

March 19, 2014

The Honorable Ron Wyden  
Attn: Anne Dwyer  
United States Senate  
Washington, D.C. 20510

The Honorable Johnny Isakson  
Attn: Jay Sulzmann  
United States Senate  
Washington, D.C. 20510

Dear Senators Wyden and Isakson:

We are senior health care and family systems professionals (clinicians, researchers and educators) with special interest and expertise in chronic illness. Collectively, we are committed to an integrated, family systems-based approach to health care delivery. As individuals, we commend you for the goals and design of the **Better Care, Lower Cost Act** (S. 1932) that aims to provide better, more coordinated and cost-efficient care to Medicare beneficiaries with multiple chronic illnesses and limitations.

While the legislation has many admirable and innovative components, it is missing a critical element of effective and efficient health care for this population: **collaboration with family caregivers**. In this letter, we explain why this collaboration is so crucial for achieving better care and reducing costs, and how this cooperation can be achieved. In the attachment, we propose several specific changes in the bill's language to make it truly patient- and family-centered.<sup>1</sup>

### ***First, who are family caregivers?***

Family caregivers are spouses, partners, adult children, siblings, friends and neighbors who provide various types of unpaid assistance to help people manage and cope with their chronic illnesses, disabilities and cognitive limitations while continuing to live at home. Most caregivers of the frail elderly are women—primarily spouses, daughters or daughters-in-law—although men are assuming an increasing role.

The umbrella term “family caregiver” obscures the unique characteristics of caregiving between spouses. Spousal caregivers live in the same household and have legal, economic, and emotional ties and obligations to their partner that are different from other family caregivers. These spousal ties need to be understood and respected by health care providers.

Spousal caregiving is much more common than often portrayed in accounts of family caregiving. According to the 2010 Census, the majority of 65 to 75 year olds are living with a married partner in the home, making their spouse the most likely day-to-day caregiver. Some of these spousal caregivers are competent and willing; others are not. Even among those older than age 75, 38% of women and 73% of men are still living with a spouse. (If longtime cohabiting heterosexual and same sex partners were included, the number of potential spousal caregivers would be larger.)

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<sup>1</sup> These suggestions build on the findings and recommendations made at the 2008 Wingspread Conference on Marriage, Couple Relationships and Health, sponsored by the National Healthy Marriage Resource Center. For the report and related publications, see [www.healthymarriageinfo.org](http://www.healthymarriageinfo.org).

## **Second, what roles do family caregivers play?**

Family caregivers have been called the backbone or the glue of the long term/chronic illness care system, enabling millions of persons to remain living in their homes and community, thereby avoiding costly institutional care or payments for in-home services. (Only about one quarter of those who use family caregivers also use paid help.)

Family caregivers play at least five overlapping roles:

- (i) **Illness prevention.** As “health-mates” spouses can promote (or hinder) safe and healthy lifestyles and behavior (good nutrition, adherence to special diets, exercise, etc.) that prevent or slow the progression of chronic conditions such as diabetes, heart disease, arthritis and depression.
- (ii) **Provider of medical treatment and services.** In a recent national survey, 46% of family caregivers reported performing medical/nursing tasks to implement adherence to prescribed regimens, including monitoring multiple medications, providing wound care, giving injections, using monitors, and operating specialized medical equipment including administering intravenous fluids.<sup>2</sup>
- (iii) **Coordinator and manager of health care services.** Family caregivers typically coordinate contacts and appointments with numerous health and social service providers. This requires navigating fragmented programs with different administrations, eligibility rules and needs assessments.<sup>3</sup>
- (iv) **Assistant in activities of daily living.** These activities include bathing, toileting, dressing, preparing meals, transportation to appointments, shopping, paying bills, etc.
- (v) **Long distance caregiving.** Family caregivers who live at a distance often shoulder the responsibility of ongoing communication with health care professionals. They must monitor the provision of appropriate services provided by institutions (nursing homes) or paid helpers in the home, manage finances, and make decisions when crises in the chronically ill person’s health or living arrangements occur.

Although many family caregivers willingly choose to be caregivers and derive satisfaction from doing so, they also report experiencing considerable anxiety, stress and high rates of depression.

## **Third, to what extent are family caregivers’ contributions and expertise currently acknowledged and supported by the health care system?**

Most studies report that few caregivers have direct communication with health care professionals and they generally receive little or no instruction or training to help them perform their complex medical tasks.<sup>4</sup> Indeed, health care professionals often are not even aware of who the caregivers are or how to contact them.

One of the perceived barriers to collaborating with family caregivers is the Health Insurance Portability and Accountability Act (HIPPA). These regulations have been widely misinterpreted in ways that prevent effective communication between health care providers and family caregivers.<sup>5</sup>

The new wave of transitions-in-care demonstration programs has put a welcome spotlight on the critical role of family caregivers, especially when the individual has to move between home and hospital—and back—or to another facility. Innovative strategies and tools are being developed and tested to engage family caregivers as partners in these transitions, to prevent a decline in health status and unnecessary and costly hospitalizations and re-admissions. **Based on the promising results of these and other studies, improved collaboration with family caregivers is expected to improve health outcomes and reduce costs.**<sup>6</sup>

The emerging lessons from demonstrations, decades of research and best clinical practice in family medicine, family

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2 Susan Reinhard, Carol Levine and Sarah Samis. Home Alone: Family Caregivers Providing Complex Chronic Care, *In Brief*, AARP Public Policy Institute

3 Judith Feder et al. *Long Term Care Commission Alternative Report*, Sept 23, 2013

4 Commission on Long Term Care, *Report to the Congress*, Sept 30, 2013

5 Carol Levine and David Gould, *Transitions in Care 2.0 An Action Agenda*. United Hospital Fund.

6 Carol Levine, Deborah Halper, Jennifer Rutberg & David Gould. *Engaging Family Caregivers as Partners in Transitions*. A Special Report, United Hospital Fund, 2013.

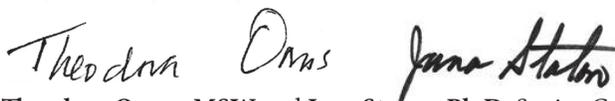
therapy and family nursing show us how to create and sustain collaboration with family caregivers in the prevention, treatment and ongoing care of chronically ill patients.

The challenge is to figure out how to make this knowledge widely available to health care practitioners in order to embed respect and support for family caregivers throughout an improved, integrated health care delivery system for the chronically ill.

**Recommendations:** The Better Care and Lower Cost Act offers several windows of opportunity to implement and integrate family caregiver collaboration in the reformed health care system. In the attachment, we recommend several small additions or changes in the legislative text that we believe will greatly strengthen and improve the bill. These proposed changes also will support and reinforce ongoing efforts within federal health agencies, state health departments and around the country to move in this direction.

We would be glad to provide any additional information or assistance as this legislation moves forward. Please contact Theodora Ooms at (301) 986-9042 ([Theodora.ooms@gmail.com](mailto:Theodora.ooms@gmail.com)) and Jana Staton at (406) 721-5558 ([jstaton@montana.com](mailto:jstaton@montana.com)).

Sincerely,



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**Barry Jacobs, Psy. D.** Director, Behavioral Sciences, Crozer-Keystone Family Medicine Residency Program, Springfield PA. and author of *Emotional Survival Guide for Caregivers*



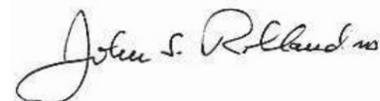
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