North Dakota Family Caregiver Supports and Services Study

FINAL REPORT

May 10, 2016

NDSU NORTH DAKOTA STATE UNIVERSITY

Acknowledgments

This study was solicited and funded by the North Dakota Legislative Management. As provided in Section 1 of 2015 House Bill No. 1279, the study was to develop a resource directory of services available to support family caregivers, to identify unmet needs, and prepare recommendations for legislative or administrative consideration. The study required input from stakeholders, including representatives of hospitals, social and clinical providers, advocacy organizations, veterans' organizations, tribal governments, state and local agencies and institutions, and caregivers in the state.

We would like to thank the following individuals for their assistance with this project:
Sheryl Pfliger and Mary Weltz, Aging Services; Kristen Hasbargen, Association of County Social Service Directors; Josh Askvig, AARP of ND; Anuchida Scholz, NDSU Graduate Student, and Deborah Tanner, NDSU Ag Communications.

In addition, we want to express our gratitude to the County Social Service staff who shared their expertise about local family caregiver resources and to the many stakeholders who were willing to share their perspective and insights with us. It is our hope this study will uncover ways in which we can better serve family caregivers.

North Dakota State University Authors:

Jane Strommen, Ph.D., Extension Gerontology Specialist (jane.strommen@ndsu.edu)
Heather Fuller, Ph.D. Assistant Professor (heather.fuller@ndsu.edu)
Greg Sanders, Ph.D., Professor (greg.sanders@ndsu.edu)
Dustin Elliott, M.S., Graduate Assistant
Kia Callahan, B.S., Graduate Assistant
Erica Raguse, B.S., Graduate Assistant

NDSU HUMAN DEVELOPMENT AND FAMILY SCIENCE

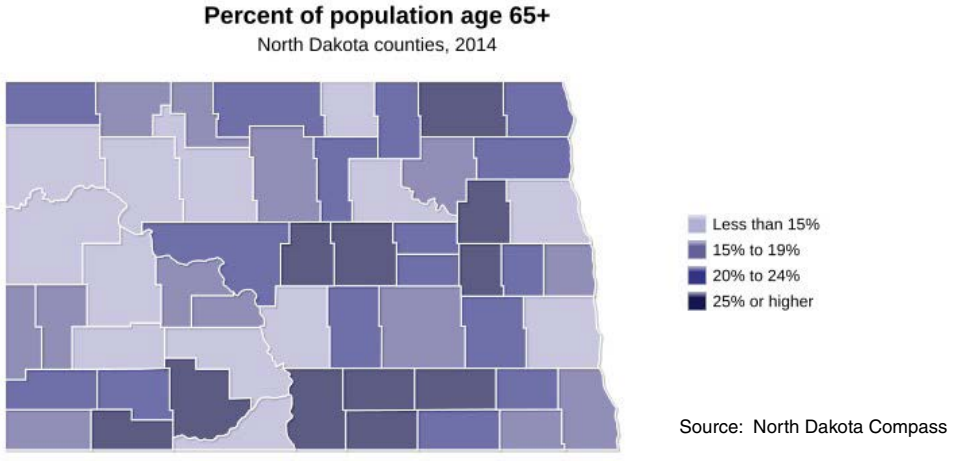
NDSU EXTENSION SERVICE

Table of Contents

Executive Summary

Introduction

Between 2011 and 2025, the number of adults ages 65 and older in North Dakota is expected to grow by 50 percent. That means there will be about 50,000 more people aged 65+ by 2025. In 2011, 14.4 percent of North Dakota's population was ages 65 and older and they are expected to be 18 percent of the state's population by 2025.



Source: North Dakota Compass

The U.S. Census Bureau estimated North Dakota to have 17,680 individuals age 85 and older in 2013. This makes up approximately 2.5 percent of the state's total population and puts North Dakota in 7th place in the country for having the oldest residents. Health issues are a common concern for this age group, with the majority indicating difficulties with dressing, vision, hearing loss, memory recall, and going outside of their residences. Between 2010 and 2040, the number of adults 85 years and older in North Dakota is expected to grow by 43 percent, an increase of about 7,200 people. (*Growing ND by the Numbers,* North Dakota Census Office, 2014)

Levels and types of disability are important for planning services and understanding the scope of caregiving needs in North Dakota. In 2014, more than one in three (34 percent) adults ages 65 and older had one or more disabilities (34 percent). The disability rates among American Indian older adults are higher than for white older adults in the state (53 percent compared to 34 percent; 2010-2014).

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. Family caregivers provide a range of daily activities, such as transportation, personal care, managing finances grocery shopping and much more. Finding ways to support North Dakota's family caregivers and bridge the gaps where they may be struggling, is the focus of the current report.

Executive Summary

Between January and May, 2016, North Dakota State University was contracted by the North Dakota State Legislative Human Services Committee to conduct the study "Identifying Gaps in Family Caregiver Supports and Services in North Dakota". A team of faculty researchers and graduate students conducted the study that focused on the following five aims:

Aim 1. Identify current public and private resources, services, and supports for family caregivers, both public and private, and by region and/or county.

Aim 2. Identify barriers and challenges family caregivers experience, which includes the need for training, respite care services, medical leave policies, and delegation of tasks to family members and nonmedical aides.

Aim 3. Identify best practice models for family caregiver support programs from other states.

Aim 4. Identify emerging practices and technology that can enhance caregiver and patient home supports.

Aim 5. Provide recommendations to the interim committee.

