

Madam Chairwoman and Members of the Committee:

I am pleased to provide some comments on the privately funded resources for family caregivers. My professional experience includes many years of helping family members obtain information, education and services needed to provide care to their loved ones while trying to keep those loved ones in their homes as long as safely possible.

More recently, I joined the ranks of family caregivers, having provided care to my mother-in-law and father-in-law for the past three years. It has been an interesting and rewarding experience, but it also has been tough. It has been sprinkled with challenges such as time constraints, competing demands, family conflict and many care transitions, just to name a few, that can cause frustration, stress and fatigue. So, I will frame my discussion of support for family caregivers today from a professional and personal perspective.

So what exists in North Dakota in terms of support and services for family caregivers that are privately funded? Well, this list will not be all-inclusive and is not intended to be, but rather it is an overview of the types of resources available, with more attention to informal care.

1. Family and friends – According to the AARP Public Policy Institute’s new report, *Valuing the Invaluable: 2015 Update*, in 2013, North Dakota had 62,100 family caregivers who provided 58 million hours of unpaid care valued at \$860 million. These caregivers are spouses, partners, adult children, other family members, neighbors and friends. These family caregivers provide a range of daily activities, such as transportation, personal care, managing finances grocery shopping and much more. Each caregiving situation is unique, and caregivers can be in different phases of caregiving, depending on the length of time they have spent in the caregiver role. The initial phase is, “I’m not a caregiver,” with individuals not defining themselves as caregivers because they are just doing what is expected as a wife, daughter, etc. Many caregivers, but not all,

progress through the additional phases of the caregiver journey to the last phase, “placement in long-term care.” Even after this stage is reached, caregivers still have a lot of work to do. You never stop being a caregiver.

## 2. Volunteers

i) HEART Program, Enderlin, N.D. – “Helping Enderlin Area Residents Thrive” since 2003, this program has been providing free and confidential volunteer services to people age 65 and older who are living in the Enderlin/Sheldon area. Staff arrange for services; meet with older adults, families and caregivers to evaluate the situation; and make plans to help elders stay in the home.

Website: [www.enderlinheartprogram.org/](http://www.enderlinheartprogram.org/)

ii) Faith in Action Health Coalition, Cavalier, N.D. - This program provides trained volunteers who offer holistic health-care services for people of all ages who live in rural and underserved areas of Pembina County. This program has received county support through a senior mill levy to help supplement its budget.

iii) Community of Care Volunteer Program – This volunteer program was established in 2004 and serves rural Cass County. In 2013, 47 local volunteers provided 670 hours of transportation services and drove 13,200 miles to medical appointments. Many other services are provided to help people remain independent in their homes.

Website: [www.communityofcarend.com/volunteerp.php](http://www.communityofcarend.com/volunteerp.php)

iv) Volunteer Caregivers for the Elderly, Bismarck, N.D. – For more than 17 years, this program has been providing whatever the elderly need to stay safely in their home from a non-medical perspective. It has 90 volunteers who provide a range of volunteer services, but transportation for medical appointments and grocery shopping

are the most frequently requested services. The program has a relationship with University of Mary, with 14 nursing students completing a seven-week rotation with this program each summer. The director shared how this partnership has been a great experience for all involved and has given the students a wonderful real-life opportunity to learn about the challenges of older adults.

- v) Faith in Action Health Coalition, Harvey, N.D. - This central North Dakota interfaith network of volunteers provides care that promotes interdependence for its rural residents, including transportation, companionship and assistance with household tasks.
- vi) Faith in Action of Carrington Health Center, Carrington, N.D.

### 3. Community-based Organizations

- i) Community of Care – It began in 2003 as a pilot project of the Evangelical Lutheran Good Samaritan Society and became an independent 501(c)3 organization in 2008. It provides a one-stop service center, volunteer program, faith community nurse program, and health and education. In 2009, the North Dakota Legislature approved an appropriation of \$120,000, and this appropriation continued at this level through the last legislative session. Community of Care recently was awarded the 2014 Bush Prize Winner for Community Innovation.

Website: [www.communityofcarend.com/](http://www.communityofcarend.com/)

- ii) HeartSprings Community Healing Center, Fargo – This community healing center provides health, hope and healing for people dealing with stress and chronic disease (Parkinson's, MS, Alzheimer's), stress, cancer, mental health, PTSD, etc. Services

offered include support groups, therapeutic exercise and complementary medicine.

