Testimony of Jill Kagan, Director
ARCH National Respite Network and Resource Center
National Respite Coalition
Before the House Subcommittee on Health, Committee on Energy and Commerce
Hearing on the "Reauthorizing Vital Health Programs for American Families"
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Chairman Pallone, Ranking Member Walden, Chairwoman Eshoo, Ranking Member Burgess and distinguished members of the Subcommittee,

I am Jill Kagan, Director of the ARCH National Respite Network and Resource Center. I am testifying today on behalf the National Respite Coalition (NRC), the policy division of ARCH. ARCH houses the Lifespan Respite Technical Assistance Center funded by the Administration for Community Living to provide training and technical assistance to the Lifespan Respite program grantees and their state and community partners. The National Respite Coalition is a network of state respite coalitions, respite providers, family caregivers, and national, state and local organizations that support respite. Thank you for the opportunity to testify today in support of the Lifespan Respite Care Reauthorization Act of 2019 (H.R. 2035). I would also like to thank the original cosponsors of the legislation, Rep. Jim Langevin (D-RI) and Rep. Cathy McMorris Rodgers (R-WA) for their support of the program.

Lifespan Respite Care Program

The Lifespan Respite Care Program is a competitive grant program administered by the Administration for Community Living (ACL). The premise behind the program is both care relief and cost effectiveness. Respite care provides temporary relief for family caregivers from the ongoing responsibility of caring for an individual of any age with special needs. The Lifespan Respite Care Program provides funding to states to expand and enhance local respite services across the country, coordinate community-based respite services to maximize use of existing resources and reduce duplication and fragmentation, and improve respite access and quality. Under the program, states are required to establish statewide coordinated Lifespan Respite care programs to serve families regardless of age or special need, provide new planned and emergency respite services, train and recruit respite workers and volunteers, and assist caregivers in gaining access. Family members, foster parents or other adults providing unpaid care to adults who require care to meet basic needs or prevent injury and to children who require care beyond basic needs are eligible.

To date, 37 states and the District of Columbia have received basic grants to build coordinated systems of community-based respite services. The Lifespan Respite Program grantee activities have evolved from important systems building grants first awarded in FY 2009 to direct service grants that are helping families pay for planned and emergency respite through consumer-directed voucher programs, supporting community, faith-based and volunteer respite services through mini-grants, recruiting and training respite providers and volunteers, and helping family caregivers access these services. Most importantly, states are able to give priority to family caregivers who are caring for individuals with disabilities and chronic illness of all ages who are not currently eligible for existing public programs, on Medicaid waiver waiting lists, or who have complex medical needs or behavioral issues for whom finding qualified and well-trained providers is especially difficult. Grantees have focused on serving the unserved, including family caregivers of individuals between the ages of 18-60, including adults with physical disabilities, MS, ALS, brain injury, paralysis, or I/DD; children and adults with special medical needs, mental health, autism or behavioral health issues; older adults with Alzheimer's disease or other dementias; grandparents raising grandchildren; rural family caregivers; culturally diverse groups and others identified as having unmet needs in the state. To sustain these efforts, many states are working on or have already successfully integrated respite activities and resources into statewide long-term services and supports and No Wrong Door systems. There are currently 20 states with active Lifespan Respite grants (AL, AR, AZ, CO, ID, MA, MD, MS, MT, ND, NV, NY, NC, OK, RI, SC, SD, TN, VA, and WA).

Respite Care Saves Money and Benefits Families

Compelling budgetary benefits accrue because of respite. Delaying a nursing home placement for individuals with Alzheimer's or avoiding hospitalization for children with autism can save Medicaid billions of dollars. Researchers at the University of Pennsylvania studied the records of 28,000 children with autism enrolled in Medicaid in 2004. They concluded that for every $1,000 states spent on respite, there was an 8% drop in the odds of hospitalization (*Mandell, et al., 2012*). A U.S. Department of Health and Human Services report found that reducing key stresses on caregivers through services such as respite would reduce nursing home entry (*Spillman and Long, USDHHS, 2007*). Additional research has corroborated the role that respite may play in reducing or delaying facility-based placements (*Gresham, 2018; Avison, et al., 2018).* Respite may reduce administrative burdens and improve maternal employment (Caldwell, 2007), strengthen marriages (Harper, 2013), and significantly reduce caregiver depression, stress and burden levels linked to caregiver health *(Broady and Aggar, 2017; Lopez-Hartmann, et al., 2012; Zarit, et al., 2014).* In a survey of caregivers of individuals with Multiple Sclerosis, two-thirds said that respite would help keep their loved one at home. When the care recipient with MS also has cognitive impairment, the percentage of those saying respite would be helpful to avoid or delay nursing home placement jumped to 75% *(NAC, 2012).*