A brief summary of the major findings for each aim is provided next. For a comprehensive overview of the methodology and findings for each aim, see the appropriate full chapter.

Aim 1. Current Resources for Family Caregivers in ND

We inventoried and **created a database of family caregiver resources, services, and supports** across the eight geographic regions of North Dakota. The categories of services and resources identified cover areas of support related to: managing the logistics of caregiving, direct support in providing care, improving caregiver's ability to provide care, and fostering the wellbeing of the caregiver. Maps were created for each category to identify availability of services across the state, and are presented in the body of the report.

Categories of Family Caregiver Resources, Services, and Supports

Managing Caregiving Logistics	Direct Support in Providing Care	Improving Caregivers' Ability to Provide Care	Fostering Caregivers' Wellbeing
Advocacy Services	Adult Day Care	Meal Services	Emotional Support
Assistive Technology & Equipment	Dementia Care	Training & Education	Respite
Care Management	Home Health Care	Transportation	Key:
Information & Referral	Homemaker / Chore	Volunteer Services	Evenly Represented
	Hospice		Rural / Urban Divide
	Personal Care		

Within these categories, **further examination is required** to fully identify gaps in service related to:

- **Availability** (Are services available across the designated region / county?)
- **Accessibility** (Does the travel distance to the service create a barrier?)
- **Appropriateness** (Do services address actual needs?)
- **Affordability** (Can families afford to pay for available services?)
- **Awareness** (Do families and communities know about these services?)

Each of these factors present challenges and need to be addressed if the service needs of family caregivers are to be met.

Aim 2. Barriers and Challenges of Family Caregiving

Caregivers' Perspective (based on data from 398 family caregivers across ND from 2014-2016):

North Dakota Family Caregivers are likely to be:

- Women
- Older adults
- Spouses (followed by children)
- Working full or part-time

Caregiving Tasks

- Shopping, transportation, & chores most common tasks
- 80% provide nursing cares, yet 50% report receiving no training
- 50% report insufficient respite from caregiving

Common benefits of caregiving:

- Satisfaction of giving back
- Helping maintain independence
- Love and appreciation

Common challenges of caregiving:

- Lack of sufficient respite
- Need help finding available services and resources
- Lack of knowledge and training about providing care
- Caregiver stress and burden
- Financial burden

Stakeholders' Perspective (based on data from 116 stakeholders across ND in 2016):

Represented service sectors:

- Healthcare
- Long-term care
- Social services
- Aging services
- Community-based organizations
- State & local government
- Advocacy agencies
- Faith-based organizations
- Veteran's organizations
- Tribal agencies

Common challenges/unmet needs of families and service organizations

- Financial costs
- Lack of available services
- Finding and navigating services
- Lack of support
- Respite
- Lack of training
- Rurality

Stakeholder recommendations

- Improve funding
- Increase education and training
- Foster outreach and awareness
- Increase respite care
- Increase overall services available

Veterans' groups: have special needs related to coordinated services with the VA, particularly challenging in rural ND

American Indian Tribes: coordinating services between Tribal and state programs is a challenge. Support to family caregivers should be provided in a culturally sensitive way.

Aim 3. Best Practices for Family Caregiver Support Programs

BEST	
Availability of Help / Support	• Telephone-based psycho-educational interventions • Virtual care • Community nurses
Financial cost of care / Funding	• Sliding scales and vouchers • Increasing access to paid family medical leave • Long-term care planning
Knowledge and ability to provide needed cares	• Interactive training (e.g. role playing) • Comprehensive discharge planning • Long-term education programming • Preventative care
Respite / Well-being of Caregiver	• In-home care • Health education programs

Aim 4. Emerging Practices and Technology to Enhance Caregiver Supports

EMERGING	
Availability of Help / Support	• Person-centered care (i.e., Money Follows the Person) • Mobile adult day care (i.e., especially in rural areas) • Working with college students • Technology (i.e., smart-homes, robotic applications, etc.) • Socially Assistive Robots • Smart Wear
Financial cost of care / Funding	• Telemedicine reduced hospitalization • Co-op models • Tax credits for caregiving
Knowledge and ability to provide needed cares	• Home visits upon discharge • Virtual learning modules in hospital waiting rooms • Use social media to increase awareness • Trainings for employers about eldercare • Mobile apps for long distance care
Respite / Well-being of Caregiver	• Online emotional support groups • Employ Behavioral Risk Factor Surveillance System's (BRFSS) caregiver module to detect caregiver burden

A series of examples of both best and emerging practices are discussed in the body of the report. Additionally, challenges related to implementing these new practices are discussed.

CHALLENGES	
Logistics and Implementation	**Limitations and Caveats**
• Balancing the needs of care recipient and caregiver • Increasing costs • Staffing shortage • Rurality	• Budget Cuts • Lack of flexibility in federal programs (i.e. Medicare) • Lack time to learn and implement technologies

Aim 5. Conclusions and Recommendations

The primary goal of family caregiving is to help older adults to maintain their independence and well-being. This study concludes that, even though family caregiving is rewarding, North Dakota family caregivers are vulnerable due to lack of support.