Website: [www.heartspringscenter.com/Pages/default.aspx](http://www.heartspringscenter.com/Pages/default.aspx)

#### 4. Faith-based Organizations

- i) Support Groups – North Dakota has many support groups, but most are disease-specific. It also has a few general caregiver support groups, such as Community of Care in Casselton and Messiah Lutheran Church in Fargo.
- ii) Faith Community Nurses – An official list of faith community nurses in the state has not been compiled. As of 2014, Concordia College in Moorhead had trained more than 7,000 nurses. The Faith Community Nursing and Health Ministry Division of Sanford Health Fargo does keep a directory of churches and agencies in the Fargo region that have at least one faith community nurse. Faith community nurses provide a valuable service to older adults and their family members.
- iii) Adult Day Care/Respite – First Lutheran Church, Fargo, has started a program, *The Gathering*, designed to support, educate and equip caregivers with skills and tools to best care for their loved ones. Respite care is provided onsite to care recipients while the program is being delivered for family caregivers.

#### 5. Education/Information

- i) AARP ND – In addition to statewide educational workshops offered on a variety of topics important to older adults and their family members, AARP has a comprehensive *Caregiving Resource Center* on its website: [www.aarp.org/home-family/caregiving/](http://www.aarp.org/home-family/caregiving/)
- ii) NDSU Extension Service – The *Powerful Tools for Caregivers Program* (PTC) is a national evidence-based program that was implemented by the Extension

Service two years ago. Fourteen Extension and community educators from across the state have completed training to be class leaders for the PTC program. During the course of six weeks, family caregivers learn about tools needed to take care of themselves as they care for an older adult. Caregivers learn how to reduce stress, improve self-confidence, better communicate their feelings, balance their lives, increase their ability to make tough decisions and locate helpful resources. Early evaluation results indicate significant improvement in participants' knowledge, confidence, ability and behavior change they needed to be more comfortable with their role as caregiver. We are excited about our collaboration with the Family Caregiver Support Program, which not only is referring clients, but also helping caregivers with the costs of registration and respite care for their loved ones while they attend the weekly workshops.

Website: <https://www.ag.ndsu.edu/aging/family-caregivers>

- iii) Alzheimer's Association of Minnesota/North Dakota – The Association provides a series of community educational workshops on dementia, in addition to the Dementia Care Program. The NDSU Extension Service will begin partnering with the association to co-teach curriculum in an effort to extend the reach to additional community members. Website: [www.alz.org/mnnd/](http://www.alz.org/mnnd/)
- iv) Disease-specific Organizations: Alzheimer's Association of Minnesota/North Dakota; American Heart Association (Jamestown office), Marv Bossart Foundation for Parkinson's Support, National Parkinson Foundation, Upper Midwest Chapter-National Multiple Sclerosis Society, American Cancer Society, Minnesota/North Dakota/South Dakota Chapter – ALS Association

- v) Directories: Cass/Clay Resource Directory for Elder Services and Senior Adult Services, Bismarck-Mandan Community
- vi) Numerous caregiver resources (websites and other online resources), while helpful, are often overwhelming in their content and presentation, difficult to navigate, filled with technical language and written from the providers' rather than the caregivers' perspective.

#### 6. Geriatric Care Management

- i) Aging Life Care Management – Lutheran Social Services of North Dakota just launched a program focused on long-term care planning, support and solutions to improve quality of life for the aging adult and to lessen the load on the primary caregivers. The program director is in Fargo.
- ii) Dignity Care – This is another new service in the Fargo/Moorhead area that empowers those affected by dementia through quality of life assessments and highly personalized caregiving strategies.
- iii) Community of Care – Through its one-stop service center, a licensed social workers helps older adults and their family members obtain the information, support and services they need to live safely in their homes.
- iv) Dementia Care Program – In 2009, the North Dakota Legislature passed the Dementia Care Services bill to provide resources, assistance and support for people of North Dakota. The Alzheimer's Association of Minnesota/North Dakota was awarded the contract to do this work. While this is a publicly funded program, what is important to note is that evaluation results indicate the program is having positive impacts on people with dementia and their caregivers, including

enhanced support for caregivers and fewer plans for placing people with dementia in nursing homes.

- v) Northland Care Coordination for Seniors – As part of the Northland Healthcare Alliance, nine care coordinators are providing services in the areas of Bismarck/Mandan, Dickinson, Bowman, Ellendale, Beulah/Hazen, Garrison and Linton/Emmons County. This new program is evolving and is providing services at no charge to individuals age 55 and older who are enrolled in Medicare. It recently became a Medicaid-approved provider under the Health Management Program, which means Northland can provide services to individuals of all ages who qualify for services. Future plans include implementing a per member/month private-pay fee.
- vi) North Dakota has several individuals with nursing, social work or gerontology educational backgrounds who offer care management services.

