

In Gratitude of Caregivers

As we approach Thanksgiving and the holiday season, so many of us turn our minds and hearts towards giving to others. This November I am reflecting on the amazing generosity of spirit I see among Vermonters of all walks of life caring for elders and people with disabilities every day. November is [National Family Caregivers Month](#), an opportunity to honor family caregivers as the backbone of our home and community based support system for Vermonters who are aging or living with a disability. More than 65 million Americans, including 64,000 Vermonters, provide care for a loved one who has a disability, is chronically ill, or is aging and spend an average of 20 hours per week providing care. This act of caring is an amazing gift to our Vermont communities.

Intuitively, I think we all recognize that long-term care of a loved one with a disability or chronic illness is challenging. Many of us have had to care for a family member at least short term at some point in our lives or have watched other family members do so, and we understand that it is a taxing job: physically, mentally and financially. The challenge is that the focus of most discussion, policy and funding is looking solely at the health of the care recipient, not the caregiver.

At the Department for Disabilities, Aging and Independent Living (DAIL), our mission is to make Vermont the best state in which to grow old or live with a disability – with dignity, respect and independence. We recognize that to accomplish this, we must take a holistic approach and not only support the individual receiving care, but also support the needs of the entire family. In partnership with DAAIL, the five Vermont regional Area Agencies on Aging offer respite grants to family caregivers who are providing care to family members with Alzheimer's or another form of dementia. In 2015, 245 families were supported through these grants. Similarly, for families caring for an individual with an intellectual or developmental disability, DAAIL provided Family Managed Respite funding for 191 families last year. These targeted programs are designed to support those families where the responsibilities and burdens of caregiving are truly greatest. We recognize that it is our responsibility to find ways to adequately support families and individuals now and into the future.

A new research report from the National Academy of Sciences entitled [Families Caring for an Aging America](#) gives us hope that more people are paying attention to this national challenge. The report highlights the growing demand for family caregivers, the increasingly complex role they play in providing care, the proven risks to their own physical and mental health while caregiving, and the growing body of research on how to support family caregivers, beginning with a robust identification of caregivers and assessment of their needs. Vermont has not yet done a comprehensive survey of caregiver needs as the research recommends, but we are beginning to try. The Governor's Commission on Alzheimer's Disease and Related Disorders has partnered with the University of Vermont to conduct a survey of family caregivers of people with dementia. The goal of this survey is to have a better picture of the landscape of dementia caregiving in Vermont and identify strategies that government and community partners can undertake to better support families. UVM is currently collecting surveys and is seeking more participants, so if you or someone you know is a caregiver to someone with dementia, please

consider taking the survey by December 1st at this link:
<https://www.surveymonkey.com/r/ADRDCaregiver>.

In addition to these state-led efforts, there is critical work happening in local communities across Vermont to support caregivers, including evidenced-based training programs such as Powerful Tools for Caregivers as well as one-on-one and group support. Many community partners, such as the Alzheimer's Association, the Area Agencies on Aging, and the designated mental health and specialized service agencies are invested in these efforts both to spread the word and inform families of community resources as well as providing the training and tools to help caregivers take care of themselves. In an effort to begin to bring community groups, caregivers, advocates and individuals together to share and learn about what's possible in community, the [Tri-State Learning Collaborative on Aging](#) is hosting three "Cross Border Conversations on Caregiving" in Maine, New Hampshire and Vermont throughout November. The conversations provide a forum for discussion around best practices and opportunities for collaboration as our entire region grapples with changing demographics and growing needs. DAIL is excited to be participating in these important conversations to advance our collective thinking to improve systems and supports.

While the challenge before us is great, November always leaves me feeling hopeful. Amid the cold, gray days between fall and winter, I see how so many minds are opened to the idea of doing good and so many hearts are warmed by the sheer act of giving. I share my deep gratitude and appreciation with all 64,000 Vermonters providing care to your loved ones. Thank you. As a state, I hope we can learn from your daily acts of giving and work together to more creatively, more concretely, and more intentionally support caregiving across the lifespan.

About the author

Angela Smith-Dieng is the Director of the State Unit on Aging in the Adult Services Division at the State of Vermont Department of Disabilities, Aging and Independent Living, which oversees the Older Americans Act work throughout Vermont, with a mission to make Vermont the best state in which to grow old or live with a disability – with dignity, respect and independence.

Angela Smith-Dieng, Burlington, VT
802-241-0309; angela.smith-dieng@vermont.gov