Key Study Conclusions and Ensuing Recommendations

Conclusions	Recommendations
The high costs of care and lack of funding for services to support caregiving prove enormously challenging for North Dakota caregivers.	**Improve avenues for sustainable funding for family caregivers and programs that support them**
Both caregivers and stakeholders clearly indicated that insufficient access to respite care is one of the most salient gaps in the services provided to North Dakota family caregivers.	**Increase access to respite care across the state**
Caregivers reported difficulty finding, connecting to, and navigating available services and resources.	**Improve outreach (i.e., marketing) and resources (i.e., technology) to help family caregivers find, connect to, and navigate available services**
Family caregivers lacked training related to the logistics and management of caregiving, including the provision of support in activities of daily living.	**Create programs and policies to foster an increase in the training and education of both informal and professional caregivers**
Both caregivers and stakeholders reported the challenge of lack of available and appropriate services especially in rural regions.	**Close the gaps in caregiver support services in rural areas**

Overarching Recommendations

Several overarching recommendations cut across the various conclusions:

- Develop family caregiving taskforce consisting of caregivers, service providers, and community leaders to create recommendations to address the service gaps identified in this study.
- Explore ways to lift restrictive eligibility criteria and cut the red tape, or expand funding opportunities to include those not currently financially eligible.
- Increase service availability for respite care, care management, training and education, emotional support, volunteer programs and a range of direct care supports (adult day care, homemaker/chore, dementia care, and personal care).
- Improve resources to address caregiver well-being (including preventative, screening, and intervention care).

Aim 1: Current System of Supports for Family Caregivers

Aim 1: Current Resources for Family Caregivers in ND

Aim 1. Identify current resources, services, and supports for family caregivers, both public and private, and by region and/or county.

Objective: Create database of current systems for caregiving in North Dakota. Systems to include: a) informal community supports (e.g., non-profits), b) private community supports (e.g., for profit), c) Governmental supports (e.g., public funded). Categories covered will include information/referral, education, advocacy, respite care, case management, direct service provision, etc.

Part A: Procedure

Part B. Statewide Family Caregiving Resources, Services, and Supports

Part C. Summary of Aim 1 Highlights

Part A. Procedure

The first task of this aim was to determine the categories of services and resources most important to family caregivers of older adults. The NDSU team reviewed the relevant research literature and consulted with ND Aging Services and County Social Service staff to identify and consolidate these categories. After carefully determining nineteen pertinent categories of services, commonly agreed upon definitions were written (and reviewed by ND Aging Services and County Social Service staff members). These nineteen categories are presented in Table 1.1.

Table 1.1: Categories of Family Caregiver Resources, Services, and Supports

1. Adult Day Care
2. Advocacy Services
3. Assistive Technology & Equipment
4. Emotional Support
5. Caregiver Training and Education
6. Dementia Care
7. Care Management
8. Home-Delivered Meals / Congregate Meals
9. Home Health Agencies
10. Personal Care
11. Homemaker/Chore
12. Hospice/Bereavement
13. Information & Referral
14. Parish Nurse / Faith Community Nurse
15. Public Health Nurse / Health Maintenance
16. Respite
17. Transportation
18. Volunteer Services
19. Individual Qualified Service Providers – Personal Care

Utilizing publicly available resources, such as the North Dakota *Aging and Disability Resource LINK,* local and county elder resource directories, and provider websites, we compiled a list of caregiver services available by county in each of North Dakota's eight regions. We then sorted the available caregiver services/supports into the nineteen previously identified service categories. We developed a plan to verify which services were currently available and whether there were additional services we had overlooked. To do this, we enlisted the assistance of county professionals working with family caregivers because of their knowledge of local resources. After developing an online Qualtrics survey that listed the services we identified in each region, we asked County Social Service Directors (or their representative) in each North Dakota county to complete the online survey, verifying the services were available in their respective counties and also adding services that were not included.

Part B. Statewide Family Caregiving Resources, Services, and Supports

A final inventory of services by category was compiled to examine availability of services by county and region (Presented in Appendix A.). A summary of the regional availability of the 19 categories of services is presented next.

Adult Day Care

Definition: *Adult Day Care Centers are designed to provide care and companionship for older adults who need assistance or supervision during the day. Programs offer relief to family members and caregivers while knowing their relative is well cared for and safe.*

Twenty-two (42%) counties reported having adult day care services. Of these 22 counties, 38 separate adult day care services were identified, with 23 (60%) located in the eastern part of the state versus 15 in the western part. In general, adult day care was more likely to be available in more populated (i.e., urban) regions than less populated (i.e., rural) regions. Cass County had the highest number of adult day care services at 6, all located in Fargo. Adult day care services were primarily offered by basic care, assisted living, and skilled nursing facilities.

Because of the daily nature of adult day care, to make use of this type of service, a family caregiver generally needs to be geographically proximate to the adult day care site. Family caregivers who live farther than 30 minutes from an adult day care are not likely to use this type of support. From the data in this map, it is evident that there are not enough current adult day care services to meet the needs across the state.

