

JEWISH DISABILITY ADVOCACY DAY

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Help Caregivers of People with Disabilities and Older Adults

Please urge Members of the House to cosponsor H.R. 3099 and H.R. 3913, both of which will provide increased support for underserved caregivers

Background: Family caregivers are the most important source of support for people with disabilities as well as those with chronic or other health conditions or functional limitations. These are family members who regularly look after a child, adult, or older adult with functional limitations or disabilities. Family caregivers help with activities such as eating, bathing, dressing, transporting, managing finances, and providing health care and care coordination. There are 16.8 million Americans caring for a loved one with special needs, 36% of whom care for a parent. Additionally, 7 out of 10 caregivers are caring for loved ones over 50 years of age at home and in their communities, providing the bulk of assistance. In 2013, approximately 40 million family caregivers provided unpaid care valued at about \$470 billion to adults who needed help with their daily activities. This more than totaled Medicaid spending for that year. Estimates show 3.5 million individuals with intellectual or developmental disabilities (I/DD) live with family caregivers, of whom over 850,000 are age 60 or older.

While fulfilling, being a family caregiver can consume a great deal of physical, mental, and emotional energy. It is troubling that nearly three quarters (72%) of family caregivers report not going to the doctor as often as they should. In addition, 20% of employed female caregivers over the age of 50 report symptoms of depression, compared to 8% of their non-caregiving peers. The divorce rate for parental caregivers of children with disabilities is between 80% and 90%. In terms of balancing caregiving and job responsibilities, family caregivers struggle greatly. Sixty percent of family caregivers work outside the home, but many must quit their jobs because of the lack of workplace flexibility necessary for them to meet their caregiving obligations. While some public support has been provided to caregivers, more assistance and information is needed.

Caregiver-Focused Legislation

RAISE Family Caregivers Act: On July 16, 2015, as a result of the continuing and sobering challenges faced by caregivers, Representatives Gregg Harper (R-MS) and Kathy Castor (D-FL) introduced H.R. 3099, the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act. The Senate version of the bill, S. 1719, passed the Senate by Unanimous Consent on December 8, 2015.

Pending before the House Education and Workforce Committee, H.R. 3099 is a bipartisan bill that would require the Secretary of Health and Human Services to develop a *National Caregiving Strategy* in conjunction with an advisory council made up of people with disabilities, older adults, family caregivers, direct support professionals, and government officials.

When developing the plan, the Secretary must consider a number of issues that affect caregivers and their loved ones including workplace policies, training and support for caregivers, respite services, as well as information and referral services among other aspects of caregiving. The RAISE Act, which was recommended by the bipartisan National Commission on Long-Term Care, also calls on the Secretary to collect and make publicly available a wide variety of data on caregiving. The legislation would provide 18 months for the development of the initial strategy, followed by annual updates of the strategy.

JFNA believes the quality of life for people with a disabilities and/or older adults is directly linked to the health and well-being of their caregivers. We believe this comprehensive examination of the challenges and needs of caregivers will result in the development of best practices and policies that will make the lives of caregivers easier.

JFNA asks that Representatives cosponsor H.R. 3099 (which will bring visibility to this issue) and then urge House passage of S. 1719 (the Senate bill) without delay.

Lifespan Respite Care Reauthorization Act: On November 3, 2015 Representatives Jim Langevin (D-RI) and Gregg Harper (R-MS) introduced H.R. 3913, the Lifespan Respite Care Reauthorization Act. Respite care occurs when caregivers are provided with a temporary break from their caregiving responsibilities. Pending before the House Energy and Commerce Committee, H.R. 3913 is a bipartisan bill introduced to reauthorize (i.e. continue providing funding) for respite services for caregivers of all individuals with disabilities, including disabilities acquired later in life.

Congress currently appropriates \$3.36 million for the Lifespan Respite Care Act for states to provide a wide variety of respite services, including in-home respite services or respite at a respite care center or provider-owned dwelling within a community. The bill would reauthorize the program at \$15 million per year for 2016 through 2020. JFNA believes respite care is essential to ensure an adequate quality of live for caregivers and the people for whom they are providing care.

JFNA asks that Representatives cosponsor H.R. 3913, urge leadership of the House Energy and Commerce Committee to quickly advance it to the House floor, and pass it without delay.

For further information, please contact Aaron Kaufman, JFNA's Senior Legislative Associate, at 202/736-5865 or Aaron.Kaufman@jewishfederations.org.

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