acute care events. We urge ACL to explore options to increase such education and training, such as through the creation of a new Medicare billing code.

Thank you again for the opportunity to provide input to help the Family Caregiving Advisory Council draft its initial report of recommendation for a national family caregiver strategy. We look forward to working with you to ensure a comprehensive and meaningful plan to help millions of American family caregivers.

Sincerely,

American Network of Community Options and Resources
American Therapeutic Recreation Association
Autism Society of America
Center for Public Representation
Lutheran Services in America-Disability Network
National Alliance for Caregiving
National Association of Councils on Developmental Disabilities
National Center for Parent Leadership, Advocacy, and Community Empowerment
National Down Syndrome Congress
National Respite Coalition
The Arc of the United States

CC: RAISE Family Caregiving Advisory Council