Figure 1.1: Adult Day Care

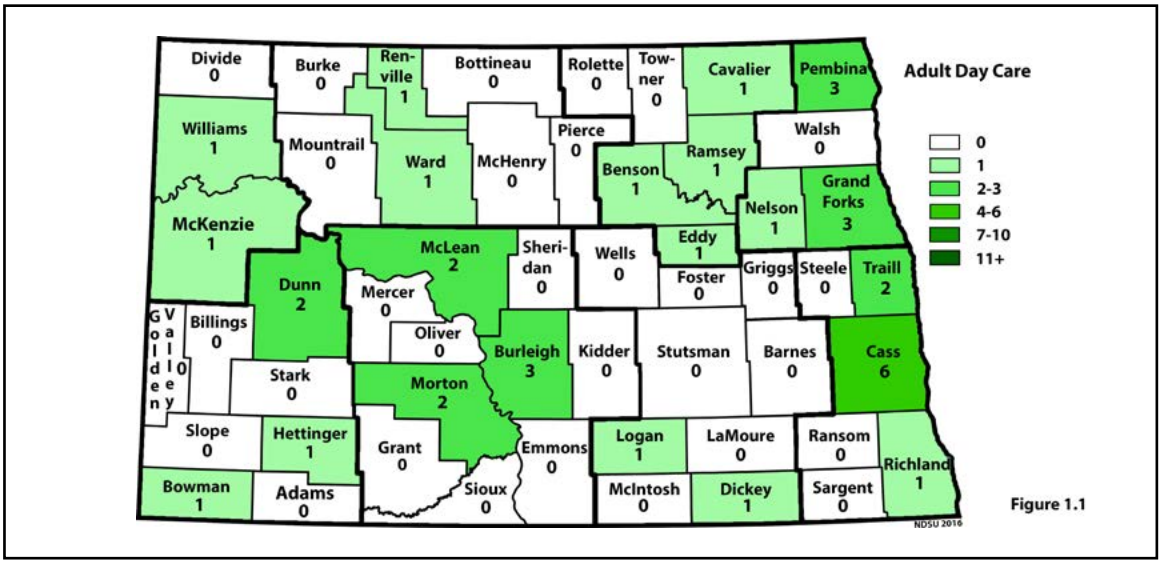


Figure 1.1

Advocacy Services

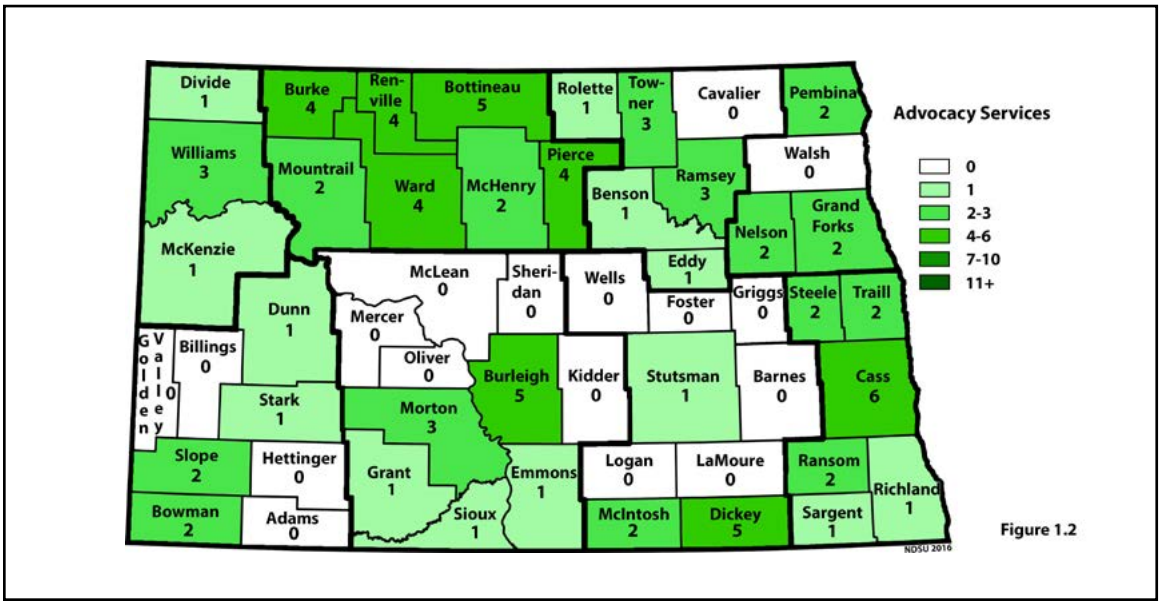
Definition: *Promotes the health, dignity, rights and quality of life of seniors by helping them select services for their needs and by protecting their rights and well-being.*

Thirty-six (68%) of the counties reported having one or more advocacy services available in their county. Of these counties, 13 indicated having 1 advocacy service, 14 indicated have 2-3 advocacy services, and 9 reported having 4-6 services. There was a range of advocacy services stated by respondents, which varied by region.

Some of the non-profit advocacy services described as available included the following: Aging Life Care Management (LSS), Easter Seals, Family Crisis Shelter, Spirit Lakes Victim Assistance, Community of Care, Services for Elder Refugees (LSS), Senior Citizen Centers, Senior Service Providers and a hospital. Public services offered were: Protections and Advocacy, Centers for Independent Living, Guardian and Protective Services, Adult Protective Services, Ombudsman, County Social Services, Veterans' Advocacy, Public Health, Family Caregiver Support Program and Money Follows the Person.

Advocacy services seem to be fairly well represented across the state, though there are some counties that report no advocacy services. The rural / urban divide is not as clearly evident in advocacy services. In particular, we note that north central region has a strong advocacy service representation, whereas several other regions lack full coverage.