With at least two-thirds (66%) of family caregivers in the workforce *(Matos, 2015*), U.S. businesses lose from $17.1 to $33.6 billion per year in lost productivity of family caregivers (*MetLife Mature Market Institute, 2006*). Higher absenteeism among working caregivers costs the U.S. economy an estimated $25.2 billion annually *(Witters, 2011).*

Lack of available respite care may interfere with parents accepting job opportunities *(Abelson, A.G., 1999).* The University of NE Medical Center conducted a survey of caregivers receiving respite through the NE Lifespan Respite Program and found that 36% of family caregivers reported not having enough money at the end of the month to make ends meet, but families overall reported a better financial situation when receiving respite (*Johnson, J., et al., 2018*).

Who Needs Respite?

More than 43 million adults in the U.S. are family caregivers of an adult or a child with a disability or chronic condition (*National Alliance for Caregiving (NAC).* They are the linchpin of of the nation's long-term services and supports system. The estimated economic value of family caregiving of adults alone is approximately $470 billion annually (*Reinhard, et al., 2015*). Eighty percent of those needing long-term services and supports (LTSS) are living at home. Two out of three (66%) older people with disabilities who receive LTSS at home get all their care exclusively from family caregivers (*Congressional Budget Office, 2013*).

With 10,000 individuals turning 65 every day, immediate concerns about how to provide care for a growing aging population are paramount. However, caregiving is a lifespan issue with the majority of family caregivers caring for someone between the ages of 18 and 75 (53%) (*NAC, 2015*). In addition, the 2017 National Survey of Children's Health found that 13.3 million children under age 18 have special health care needs, who are defined as "having or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally." (*Child and Adolescent Health Measurement Initiative, 2019*).

National, State and local surveys have shown respite to be among the most frequently requested services by family caregivers *(Anderson, L, et al., 2018; Maryland Caregivers Support Coordinating Council, 2015*). By helping to reduce stress, caregiver burden and social isolation, th**e** beneficial effects of respite on family caregiver health and well-being, on caregivers' and care recipients' quality of life, and other positive familial, societal, and cost-savings outcomes are well-documented *(Kirk, R, 2015; Avison, C, et al., 2018).*

Yet, 85% of family caregivers of adults are not receiving respite services at all *(NAC, 2015).* Nearly half of family caregivers of adults (44%) identified in the *National Study of Caregiving* were providing substantial help with health care tasks. Of this group, despite their high level of care, fewer than 17% used respite (*Wolff, et al., 2016*). A 2014 Rand Corporation report prepared for the Elizabeth Dole Foundation, *Hidden Heroes: America's Military Caregivers*, recommended that more appropriate community-based respite care should be more widely available to military caregivers *(Ramchand, et al., 2014).*

Respite Barriers and the Effect on Family Caregivers

While most families want to care for family members at home, and many family caregivers rate their caregiving experiences as positive, research shows that family caregivers are at risk for emotional, mental, and physical health problems *(Population Reference Bureau, 2016; American Psychological Association, 2012; Spillman, J., et al., 2014)*. When caregivers lack effective coping styles or are depressed, care recipients may be at risk for falling, developing preventable secondary health conditions or limitations in functional abilities. The risk of care recipient abuse increases when caregivers are depressed or in poor health *(American Psychological Association, nd).* Parents of children with special health care needs report poorer general health, more physical health problems, worse sleep, and increased depressive symptoms compared to parents of typically developing children *(McBean, A, et al., 2013).*

