Caregiving in Congress

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Rep. Michelle Lujan Grisham
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Family Caregivers

- Currently, the vast majority of care in the United States is provided by family caregivers; more than 40 million Americans provide more than $470 billion in care to seniors and adults with disabilities every year.
- Nearly four times Medicaid LTSS spending, and more than total Medicaid spending for health care and LTSS
- “An invisible, isolated army carrying out increasingly complicated tasks and experiencing challenges and frustrations without adequate recognition, support, or guidance, and at great personal cost.”

- AARP, Valuing the Invaluable 2015 Update
Caregiving & Individuals with Intellectual/Developmental Disabilities

- There are approximately 2.9 million family caregivers of people with intellectual/developmental disabilities (I/DD).
- They face unique challenges; levels of responsibility can be greater, and care is often lifelong.
- Support services are limited; only 17% of families of persons with I/DD receive financial support, and federal programs are underfunded.
- There are over 860,000 caregivers for individuals with I/DD over the age of 60, and this number is expected to grow.
The Caregiving Gap

- As our population continues to age, demand for long-term supports and services will grow, placing a huge burden on a fragmented system that is already struggling to provide and finance care for current seniors and individuals with disabilities who want to remain independent and receive services in their homes and communities.
- By 2030, there will be more than 72 million older Americans, making up 19% of the total population.
- In 2010, there were seven potential caregivers for every person over the age of 80. By 2030, that ratio is projected to drop by almost half, to 4:1.
- In the paid workforce, 4 million direct care workers provide long term supports and services already. Demand is projected to grow so that the U.S. will need to add at least 1 million more direct care workers over the next ten years.
Assisting Caregivers Today (ACT) Caucus

- Bipartisan, bicameral caucus established in March 2015
- Co-chairs: Reps. Michelle Lujan Grisham and Diane Black, Sens. Michael Bennet and Kelly Ayotte
- Currently more than 50 members, split about evenly between two parties
- Goal: Educate members of Congress about caregiving issues, create an environment conducive to reaching bipartisan solutions, and build a sense of urgency to act
Assisting Caregivers Today (ACT) Caucus Activity

- Sent a letter to the Appropriations Committee in support of funding for the National Family Caregiver Support Program, Lifespan Respite Care, and Aging and Disability Resource Centers.
- Supported two briefings: “Family Caregiving 101” in May and “Family Caregiving Challenges Across Subpopulations” in July.
RAISE Family Caregivers Act (H.R. 3099)

- Based on recommendations by the 2013 Commission on Long Term Care
- Directs the Department of Health and Human Services to develop, maintain, and periodically update a National Family Caregiving Strategy with the help of a Family Caregiving Advisory Council.
- Passed Senate in December 2015
National Care Corps Act (H.R. 2668)

- Creates a national Care Corps, housed within the Administration for Community Living at the Department of Health and Human Services.
- Places Corps volunteers in communities where they will provide services that help seniors and individuals with disabilities remain independent.
- Provides volunteers with health insurance and other benefits during their time of service, along with an educational award that can be used to pay education costs or loans.
- Helps build the caregiving and health care work force needed to meet the growing demand for services.
- Provides opportunity for unemployed or underemployed young people, along with other workers interested in retraining for work in an in-demand field.
- Fosters intergenerational relationships and better understanding of individuals with disabilities.
Potential Impact on States and Individuals with Disabilities

- Expand the pool of available caregivers
- Extend the length of time a caregiver is able to provide care and increase the quality of care provided
- Improve quality of life for the caregiver and those receiving care by allowing them to remain in their homes and communities