Figure 1.2: Advocacy Services



Assistive Technology and Equipment

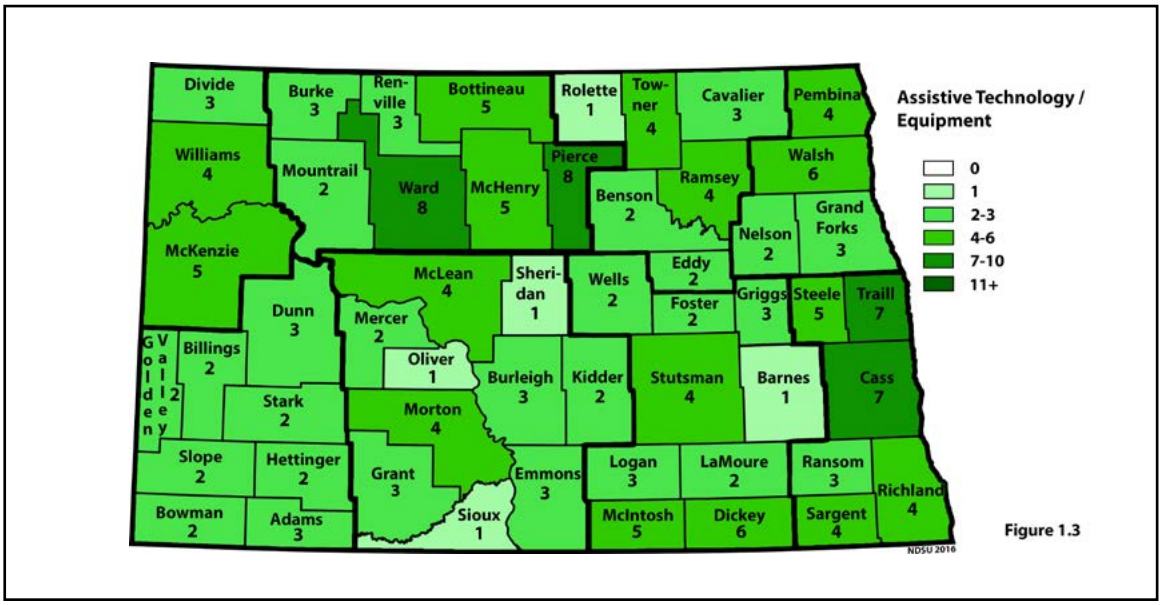
Definition: *An organization that provides help in selecting, locating and using assistive technology (assistive, adaptive, and rehabilitative devices for people with disabilities). Assistive technology promotes greater independence by enabling people to perform tasks that they were formerly unable to accomplish, or had great difficulty accomplishing, by providing enhancements to, or changing methods of interacting with, the technology needed to accomplish such tasks.*

All 53 counties reported having one or more assistive technology/equipment services available. Fifty-three percent (28 counties) indicated having 2-3 services available. Thirty percent (16 counties) indicated having 4-6 services available. Additionally, nine percent (5 counties) reported having one services available and eight percent (4 counties) reported having 7-8 services available.

Respondents listed a number of private entities providing home medical equipment and accessories. Non-profit organizations mentioned were: IPAT, Easter Seals, American Legion, HERO, North Dakota Association of the Disabled, Oakes Senior Center, Minot Commission on Aging and a hospital. Public entities included the following: Vocational Rehabilitation Services, Centers for Independent Living, Public Health, and ND School for the Deaf.

This service appears well represented across the state. Importantly, there are multiple programs that have region-wide or state-wide reach. However, it is unknown if these programs are able to fully meet the needs of family caregivers. Programs in this area need to stay up-to-date with the newest technologies/equipment, so it is important to maintain continued support of these programs.

Figure 1.3: Assistive Technology and Equipment



Emotional Support

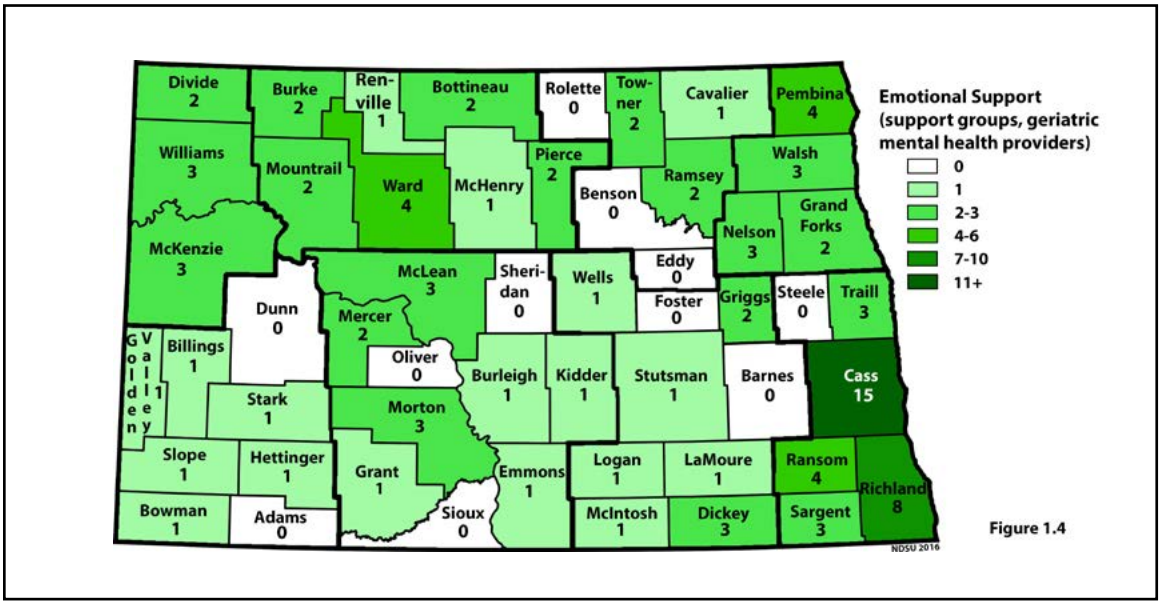
Definition: *Support groups and/or geriatric mental health providers that provide opportunities to learn coping strategies, to feel more empowered, and improve mental stability. Support groups provide the opportunity to share experience and develop a sense of community; Geriatric mental health providers target individualized emotional concerns.*

The map indicates the following level of emotional support services available: eleven counties (21%) have no services, 19 counties (36%) have one service, 18 counties (34%) have 2-3 services and 3 counties (5%) have 4-6 services, 1 county (2%) has 7-10 services and 1 county (2%) has 11+ services. Cass County reported having the highest number (15) of emotional support services available.

