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Public Comments on Draft National Plan to Address Alzheimer's disease

I applaud your efforts at drafting this national plan to address Alzheimer's disease.

The Rosalynn Carter Institute for Caregiving has spent several years of intensive study on the caregiving process, evidence-based programs to help family caregivers living with Alzheimer's disease, and translational strategies for making effective programs widely available to caregivers. We have convened national panels composed of researchers, practitioners, and community members to examine how to enable family caregivers to provide care while maintaining their own health and well-being.

The work of a caregiver is done willingly and selflessly. Many caregivers do their work quietly, invisibly and around the clock in homes, hospitals and other places across the country. We are facing a caregiving crisis in the United States. Our aging population, increased longevity and the growing burden of Alzheimer's disease and other illnesses, escalate the need for caregivers.

Evidence-based effective caregiver support programs in the community are critically needed. Evidence and action must be linked. Caregivers need support through community programs to help them remain healthy and maintain caring for another. The ADSSP demonstrations have provided an excellent base for translating caregiver support programs (originating in randomized control trials), into community agencies to reach individuals living with Alzheimer's disease.

Increased and continued funding is needed for additional translational research, specifically more demonstration projects for evidence-based interventions to support caregivers caring for individuals with Alzheimer's disease. More programs are desperately needed in community agencies across our nation. Critical to start up and sustainable translational research is the knowledge of which programs work in community agencies, the expertise to determine agency readiness, the ability to train staff within an agency, and the ability to provide on-going technical assistance. Translational funding should include monies for these technical assistance networks.

A culturally competent assessment for all caregivers is also needed to accurately identify their specific needs and level of risk. This assessment would enable service providers to match available evidence-based caregivers support programs to effectively address these needs. Ideally, a menu of service options based on identified caregiver risk levels would be available through community-based services.

Research indicates that caregivers who are supported throughout their caregiving journey are more likely to provide quality, safe care to their loved, resulting in an improved quality of life for both. I thank you for this important opportunity to be a voice for the needs of caregivers.

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Executive Director