
UCP Affiliate Topical Conference Call

**Topic: Get an Inside Look into What's Happening with
Respite Care and Why it's Important**

Thursday, December 10, 2015

3:00 – 4:00 p.m. ET

Please join us for a call with Jill Kagen, Director of the Lifespan Respite Coalition and a leader in the field of respite care to learn about what is happening from a federal level in respite care, why it matters for affiliates and opportunities to engage.

PRESENTED BY:

Jennifer McCue, UCP Director of Advocacy

**Jill Kagen, Chair National Respite Coalition and Program Director of
ARCH National Respite Network and Resource Center**

HOSTED BY WEST RAC, CHAIR DAVE CARUCCI

Space is limited. Call in information (no PIN needed):

888-402-6958





Legislative Alert, November 2015

Seeking Congressional Cosponsors for *Lifespan Respite Care Reauthorization Act of 2015 (HR 3913)*

The ***Lifespan Respite Care Reauthorization Act of 2015*** (HR 3913), is a bipartisan straight reauthorization of the Lifespan Respite Care Program, authorizing it through FY 2020 at \$15 million annually. The bill was introduced by Rep. Jim Langevin (D-RI) and Rep. Gregg Harper (R-MS).

The Lifespan Respite Care Program (LRCP) provides competitive grants to state agencies working in concert with Aging and Disability Resource Centers and state respite coalitions or organizations to make quality respite available and accessible to family caregivers regardless of age or disability through the establishment of State Lifespan Respite Systems.

Funding: LRCP has been essentially level funded at \$2.3 - \$2.5 million each year since FY 2009. The new legislation authorizes \$75 million over five years (FY16-FY 20).

Implementation Status: Thirty-three states and DC have received LRCP grants from the US Administration for Community Living (ACL) since 2009 (see www.archrespite.org).

→ ACTION:

- Ask your Representative to cosponsor the *Lifespan Respite Care Reauthorization Act of 2015* (HR 3913). The best way to contact House Members is to call 202-225-3121 and ask for their office and then their health or disability staff. Even if you don't reach them directly, leave a message!
- For additional contact information or to send an email to your Member of Congress, visit <http://www.house.gov/representatives/>.

Respite Among Most Critically Necessary and Beneficial Family Support Services

- ***The nation's 43 million family caregivers provide the vast majority of long-term services and supports at home, yet 85% do not receive any respite services (National Alliance for Caregiving (NAC) and AARP Public Policy Institute, Caregiving in the US, 2015).***

- Caregiving is a lifespan issue. Care for the aging population is a growing issue, but currently more than half of care recipients (53%) are under age 75 (*NAC and AARP, 2015*). More than 10 million children have at least one chronic health condition (*2011/12 National Survey of Children's Health, 2015*).
- Family caregivers have higher mortality rates, rates of acute and chronic conditions and depression than noncaregivers. Respite, the most frequently requested support service among family caregivers, has been shown to provide them with relief necessary to maintain their own health, bolster family stability, keep marriages intact, and avoid or delay more costly out-of-home placements.
- According to AARP, the estimated value of family caregiving is \$470 billion. This amount is more than total Medicaid spending in 2013, and as much as the total sales of the world's largest company, Wal-Mart (*AARP Public Policy Institute, Valuing the Invaluable, 2015*).
- Researchers at the University of Pennsylvania studied the records of over 28,000 children with autism ages 5 to 21 who were enrolled in Medicaid in 2004. They concluded 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*).
- In an Institute of Medicine (IOM) report on living with chronic illness, authors concluded that "although respite services provide proven benefits, most caregivers feel that what's out there is not enough" and "more services should be offered" (*Institute of Medicine, 2012*).

Lifespan Respite State Accomplishments

- Many lifespan respite programs including those in **Alabama, Arizona, Delaware, Montana, Nebraska, Nevada, North Carolina, Oklahoma, Rhode Island, South Carolina, Tennessee, Virginia, and Washington** have successfully used consumer-directed voucher respite to expand respite options, especially for underserved populations, such as individuals with Multiple Sclerosis, adults with I/DD, or those on waiting lists for services.
- States, including **Idaho, Illinois, Iowa, and Nebraska** are now able to offer support for emergency respite services.
- **Alabama, Arkansas, Massachusetts, Nebraska, Ohio, Pennsylvania, South Carolina and Tennessee** and many more are providing new volunteer or faith based respite services.
- Innovative and sustainable respite services have been funded in **Colorado, Massachusetts, North Carolina and Ohio** through mini-grants to community or faith-based agencies and have been or are being evaluated for the benefits that accrue to family caregivers and their loved ones.
- Recruitment and training of new respite providers are a priority in many states including, **New Hampshire, Virginia, and Wisconsin**.
- **Alabama, Arizona, Colorado, Delaware, Massachusetts, Nebraska, New Hampshire, Virginia, and Texas** have developed statewide registries to help family caregivers find respite.

JILL B. KAGAN, MPH
ARCH National Respite Network and Resource Center

Ms. Kagan is Program Director for the ARCH National Respite Network and Resource Center. The Resource Center houses the Lifespan Respite Technical Assistance Center funded by the US Administration for Community Living. She has served on numerous national advisory boards, including her current role on the National Advisory Council to the federally funded Family Support Research & Training Center. Ms. Kagan represents ARCH on several prominent national coalitions, including the newly formed core advisory group to the Assisting Caregivers Today (ACT) Congressional Caucus and the National Child Abuse Prevention Partners of the Children's Bureau. She is co-chair of the Elizabeth Dole Foundation's Respite Impact Council of the Military Caregivers Coalition, co-chair of the Autism, Developmental Disabilities and Family Support Task Force of the Consortium for Citizens with Disabilities, and facilitator of the national Lifespan Respite Task Force.

Prior to this, Ms. Kagan served as deputy staff director and as professional staff for ten years to the Select Committee on Children, Youth, and Families in the U.S. House of Representatives. She also worked as a consultant to national disability, aging, and maternal and child health organizations for more than 15 years.

Ms. Kagan received her masters in public health in maternal and child health from the University of North Carolina at Chapel Hill, and her bachelor's degree from Brandeis University, Waltham, Massachusetts.