There were several publicly-funded entities providing emotional support, including: Family Caregiver Support Services, County Social Services, Centers for Independent Living, Regional Human Services Centers, and Veterans' Caregiver Support Services. Non-profit entities reported were as follows: Alzheimer's Association, First Link, Solutions, Lutheran Social Services, Catholic Family Services, HeartSprings Lost & Found Ministry, Community of Care, Mental Health Association, Multiple Sclerosis Society, and seven hospital and/or skilled nursing care facilities.

Given the impact of caregiving on stress levels and mental health, emotional supports to family caregivers are relevant. It is important to recognize the distinctions of and need for specialized services for caregivers as their emotional needs are unique. In rural areas it seems quite difficult to get this targeted emotional support.

Figure 1.4: Emotional Support



Caregiver Training and Education

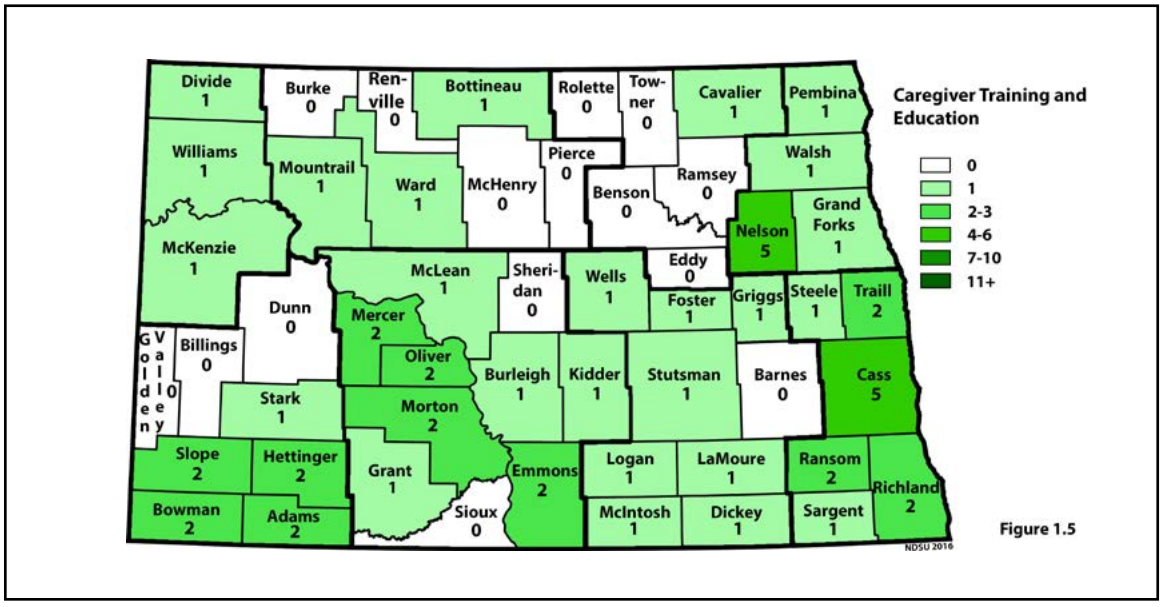
Definition: *Programs designed to educate informal caregivers on issues related to providing care such as safety, general care, nutrition, etc. Additionally, caregiver education programs may educate caregivers on issues related to coping and self-care.*

Caregiver training and education availability across the state is limited. Fifteen counties (28%) report no services available; twenty-five counties (47%) report one service as available; eleven counties (21%) state 2-3 services are available; and, two counties (4%) indicate 5 services are present.

The most frequently mentioned service was the Family Caregiver Support Program followed by the Alzheimer's Association and the NDSU Extension Powerful Tools for Caregivers Program.

This is an area of opportunity to broadly disseminate training and education through healthcare systems, organizations and other locations where family caregivers are frequently present. Online methods of training and education could potentially reach family caregivers in rural counties where services are unavailable or very limited as evidenced in the map.

Figure 1.5: Caregiver Training and Education



Dementia Care

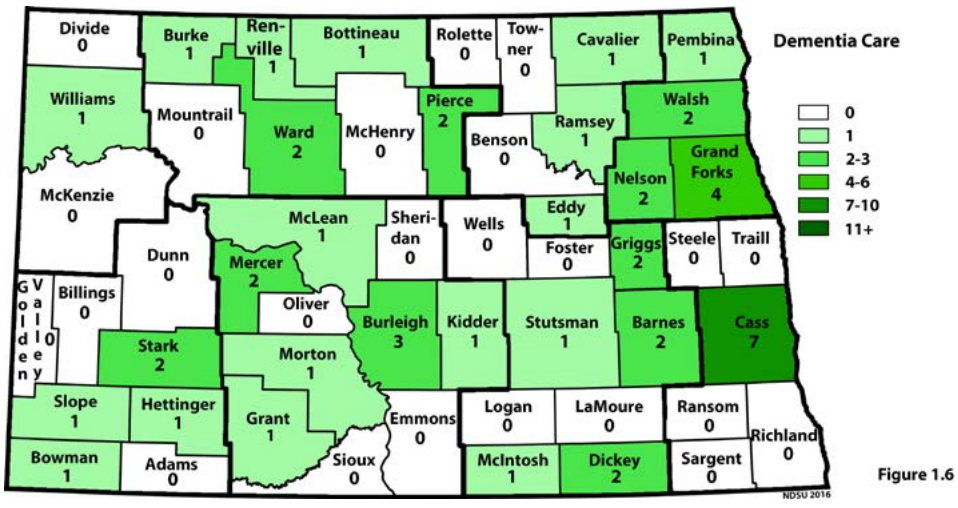
Definition: *Agencies that offer expert care for individuals with dementia. Services include catered memory care services, attention and medication management.*

