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Alice-Lynn Ryssman  
U.S. Administration for Community Living  
One Massachusetts Avenue NW  
Washington, DC 20001

January 17, 2014

Re: Administration for Community Living, Agency Information Collection Activities; Submission for OMB Review; Comment Request; OAA Title III-E Evaluation National Family Caregiver Support Program

Dear Ms. Ryssman,

Thank you for the opportunity to comment on the Administration for Community Living's (ACL) proposed collection of data to evaluate the National Family Caregiver Support Program (NFCSP). As noted in the National Plan to Address Alzheimer's Disease,<sup>1</sup> the federal government needs improved data on people with Alzheimer's disease, their caregivers, and the services and supports they use in order to address policy questions and to plan and evaluate initiatives, like the NFCSP. The Alzheimer's Association supports ACL's efforts to improve this critical program and advance the National Plan.

The Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support, and research. Today, there are more than 5 million Americans living with Alzheimer's disease. Alzheimer's is the sixth leading cause of death in the United States, and the only cause of death among the top 10 without a way to prevent, cure or even slow its progression. Given the lack of treatments and the degenerative nature of the disease, caregivers are central to the health, safety and quality of life of those with dementia.

However, caregiving takes its own tolls. In 2012, 15.4 million family and friends provided 17.5 billion hours of unpaid care to those with Alzheimer's and other dementias — care valued at \$216.4 billion. More than 60 percent of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high; more than one-third report symptoms of depression. Due to the physical and emotional toll of caregiving, Alzheimer's and dementia caregivers had \$9.1 billion in additional health care costs of their own in 2012.

### Specific Comments

**1. The Alzheimer's Association encourages ACL to adopt the BRFSS definition of "caregiver" and reword the survey instruments to align with the language used in the BRFSS Caregiver Module.** Since 2005, the Centers for Disease Control and Prevention (CDC) and the Alzheimer's Association have partnered to promote cognitive health and impairment as a public health issue. As a result of this partnership, The Healthy Brain Initiative: The Public Health Road Map for

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<sup>1</sup> U.S. Department of Health and Human Services. (2013). National Plan to Address Alzheimer's Disease: 2013 Update.

State and National Partnerships (“Road Map”) is designed to guide public health agencies and other key partners in serving individuals with cognitive impairment and their caregivers.

The Road Map recommends that agencies track the public health burden through existing surveillance systems like the Behavioral Risk Factor Surveillance System (BRFSS) and develop standardized questions that can be used at all levels. Standardized tools are more likely to yield valid, reliable data that can be generalized to the broader population. Consistent terminology and language can also aid in consistent interpretation of data, regardless of the instruments used. The BRFSS has a long history<sup>2</sup> of helping states survey adults about a wide range of behaviors that affect their health, including caregiving. Several federal agencies are current sponsors of the BRFSS survey, including most divisions of the CDC, the Health Resources and Services Administration, the Administration on Aging, the Department of Veterans Affairs, and the Substance Abuse and Mental Health Services Administration.

**2. The Alzheimer’s Association has suggestions about specific elements of the surveys, including their length.** First, we encourage ACL to include “Caregivers of individuals with dementia” as a special population of caregiver in the “Targeting” sections of the State Unit on Aging (SUA) and Area Agency on Aging (AAA) surveys, as an overwhelming number of caregivers care for individuals with dementia. Several of the interventions listed on the surveys are dementia-specific, indicating a prevalence of dementia-specific caregivers served by these agencies.

The Association is concerned by the length of the caregiver survey. As ACL knows, caregivers’ time is strained; 45 minutes of unscheduled time over the phone could be a significant burden. Additionally, the length of the surveys of both the caregivers and the agencies may impact the number of people and/or agencies who participate and the quality of the data. The Alzheimer’s Association recognizes the need to ask the right questions, but participation must be as simple as possible so that enough relevant data may be gathered.

The Association strongly encourages ACL to streamline the proposed instruments. Several similar but ultimately duplicative questions could be removed, and others can be combined, such as questions 57 and 58, relating to strained relationships. Similarly themed national surveys, such as the National Health and Aging Trends Study (NHATS) use in-person methodologies, while the National Survey of Caregiving limits its telephone interview to 30 minutes.

The Association is also concerned by the extensive use of open-ended questions throughout the caregiver instrument. While such questions are appropriate and helpful in capturing, for example, the additional types of care needed in question 21a, they are frequently cumbersome for both the interviewer and respondent, such as in question 24c, relating to how caregiver education and training helped the respondent. Open-ended questions may lead to longer survey times, lower response rates, and digression by the respondent.

Dementia training should be added to the list of options under “Staff and Volunteer Trainings” in the SUA and AAA instruments. The greatest known risk factor for Alzheimer’s disease is advancing age,

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<sup>2</sup> Recognizing the need for state and local data on personal health behaviors, the CDC established the BRFSS in 1984 with the participation of 15 states. The survey became nationwide in 1993.  
[http://www.cdc.gov/brfss/about/about\\_brfss.htm](http://www.cdc.gov/brfss/about/about_brfss.htm).

and these agencies serve the aging population.

We respectfully suggest that “voluntary health and/or advocacy organization” be added to the list of possible referral sources in the AAA survey. The Alzheimer’s Association 24/7 Help Line and Chapters refer constituents to aging service providers as appropriate.

**3. The Association strongly encourages ACL to consistently collect and publish this data.** Data collection, used for surveillance, is a core function of public health. The cognitive impairment module of the BRFSS, for example, helps to demonstrate the burden of cognitive impairment, inform policy and programming, and evaluate progress. Though ACL intends to use its surveys to evaluate the effectiveness of the NFCSP, the Alzheimer’s Association believes the proposed data collection creates significant opportunities beyond program evaluation to address the challenges and needs of family caregivers.

The data ACL proposes to collect can be incredibly valuable if it is collected and published consistently. If collected consistently, ACL will be able to continuously evaluate and improve the NFCSP. If made available to the public, ACL and community partners will be able to identify and fill resource gaps. The community needs assessment questions included in the SUA and AAA surveys, for example, are particularly useful for public health agencies and other community partners. Access to such information prevents duplicative efforts and can lead to improved coordination among groups.

**4. The Alzheimer’s Association encourages ACL to work with public health partners to coordinate and implement strategies to improve service delivery to caregivers.** As called for in the Road Map, agencies at every level should partner to develop a locally-tailored, coordinated approach to serving those with cognitive impairment and their caregivers. The Alzheimer’s Association would be pleased to assist ACL in this process.

Thank you for the opportunity to comment on the proposed collection of data to evaluate the National Family Caregiver Support Program. Please contact Laura Thornhill, Manager of Regulatory Affairs, at 202-638-7042 or [lthornhill@alz.org](mailto:lthornhill@alz.org) if you have questions or if we can be of additional assistance.

Sincerely,



Robert Egge  
Vice President, Public Policy