Respite, that has been shown to ease family caregiver stress, is too often out of reach or completely unavailable. In a survey of more than 3000 caregivers of individuals with intellectual and developmental disabilities (ID/DD), nine in ten reported that they were stressed. Nearly half (49%) reported that finding time to meet their personal needs was a major problem. Yet, more than half of the caregivers of individuals with ID (52%), Autism Spectrum Disorder (ASD) (56%) or ID and ASD (60%) reported that it was difficult or very difficult to find respite care (*Anderson, L., et al., 2018*). Despite their higher burden of care, caregivers of persons with dementia are more prone to underutilizing and/or delaying respite. The 2013 Johns Hopkins Maximizing Independence at Home Study, in which researchers surveyed persons with dementia residing at home with their family caregivers, found that nearly half of the caregivers had unmet needs for mental health care and most of these, needed emotional support or respite care *(Black, B, et al., 2013).* Respite may not exist at all for children with autism, adults with ALS, MS, spinal cord or traumatic brain injuries, or individuals with serious emotional conditions.

Barriers to accessing respite include difficulty navigating fragmented and narrowly targeted services, prohibitive cost to the family, and the lack of information about respite or how to find or choose a provider. Moreover, a critically short supply of well-trained respite providers or preferred respite programs available in community settings or for overnight or extended care, even when families have the resources to pay for respite, may prohibit a family from making use of a service they so desperately need.

How is Lifespan Respite Program Making a Difference?

In describing the Lifespan Respite Care Program, a distinguished panel from the National Academies of Sciences, Engineering, and Medicine recently 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.”

Lifespan Respite grantees are engaged in innovative activities to provide respite services to families:

- **AL, AZ, CO, DE, IL, MD, MT, NE, NV, NC, OK, RI, SC, TN, TX, VA**, **WI** and **WA,** have successfully used consumer-directed respite vouchers for serving underserved populations often not eligible for other public programs, including individuals with traumatic brain injury, MS or ALS, adults with intellectual or developmental disabilities (I/DD), children with autism or special medical needs, individuals with mental health issues, rural caregivers or those on waiting lists for services.
- During their 3-year grant, Aging and Disability Resource Centers (ADRCs) and a network of community partners in **Texas** delivered 37,063 hours of direct service respite care to 993 caregivers of children, youth, and older adults with physical, intellectual and cognitive and developmental disabilities, including respite provided through new nonprofit providers that included summer camps and emergency respite programs.
- **Rhode Island** leverages grant funds with the Older Americans Act Title III-E National Family Caregiver Support Program and RI state funds designated for respite services to increase participation in the CareBreaks (CB) program. The CB program, established with Lifespan Respite grant funds, helps pay part of the respite care costs for families with low to moderate income who have no access to any other program for subsidized respite care.
- The statewide **Virginia** Lifespan Respite Voucher Program covered regions representing significant cultural and economic diversity, from extremely rural to large urban areas. Working with local partners, the Virginia Department for Aging and Rehabilitative Services provided 711 families, on average, 41 hours of respite care and reached caregivers in urban as well as isolated underserved rural areas, and in diverse cultural communities during their 2014-2017 grant.
- The **Washington** State lead agency for the Lifespan Respite grant and key partners expanded respite services to underserved populations, including tribal nations, through a streamlined, user-friendly voucher system. Thirty-seven Respite Provider Agencies joined the Voucher Program providing in-home and medical in-home care, adult day programs, specialized case aides and camps, parks, and recreation programs.
- States are reporting positive family caregiver outcomes. **Alabama's** respite voucher program found a substantial decrease in the percentage of caregivers reporting how often they felt overwhelmed with daily routines after receiving respite. Caregivers in **Nebraska's** Lifespan Respite program reported significant decreases in stress levels, fewer physical and emotional health issues, and reductions in anger and anxiety. The reduction of reported health symptoms was consistent across all three years of the evaluation.

- Innovative and sustainable respite services funded in **CO, MA, NC, NY**, **OH, PA, and SC** through mini-grants to community-based agencies have demonstrated caregiver benefits. During the three years of funding from 2014-2017 in **Massachusetts**, through Respite Innovation Mini-Grants, 455 caregivers received 5,553 hours of respite.

