



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

ACTION ALERT – Seeking Input on Family Caregiving National Strategy

The [RAISE Family Caregivers Act of 2017](#) established an advisory council that reflects the diversity of the 43+ million caregivers in America. The Administration for Community Living wants to hear about your **experiences, challenges, successes, and ideas** to help the advisory council develop its national strategy on family caregiving.



TAKE ACTION

Submit your input by **February 7, 2020** [HERE](#)

Please add information about your personal experiences, challenges, and successes and feel free to use the sample comments below regarding ideas for the national family caregiver strategy.

Please note that you can submit more than one online form. Each online form is for one issue and has a prompt for needs/concerns and recommendations.

SAMPLE COMMENTS on IDEAS for the national strategy

1) Financial security and workplace issues

Paid leave. Many caregivers are employed outside 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.

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.

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. Businesses should receive 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 RAISE Advisory Council should examine Medicaid programs that allow for payment of family caretakers and consider recommending incentives for all state Medicaid programs to adopt such programs.

2) Respite Options

Family caregivers consistently rate respite as their greatest service need. The Lifespan Respite Care program should serve as a model for a 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 work force 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. In addition, incentives should be provided for private insurers to offer respite as a covered benefit.

3) 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.

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.