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The Honorable Nora Super  
Executive Director  
2015 White House Conference on Aging  
200 Independence Avenue SW, Suite 637D  
Hubert H. Humphrey Building  
Washington, DC 20201

Dear Nora:

We would like to extend a resounding “Thank You” on behalf of family caregivers across the United States for participating in the Family Caregiving Tele-Town Hall on Thursday, February 26. There were 200 family caregivers and aging professionals who participated in this event, many of whom submitted questions and concerns about the upcoming White House Conference on Aging.

We would also like to commend you on your excellent staff, Michele Patrick and Sarah Plante, who helped make this event possible.

As part of our continuing conversation, we have included in this letter the comments and observations of these family caregivers. Our team has organized the comments into a series of general responses and policy recommendations, below. Full comments can be found in the Appendix to this letter.

### **Long-Term Services and Supports**

- **Suggestions for the Conference:** Family caregivers wanted more information on programs that would mitigate the medical costs of caring for a loved one, information on the overlap between caregivers and the direct-care workforce, and information on the role of new technologies in supporting family caregivers.
- **Suggested Policy Solutions for the Executive Branch:**
  - Collaboration with the Office of the National Coordinator for Health Information Technology to identify new innovations in technology that support family caregivers.

- Formal recognition of family caregivers by the federal government, such as a U.S. Census question that asks whether a person is caring for an adult who needs assistance with Activities of Daily Living (ADLs) or an IRS designation of “Family Caregiver” in addition to “Head of Household” to encourage caregivers to self-identify.
- A national education campaign on family caregiving and self-identification, with referral to agency resources at ACL, CMS, SSA, and the Department of Veterans Affairs.
- Collaboration with CMS to provide reimbursement for respite services under the Medicaid program, including stipend payments for family caregivers.

In addition to the above policy solutions, the National Alliance for Caregiving (the “Alliance”) and Caregiver Action Network (“CAN”) are supportive of the recommendations of the Long Term Care Commission<sup>1</sup> to support family caregivers and would ask that the White House consider the Conference on Aging as a national forum that may identify additional long-term care solutions for America’s families.

Featuring federal programs that support family caregivers may be one way to inspire conversation on effective long-term care models. In particular, the federal government provides high-impact support for family caregivers through the Department of Veterans Affairs’ VA Caregiver Support program. This program includes education, training, and financial support to family caregivers for servicemembers returning from post-9/11 wars.<sup>2</sup> Both the Alliance and CAN support this program and current bipartisan legislative efforts to expand it.

Our organizations have also supported the National Care Corps Act of 2014 (H.R. 5288) and the Caregiver Corps Act of 2014 (S. 2842), which would create a volunteer workforce to train volunteers to provide care to those in need. Highlighting these programs would raise awareness of the needs of family caregivers and potential solutions to support families across the lifespan.

## **Retirement Security**

- **Suggestions for the Conference:** Caregivers suggested a focus on policy solutions that can reduce the financial strain of caregiving so that they could protect against the deterioration of their own retirement. Many were interested in the role of retirement accounts and Social Security benefits in helping them to cover the costs of caring for a loved one.

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<sup>1</sup> See <http://www.gpo.gov/fdsys/pkg/GPO-LTCCOMMISSION/pdf/GPO-LTCCOMMISSION.pdf>. Key recommendations included: ensure family caregivers have access to key information to make informed decisions on LTSS, institutional care, and care transitions; maintain and strengthen a person-and family centered LTSS system with the patient and family caregiver as the focus for services and supports. Include the family caregivers in assessment and care planning; include caregivers in patient records, including Electronic Health Records, and as a member of the care team; improve caregiver access to information technology that can assist with caregiving through information and resources; and encourage caregiver interventions, including respite options and integration with volunteer efforts.

<sup>2</sup> See <http://www.caregiver.va.gov/>.

- **Suggested Policy Solutions for the Executive Branch:**
  - Encourage the Social Security Administration to work with family caregivers to help them understand the impact that caregiving can have on their retirement security.
  - Work with the IRS to create a hardship exclusion for family caregivers that would keep them from being penalized from early withdrawals from 401ks to care for a loved one.

Related to these suggestions, the Alliance and CAN have been supportive of Congresswoman Nita Lowey’s Social Security Caregiver Credit Act, proposed in the last Congress, which would establish a Social Security credit for family caregivers.

The White House’s focus on paid family and medical leave during the 2014 White House Summit on Working Families may also support family caregivers. The national “FAMILY Act”<sup>3</sup> which would expand paid family and medical leave to family caregivers through the use of a payroll deduction. This program is similar to California’s Paid Family Leave program, which has offered new solutions for family caregivers struggling to balance work and care. We would encourage the White House Conference on Aging to include information about programs like these that can support family caregivers as part of the overall conference efforts.

### **Healthy Aging**

- **Suggestions for the Conference:** Family caregivers and their advocates were interested in conference content that includes a focus on families managing Alzheimer’s or related dementias, information on families managing chronic disabilities (especially in pediatric populations), and guidance on culturally competent resources that reflect the diversity of the American family (such as ethnically-inclusive or LGBT-inclusive language).
- **Suggested Policy Solutions for the Executive Branch:**
  - Work with CMS to include family caregivers as a trusted member of the healthcare team by ensuring that the caregiver is named and listed in the patient’s medical record.
  - Work with CMS to provide training for clinicians on the impact of caregiving on the family caregiver’s health, with referrals to appropriate home- and community-based resources and assessment of the health risks to the caregiver.
  - Work with federal agencies to ensure that family caregiving resources (where available) are offered in multiple languages, with culturally appropriate information, and that resources have inclusive language for families of choice in addition to families of kin.

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<sup>3</sup> See <http://www.nationalpartnership.org/research-library/work-family/paid-leave/family-act-fact-sheet.pdf>.

## **General Comments**

Family caregivers raised several general issues related to the conference that may provide additional insight into your planning:

- The need for cross-agency collaboration on family caregiving issues;
- The need for a more seamless referral by healthcare providers and community-service providers to caregiving supports and long-term services (where available); and
- Identification of non-government solutions to support family caregivers, such as innovations in the technology sector, private health insurance plans, or health care providers.

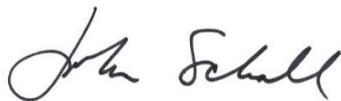
Thank you again for your continued work to elevate the national conversation on aging. We look forward to a continued partnership through our shared interest in family caregiving.

If you would like to discuss these ideas further, please do not hesitate to reach out to us at the contact information below.

Sincerely,



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