- **AL, AR, CO, NE, NY, PA, RI, SC and TN** are providing new volunteer or faith-based respite services through mini-grants and other capacity building approaches. In **Alabama,** 4-5 mini-grants were awarded each year to faith-based programs, and to agencies representing YMCA, Alzheimer's organizations, The Arc, Hospice, Mental Health, Autism organizations and others to provide respite services.

- **AL, IL, MD, ND** and **NE** offer emergency respite support. **Maryland's** emergency respite program provides financial assistance to family caregivers to pay for emergency respite and contracts with a statewide home care agency to provide a respite provider on short notice.

States are engaged in capacity building through respite worker and volunteer training and through public education.

- Respite provider recruitment and training are priorities in **AR, CO, MA, NE, NV, NY, SC, VA,** and **WI**. In **New York**, by the end of 2017, 3 master trainers, 100 trainers, and 100 companion volunteers were trained to provide respite in 26 counties. In **Tennessee**, the TN Respite Coalition (TRC) and the state agency grantee, in partnership with Tennessee Tech University (TTU), are developing curricula and training delivery methods, including technology supported training. The TRC entered into a three-year agreement with TTU to create a respite provider training video.

- In 2016, the **Rhode Island** grantee launched the Student Respite Initiative, a workforce development respite option with RI Island College (RIC) and University of Rhode Island (URI) nursing programs that offered student nurses clinical experience and course credit while being matched to low to moderate income families who had no access to subsidized respite care. In 2018, they added two more nursing programs to the initiative.

- Grantees in **AL, CO, FL, MA, MT, NE, TN, and TX** engaged in statewide public awareness campaigns to educate family caregivers about respite and how to find it. The **Florida** grantee launched a statewide public education campaign using PSAs distributed via television, radio, web, and social media that directed traffic to the Florida Lifespan Respite Alliance website. Through the Montana Broadcasters Association, the **Montana Lifespan Respite Coalition** developed and aired more than 10,000 radio and television PSAs about the importance and availability of their Lifespan Respite voucher program.

Partnerships between state agencies are changing the landscape for respite service delivery.

- **Lifespan Respite WA**, housed in WA's Aging & Long-Term Support Administration, partnered with WA's Children with Special Health Care Needs Program to provide respite vouchers to families across ages and disabilities. The WA Lifespan Respite grantee also partnered with Tribal entities to provide respite to kinship caregivers. Currently, they are working with Traumatic Brain Injury and developmental disability organizations to expand services to these populations.
- The **OK Lifespan Respite program** partnered with the state's Transit Administration to develop mobile respite to serve isolated rural areas of the state.
- **North Carolina** expanded the No Wrong Door partnership between the Division of Aging and Adult Services (DAAS) and United Way 2-1-1 by increasing the quantity and quality of respite resources available for caregivers through the 2-1-1 system and by enhancing training on respite resources for 2-1-1 Call Center staff. Recognizing the importance of a No Wrong Door approach to long-term services and support, the NC General Assembly appropriated funding for a full-time position within DAAS to partner with United Way 2-1-1 for statewide information and assistance with access.

State grantees are collaborating with their Aging and Disability Resource Centers (ADRCs) or No Wrong Door (NWD) Systems to increase access to respite services and providers.

- Grantees in **AL, FL, ID, MT, NC, NV, NY, SC, SD, TN, TX** are building respite registries and "no wrong door systems" in partnership with Aging and Disability Resource Centers/No Wrong Door systems to help family caregivers access respite and funding sources.
- New York State Office for Aging, the **NY Lifespan Respite grantee**, expanded access to caregiver services through improved respite listings in the NY Connects Resource Directory, the state No Wrong Door System, across all ages and disabilities. This interagency directory provides consistent and comprehensive information on long-term services and supports, including respite.
- In **Alabama**, a Universal Intake Form (UIF) for respite, a screening tool, was developed for use by ADRC staff at 13 Area Agencies on Aging to ensure callers enter a "no wrong door". Callers are screened and referred to appropriate resources within their local community. Follow-up is provided to ensure the individual's needs were addressed. All ADRC Specialists received training collaboratively planned and provided by Alabama Lifespan Respite staff and Alabama Department of Senior Services.
- The **Idaho** Lifespan Respite grantee, working with the ADRC and the Idaho Department of Health and Welfare 211 Careline, created a caregiver landing page on the 211 website that includes an online respite information site with search capability.