## 7. Services

- i) Adult Day Care/Respite – This is described as day or relief overnight care for older adults needing supervision. Approximately 25 facilities/organizations are listed with Aging & Disability Resource - LINK as providing this service.
- ii) Home Care
  - a. Mom’s Meals NourishCare – Located in Ankeny, Iowa, this organization provides nutritious home-delivered meals that are delivered by FedEx.
  - b. Easter Seals Goodwill of North Dakota Inc. – This organization offers a variety of services on behalf of elderly individuals and people with disabilities, including an equipment loan program, respite care, advocacy,

supportive home care, family support services, individualized supportive living arrangements and services for the elderly.

- c. Equipment – HERO, VFW (wheelchairs), HealthCare Accessories
- d. Transportation – In addition to the volunteer transportation services provided, metro transit and taxi services are offered in the larger cities. Transit options in rural areas are extremely limited.
- e. Personal Care Services – Non-medical services
  - i. Agencies: A number of private agencies provide services such as bathing, dressing, housekeeping, cooking and companionship. Examples: Tami’s Angels, Spectrum, Griswold Home Care, Comfort Keepers.
  - ii. Qualified Service Providers – In-home provider list on DHS website or privately arranged by family
- f. Home Health Agencies/Hospice/LTC facilities/Hospitals – A directory of these licensed facilities is maintained by the North Dakota Department of Health. Many health-care providers, such as nursing homes, have expanded their services to offer a broader continuum of care in their community. But North Dakota still has pockets in which some of these services are not available.

North Dakota is fortunate to have caring communities and a variety of resources to help older adults and the family caregivers. However, what is important to note is that where you live makes a big difference in your ability to access these resources. If you live in a metro

area, a broader array of resources is available to family caregivers to draw upon when needed.

Many rural residents experience special challenges in accessing resources, such as transportation, health care and housing, which are essential to aging in place. In some small towns, even the basic services, such as a café, grocery store or post office, are not available. Those older adult residents who remain in communities with a declining population often are forced to move to a different community or simply “go without.” Future discussions about family caregiving should include the accessibility of resources in rural areas.

So, more generally, what is needed for North Dakota to help family caregivers? I will offer my personal perspective on a few issues:

1. Awareness/Education – Caregivers are hard to reach. Some don’t identify themselves as caregivers. Others struggle with accepting help from anyone. And, there are those caregivers who are overwhelmed and “hanging on by a thread,” and don’t have the energy or time to reach out for help. Having all of the public and private agencies that share the goal of helping family caregivers work together to develop a statewide outreach campaign would be beneficial. The campaign could help family caregivers self-identify, and recognize the need for assistance and how to locate it to provide more effective care while protecting their own health and well-being. The campaign also should emphasize how individuals, communities, employers and faith communities can best offer support to family caregivers. Leadership for this coordinated effort would be essential.
2. Caregiver Coaching and Support – Research has found the biggest stress for caregivers is their lack of confidence in what they are doing. They may be asking themselves these types of questions: Is my family member safe at home? How do I hire in-home care?

How can I learn and remember technical procedures, such as handling IVs and catheters?

How can I best share information with family living at a distance? How can I prevent/manage decline? How can I organize complex duties? Often caregivers are unprepared for transition points and have not anticipated what is coming. They also have not researched or understood options needed to make informed decisions. Also, most caregivers receive little or no training to care for themselves. Research has shown that caregivers who are supported throughout their caregiving journey are more likely to provide high-quality, safe care to their loved one, resulting in an improved quality of life for both. Ongoing support and education from health-care and caregiving professionals will help equip family caregivers with the skills necessary to care for their loved ones.

3. Workforce – North Dakota has a significant need to expand the availability of trained workers who can provide personal care, home care and home health care. Without the stability of adequately trained and available staff, many caregivers will not be able to keep their loved ones at home.
4. Research – I also see a need for more evidence-based programming to help caregivers. What programs/service models are providing effective outcomes? What programs/services models are saving money? One area of research that is receiving more attention is technology. Data support the increased use of technology among seniors, such as the use of smartphones, social media and the Internet. The University of Wisconsin-Madison School of Nursing is developing a Web-based tool and app to assist family members providing help to older adults. The project, *eCARE*, is aimed at creating practical tools and supports, and leveraging existing ones, to help caregivers and older adults better prepare and successfully navigate these challenges. *eCare*'s focus is on

complex transitions for the older adults and caregivers, with an emphasis on anticipatory planning, and its use of technology to provide personalized information and support. The NDSU Extension Service has been contacted to potentially pilot this new tool in the state.

In conclusion, last month's 2015 White House Conference on Aging convened thousands of people across the country to draw attention to issues facing Americans as they age.

Conference participants called for, among many things, enhanced caregiver support and training, improvements in technology-enabled care, improvements in the direct-care workforce shortage, and encouragement of public-private solutions to the financing and delivery of care. I believe we have the opportunity to move in this direction in North Dakota by promoting and enhancing what we already have in place and by collaborating on shared goals that will help our family caregivers. Thank you for your time and effort in studying this important issue.