Dementia care identified by respondents included two types of services. The first was an in-home service, the Dementia Care Program provided by the Alzheimer's Association Minnesota-North Dakota Chapter, and the second was special dementia care units provided by long term care facilities. These special care units were located primarily in metro areas.

Twenty-five counties (47%) reported no dementia care services available. Another sixteen counties (30%) reported only one service available. Ten counties (19%) indicated 2 to 3 as available, followed by one county reporting 4 to 6 services, and one county reporting 7 services as available.

This type of care is the most intensive and resources/supports need to be provided in-person. This map suggests that half of the state is at great risk in terms of caregiver stress/burden and care recipient safety.

Figure 1.6: Dementia Care



Care Management

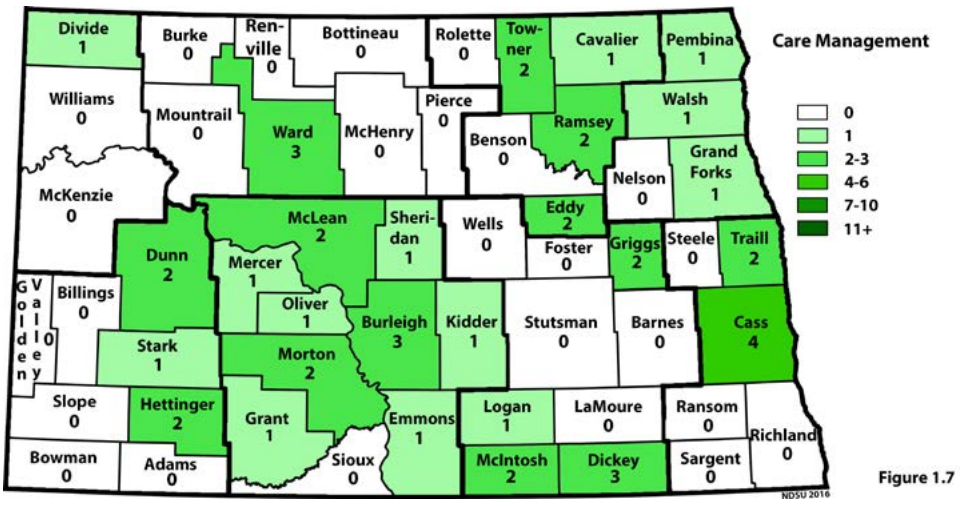
Definition: *Services aimed at planning and coordinating the care of older adults with physical and/or mental impairments in order to meet their long term care needs, improve their quality of life, and maintain their independence for as long as possible.*

Care management services were also very limited across the state with twenty-six counties (49%) reporting no services available, fourteen counties (26%) reporting one service available, twelve counties (23%) reporting 2 to 3 services as available and one county (2%) reporting 4 services as available.

The most frequently mentioned care management service was provided by county social service departments, followed by a variety of providers, such as Northland PACE, Northland Care Coordination, Aging Life Care Management, Family Caregiver Support Program, Dignity Care, Community of Care, and Senior Service Providers.

This type of service does not need to be provided on a daily basis, and thus can be received from more of a distance. However, it is helpful for the care managers to be within the community so that they are aware of the institutions, programs and resources that need to be managed. Moreover, it does not seem there are enough current resources to cover the need across the state even if these services can be provided at a distance.

Figure 1.7: Care Management



Home-Delivered Meals/Congregate Meals

Definition: *Programs that address dietary inadequacy and/or social isolation among older adults either via in-home meal delivery or on-site group dining. Additionally, may provide nutrition education, nutrition risk screening and, nutrition counseling.*

All counties indicated having one or more home-delivered and congregate meal service available. However, it is less useful to analyze number of services by counties to determine availability of service because of reporting variance across regions and counties. Home-delivered and congregation meals are funded under the Older American Act and administered by the Department of Human Services, Aging Services Division. The Aging Services Division contracts with local entities to provide these nutrition programs. Local entities or contractors can provide these programs at multiple sites, such as local senior centers, in a county or a multi-county region. Some respondents listed the local contractor while others listed each site or community where the meals were served or delivered. In addition to the Older American Act nutrition programs, several other nutrition options were listed, such as Mom's Meals, SNAP, Community Action Agencies, food banks, hospitals and long term care facilities.

The ability of both family caregivers and care recipients to receive home-delivered meals can reduce the stress of caregiving and address their nutritional needs. In Feeding Grandpa: A 2015 Legislative Report, it states North Dakota had 215 meal sites and served 13,644 congregate clients and 5,215 home-delivered meal clients. Over 70% of these clients were from rural areas. It may be more beneficial to track these utilization numbers over time and to survey the North Dakota Senior Service Providers to better understand the challenges and barriers to reaching and serving older adults and their caregivers.

