Urge your Senators to Support the Bipartisan Lifespan Respite Care Reauthorization Act of 2019 (S. 995 as amended)

The Lifespan Respite Care Reauthorization Act of 2019 (S.995) reauthorizes the program through FY 2024 at $50 million over five years (FY2020 - FY 2024). The bill was introduced in the Senate by Sen. Susan Collins (R-ME) and Sen. Tammy Baldwin (D-WI) and was unanimously approved by the Senate Health, Education, Labor and Pensions Committee. The House companion bill, which authorizes $200 million over five years (H.R. 2035), was introduced by Reps. Jim Langevin (D-RI) and Cathy McMorris Rodgers (R-WA). HR 2035 passed the House on July 24, 2019. Now the full Senate must act!

The Lifespan Respite Care Program (LRCP): The U.S. Administration for Community Living (ACL) awards competitive grants to state agencies working with Aging and Disability Resource Centers/No Wrong Door Systems and state respite coalitions. The program’s purpose is to make quality respite available to family caregivers regardless of care recipient’s age or disability through coordinated State Lifespan Respite Systems.

Funding: Congress funded the LRCP at $4.1 million in FY 2018 and in FY 2019. Advocates are urging higher funding for FY 2020.

Program Status: Thirty-seven states and DC have received LRCP grants from the U.S. Administration for Community Living (ACL) since 2009 (see archrespite.org/lifespan-programs).

ACTION:

- Ask your Senators to support the Lifespan Respite Care Reauthorization Act (S. 995) and urge them to bring the bill to the floor for a vote. Call 202-224-3121 and ask for health or disability staff. If you don’t reach them, leave a message!
- Phone calls and personal visits with Senators or staff are the most effective ways to deliver your message. Visit https://www.contactingcongress.org/.

Despite Demonstrated Benefits, Respite Need is Still Significant

- The nation’s 43 million family caregivers provide the vast majority of long-term services and supports to individuals of all ages living at home, yet 85% of those caring for adults have not received respite services (National Alliance for Caregiving (NAC) and AARP Public Policy Institute, Caregiving in the US, 2015).
- Respite, the most requested service by family caregivers, has been shown to reduce caregiver stress, improve their health, bolster family stability and economic well-being, keep marriages intact, and help avoid or delay costlier out-of-home placements.

- Caregiving is a lifespan issue. Care for the aging is a growing issue, but currently more than half of adult care recipients (53%) are between the ages of 18 and 75 (NAC and AARP, 2015). According to the most recent National Survey of Children’s Health, more than 13 million children under age 18 have special health care needs.

- The estimated value of family caregiving of adults is $470 billion annually. This amount is more than total Medicaid spending in 2013 (AARP PPI, 2015).

- University of Pennsylvania researchers studied 28,000 records of children with autism ages 5 - 21 who were enrolled in Medicaid in 2004. They found that for every $1,000 states spent on respite services in the previous 60 days, there was an 8 percent drop in the odds of hospitalization (Mandell, David S., et al, 2012).

State Lifespan Respite Accomplishments

- In describing the Lifespan Respite Care Program, a distinguished panel from the National Academies of Sciences, Engineering, and Medicine concluded in the report Families Caring for an Aging America, “Although the program is relatively small, respite is one of the most important caregiver supports.”

- AL, CO, DE, MD, MT, NE, NV, NC, OK, RI, SC, TN, TX, VA, WI and WA Lifespan Respite grantees successfully use respite vouchers to help family caregivers pay for respite for underserved populations, such as individuals with Multiple Sclerosis or ALS, adults with intellectual or developmental disabilities (I/DD), or those on waiting lists for Medicaid home and community-based services.

- Caregivers in NE’s Lifespan Respite Network reported significant decreases in stress levels, fewer physical and emotional health issues, reductions in anger and anxiety, and reported being in a better financial situation when receiving respite. AL Lifespan Respite’s voucher program found a substantial decrease in the percentage of caregivers reporting how often they felt overwhelmed with daily routines after receiving respite.

- States, including NY, NV, and others are collaborating with No Wrong Door systems to improve respite access.

- Innovative and sustainable respite services funded in AL, CO, MA, NY, NC, and PA through mini-grants to community-based agencies are demonstrating benefits to family caregivers and their loved ones.

- States, including AL, IL, MD and NE, offer emergency respite services, and AL, AR, CO, NE, NY, PA, RI, SC, TN and others are providing new volunteer or faith-based respite services.

- Respite provider recruitment and training are priorities among many current and former state grantees, including AL, CO, MA, NE, NV, NY, SC and WI.