- **The Montana** Lifespan Respite grantee and the MT Lifespan Respite Coalition coordinated with the ADRCs to expand the online statewide resource database to include respite providers. A state map was also added to the website, allowing caregivers and stakeholders to view where the Lifespan Respite vouchers are being used.
- The **Florida** grantee established partnerships with the ADRCs providing the infrastructure for a No Wrong Door single point of entry. The partnership ensures linkages for respite inquiries statewide across all disability types. Over 1,000 respite care resources added or updated in the Aging and Disability Resource Centers' (ADRCs') Statewide Resource Database.

Grantees and their partners are leveraging other federal and state dollars because of their federal grants.

- The **Colorado Lifespan Respite Care Program**, with the help of Easterseals Colorado and in partnership with the Colorado Respite Coalition, successfully advocated for $350,000 State General Funds for State Fiscal Years (SFY) 2016 and 2017, an increase from $250,000 in 2015 and $150,000 in 2014. The funds were designated for Lifespan Respite supports, with the majority distributed as community grants and family respite vouchers.
- In 2015, the lead agency in **South Carolina** and the South Carolina Respite Coalition successfully advocated for the creation of a $1 million-line item in the state budget for vouchers for lifespan respite and a process for disseminating those vouchers to traditionally underserved caregivers. By SFY 17-18, with advocacy from respite champions and coalitions built across the state, the total appropriation was further increased to $2.4 million in recurring respite funds. In addition, lead partner groups worked to incorporate short-term respite services as a benefit under the state's Medicaid home and community-based waivers, including a 1915(c) Medicaid waiver for children and youth with severe behavioral conditions.

Funding Levels

In 2006, Congress passed the Lifespan Respite Care Program Act in a bipartisan manner and the program maintains strong, bipartisan support in Congress. The program was initially authorized at $289 million over five years based on the magnitude of the nation's family caregivers' needs, However, Congress appropriated only $2.5 million annually from FY 2009 through FY 2012. The program received slightly less funding in FY13-FY15 due to sequestration. In FY16, given the strong bipartisan support for the program, Congress increased appropriations by $1 million to $3.36 million. This allowed six of the current grantees to receive one-year expansion grants to provide direct services to unserved groups and provided first-time awards to Maryland and Mississippi. For FY 2017, the program was once again funded at $3.36, permitting funding of two new states (ND and SD) and enabling 12 grantees to continue their ground-breaking work to serve more families. An increase in funding to $4.1 million in FY18 and FY19 allowed an additional four states to continue to implement their Lifespan Respite grant activities.

Recommendation to Reauthorize the Program and Retain Current Law – It's Working

Reauthorization will ensure the stability of the program so that states can continue to serve more family caregivers, build respite capacity as the demand for respite increases, and have expectations that they will have time to develop sustainability plans for their innovative state efforts. ACL will be able to work to expand grants to new states that have not yet received a Lifespan Respite grant.

The Lifespan Respite Care Program is the only federal program that prioritizes respite for all ages and conditions, allows states to use funds for start-up of new innovative and evidence-informed programs, encourages and supports collaboration to maximize use of existing funds, and supports training and recruitment of respite providers to address the direct service worker shortage. That is a tall order, but states are meeting the challenges head on. Given that it is working so well, the National Respite Coalition recommends no changes to the pending bill, H.R. 2035, which modifies current statutory language only to give ACL additional authority for improved data collection.

A strong knowledge base about state best practices has emerged from ten years of program implementation. The Lifespan Respite grantees and partners freely share respite best practices information and models that can be adapted to meet states' needs without having to reinvent the wheel. Most importantly, current law gives states flexibility and local control in meeting the program's requirements so that each state can determine the best approaches to address their own unique, identified needs for respite and provide critical gap-filling services. We urge you to reauthorize the Lifespan Respite Care Act with minimal changes to current law as written in H.R. 2035. Families will be able to keep loved ones at home, saving Medicaid and other federal programs billions of dollars.

Thank you for the opportunity to testify.

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