

JEWISH DISABILITY ADVOCACY DAY

ON CAPITOL HILL, WASHINGTON DC SPONSORED BY THE JEWISH DISABILITY NETWORK



The Jewish Federations®
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THE STRENGTH OF A PEOPLE.
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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 Caregiver 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.

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 Members of the House of Representatives cosponsor H.R. 3099 and H.R. 3913 and to urge leadership of the relevant committees to quickly advance them to the House floor and pass these bills without delay.

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

The Jewish Federations of North America represents 151 Jewish Federations and over 300 Network communities, which raise and distribute more than \$2 billion annually for social welfare, social services and educational needs. The Federation movement, collectively among the top 10 charities on the continent, protects and enhances the well-being of Jews worldwide through the values of Tikkun Olam (repairing the world), Tzedakah (charity and social justice) and Torah (Jewish learning).

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Help People with Disabilities Gain Competitive, Integrated Employment

Urge Members of the Senate and the House of Representatives to support S.1604, the Transition to Independence Act, or companion legislation. This bill would provide funding for a demonstration program for states to undertake innovative approaches to increase competitive, integrated employment opportunities for people with disabilities.

Background: While the Americans with Disabilities Act made much progress in achieving equality for people with disabilities, unemployment, and, as a result, poverty are still issues of great concern for this community and their families. Shockingly, 28% of all Americans with disabilities live in poverty (approximately 19,588,600 people).

A lack of employment or payment below the minimum wage perpetuates the cycle of poverty for people with disabilities and increases reliance on government programs. Businesses may apply to the Federal government to pay people with disabilities less than minimum wage, which is permitted under the Fair Labor Standards Act of 1938. Furthermore, employment in non-integrated settings, where all of the staff with the exception of the supervisor have a disability, often do not allow people with disabilities to learn the necessary skills needed for working in an integrated environment.

Sheltered workshops and enclaves are two types of employment settings that have historically been created exclusively for people with disabilities, particularly for those with developmental disabilities. Typically, individuals in these settings perform the same routine task many times daily and can often earn far less than minimum wage for their work.

In recent years, the U.S. Justice Department's Civil Rights Division has reached legal settlements with Rhode Island and Oregon finding that those states' low wages paid at sheltered workshops and enclaves violated the civil rights of people with disabilities. In a sheltered workshop, people with disabilities seldom have the opportunity to interact with peers who do not have a disability with the exception of the direct support professionals hired to help them.

There is a new emphasis on competitive, integrated employment due to the enactment of the Workforce Innovation and Opportunity Act of 2014 (WIOA). WIOA defines, for the first time, the term "competitive, integrated employment" as: full or part-time work at the minimum wage or higher, with wages and benefits similar to those without disabilities performing the same work and in an environment that is fully integrated with co-workers without disabilities. WIOA places

a number of restrictions on states to avoid putting young adults with disabilities into sheltered workshops or enclaves when at all possible.

Proposed Legislation: On June 18, 2015, as a result of the significant employment and socio-economic challenges faced by people with disabilities, Senators Chuck Grassley, (R-IA), Bob Casey Jr. (D-PA), and Ron Wyden (D-OR) introduced S.1604, the Transition to Independence Act. It is pending before the Senate Finance Committee. At this time, the bill has not yet been introduced in the House.

This bill would allow a set number of states to compete for funding through a demonstration program that would provide Federal Medicaid dollars for both closing sheltered workshops and creating innovative opportunities for competitive, integrated employment. These “demonstration projects” would provide opportunities for the government to learn from the experience of the participating states and to share their findings with other states so that they can learn from participants’ experiences and best practices. To apply, states would be required to participate in the Medicaid Buy-In Program. Furthermore, participating states would be given minimum targets that each would need to meet regarding closures of sheltered workshops and placements of employees into competitive, integrated positions.

JFNA supports this legislation as we have long been committed to increasing the number of people with disabilities who are employed in integrated settings and providing avenues for economic self-sufficiency.

We urge members of the Senate to cosponsor S.1604 and to encourage the Senate Finance Committee to pass this legislation swiftly. Furthermore, we urge House members to consider introduction of a House companion bill and to cosponsor the legislation upon its introduction.

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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