**National Alliance for Caregiving**
*Advancing Family Caregiving through Research, Innovation & Advocacy*

January 26, 2016

The Honorable Orrin G. Hatch
Chairman
Committee on Finance
United States Senate
219 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Ron Wyden
Ranking Member
Committee on Finance
United States Senate
219 Dirksen Senate Office Building
Washington, DC 20510

**Re: United States Senate Committee on Finance**
**Bipartisan Chronic Care Working Group – Policy Options Document**

Dear Chairman Hatch and Senator Wyden:

Thank you for the opportunity to provide comments on the Policy Options Document put forth by the Bipartisan Chronic Care Working Group of the United States Senate on Finance.

By way of background, the National Alliance for Caregiving (the "Alliance") is a non-profit coalition established in 1996 and comprised of nearly 60 national organizations dedicated to advancing family caregiving through research, innovation, and advocacy. The Alliance conducts research, does policy analysis, develops national best practices, and works to increase public awareness of family caregiving issues. As part of our work, we foster a network of more than 80 state and local caregiving coalitions and serve as Secretariat for the International Alliance of Carer Organizations. As the head of the Alliance, I also am honored to serve on the Governing Board of the Patient-Centered Outcomes Research Institute. These comments reflect our recommendations related to family caregivers in the health care systems and the policy proposals specific to patient-and-family centered care.

### *Family Caregivers in the Health Care System*

There are an estimated 43.5 million adult family caregivers of people of all ages in the United

States.[1] These caregivers provide on average just over 20 hours each week supporting a loved one with ongoing health care needs or disabilities. Care typically includes helping patients with Activities of Daily Living, Instrumental Activities of Daily Living, or medical/nursing tasks. A majority of family caregivers (57 percent) provide help with medical/nursing tasks, such as giving injections, tube feedings, managing wound care, monitoring blood pressure or blood sugar, or operating medical equipment like respirators and oxygen tanks. Many of the caregivers providing medical/nursing assistance do so without prior training or instruction.

As America ages, family caregivers are increasingly helping loved ones who have multiple chronic conditions. We applaud the effort of your office to better include family caregivers into the proposed policy reforms and as trusted members of a patient's health care team.

**In addition to our support of your effort to improve lives for patients and their families, we offer the following specific comments on the policy options most relevant to caregiving:**

## I. Developing Quality Measures for Chronic Conditions: Recommendations

Quality measures for patient and family engagement should include caregiver-reported outcomes in addition to patient-reported measures. Family caregivers often function as a member of the health care team[2] and even conduct tasks that would otherwise be described as "medical or nursing tasks," such as giving injections, tube feedings, managing wound care, and monitoring the signs and symptoms of a disease.

When a patient is cognitively impaired (such as a patient with dementia or an intellectual or developmental disability) or is struggling with impaired perception (such as a patient with mental illness), a family caregiver can provide additional information as observers of the patient's health. This might include reporting on functional status and observable signs that a disease is progressing or not responding to treatment. For example, a caregiver could report that their child can no longer ambulate or that their elderly parent has difficulty getting dressed without assistance. For this reason, we would urge the committee to consider including quality measures that capture caregiver-reported outcomes.

Likewise, quality outcomes for shared decision making should incentivize health care providers to include the family caregiver when developing a plan of care. We support the inclusion of family and caregiver experience during hospice and end-of-life care, but would expand the

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[1] See National Alliance for Caregiving and AARP, Caregiving in the U.S. – Final Report (2015), available at www.caregiving.org/caregiving2015.

[2] See National Alliance for Caregiving & AARP, Caregiving in the U.S. (2015), available at www.caregiving.org/caregiving2015 and AARP, Home Alone: Family Caregivers Providing Complex Chronic Care (2012), available at http://www.aarp.org/home-family/caregiving/info-10-2012/home-alone-family-caregivers-providing-complex-chronic-care.html.

inclusion of the caregiver experience to all chronic diseases. Additionally, we support the proposal to include measures for family caregivers for Alzheimer's and dementia patients, but would expand this to all chronic diseases, or in the alternative, all conditions where cognition or mental perception may be impaired.

## II. Empowering Individuals & Caregivers in Care Delivery: Recommendations

We would encourage the committee to include family caregivers in delivery models for chronic care management as a member of the health care team, with access to the patient's health care data and the opportunity to consult with clinicians about the patient's plan of care. Medicare beneficiaries should be given the option to voluntarily identify a family caregiver and provide caregiver contact information in the medical record. Providers should then consult with the family caregiver before transferring the patient from one heath care setting to another.

In addition to conferring with the caregiver, Medicare providers should assess the family caregiver to include: the caregiver's health and ability to support the patient; the anticipated tasks that the caregiver will be expected to conduct; the caregiver's willingness to provide care; whether additional training is needed for the caregiver; and the need for support services, such as nutrition assistance or transportation, that can help the caregiver. Assessment is critical to understanding how a family caregiver can support a patient and what additional help they may need to support better patient outcomes. Where appropriate, Medicare providers should provide referral to resources in the community, such as the Area Agencies on Aging, the Aging & Disability Resource Center, and other community or disease-specific organizations that may be able to offer assistance.

### a. Expanded access to digital coaching should include resources for the family caregiver, as this is an effective way to help support the care of the patient.

In response to the questions within the Policy Options Document, the Medicare.gov website is an effective place to house information for patients and their families about chronic care management. Medicare should work with community organizations to provide links to the chronic care website on other websites that caregivers may visit. Medicare should work closely with other federal agencies to provide links to this information for family caregivers, including leveraging the resources available on existing federal websites:

- Medicare – Caregiving Page, https://www.medicare.gov/campaigns/caregiver/caregiver.html
- Department of Veterans Affairs – Caregiver Support Program,

  http://www.caregiver.va.gov/

- Administration on Aging – National Family Caregiver Support Program, http://www.aoa.acl.gov/AoA_Programs/HCLTC/Caregiver/
- National Library of Medicine (HHS) – NLM 4 Caregivers, https://sis.nlm.nih.gov/outreach/caregivers.html

Many patients and their families are not aware of what type of support Medicare can offer for chronic disease and the associated out-of-pocket costs for chronic care management. Medicare initiatives around "digital coaching" should include educational seminars, such as webinars and social media chats, to teach patients and their families about how to use Medicare resources, how to cover the out-of-pocket cost of care, and where to find additional information if they are having difficulty understanding how to manage the patient's underlying conditions.

***Conclusion***

In conclusion, we appreciate the opportunity to provide comments and would be happy to provide additional information to guide this work. Should you have questions, you may reach me at my contact information below or contact our Director of Strategic Partnerships, Grace Whiting, at gracewhiting@caregiving.org.

Sincerely,

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