Figure 1.8: Home-Delivered Meals/Congregate Meals

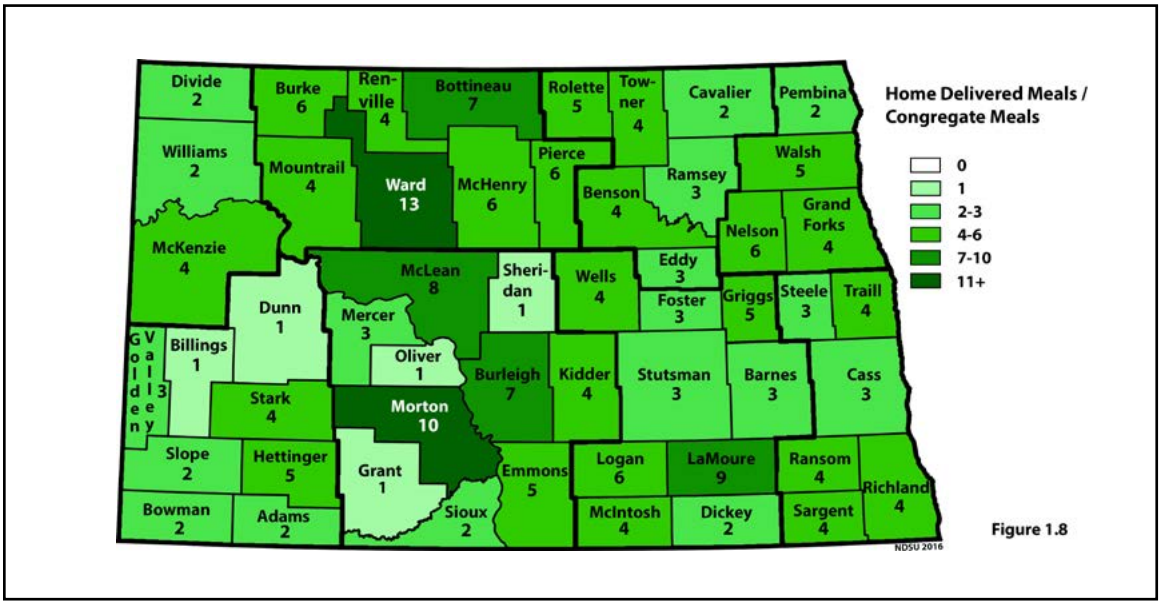


Figure 1.8

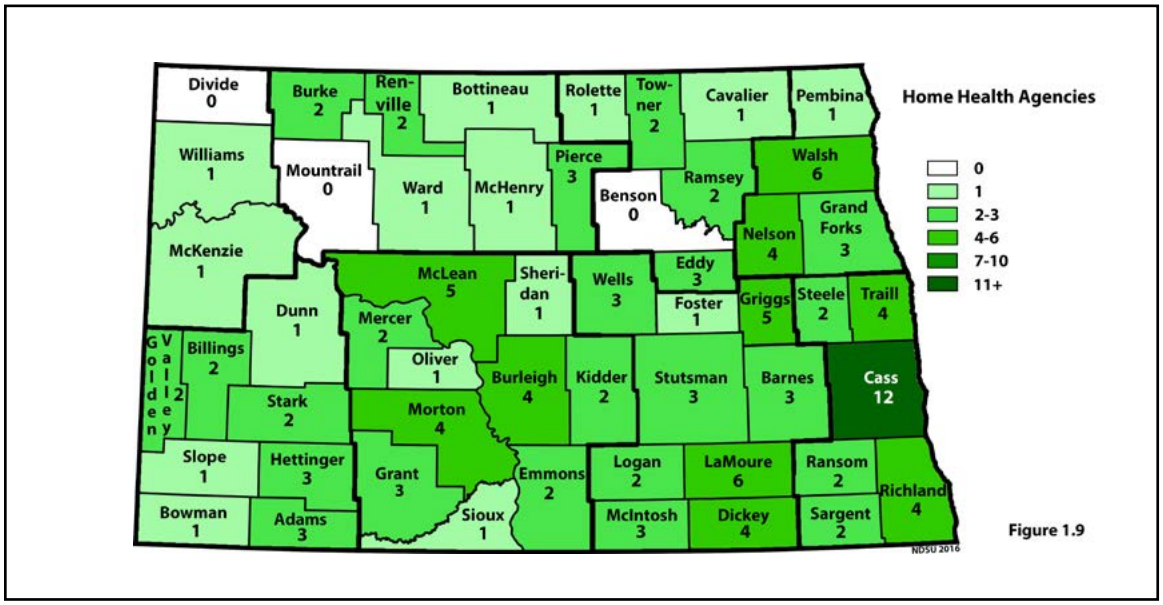
Home Health Agencies

Definition: *Works with older adults in their homes on a long-term basis to provide a wide array of medical services including (wound care, nutrition therapy, medication management, etc.) in order to help them regain their physical independence and/or stay at home for longer.*

While three counties reported no home health services offered, fifteen counties (28%) indicated having one home health service. Another twenty-five counties (47%) conveyed having 2 to 3 services available and nine counties reported 4 to 6 services. Cass County had the highest number of home health services at 12.

Home health care agencies seem to be well represented across the state. However, this map does not speak to staffing of those agencies. Moreover, as home healthcare can be a daily need, within remote areas it may be very difficult for these few agencies to meet the needs of families given extended driving times.

Figure 1.9: Home Health Agencies



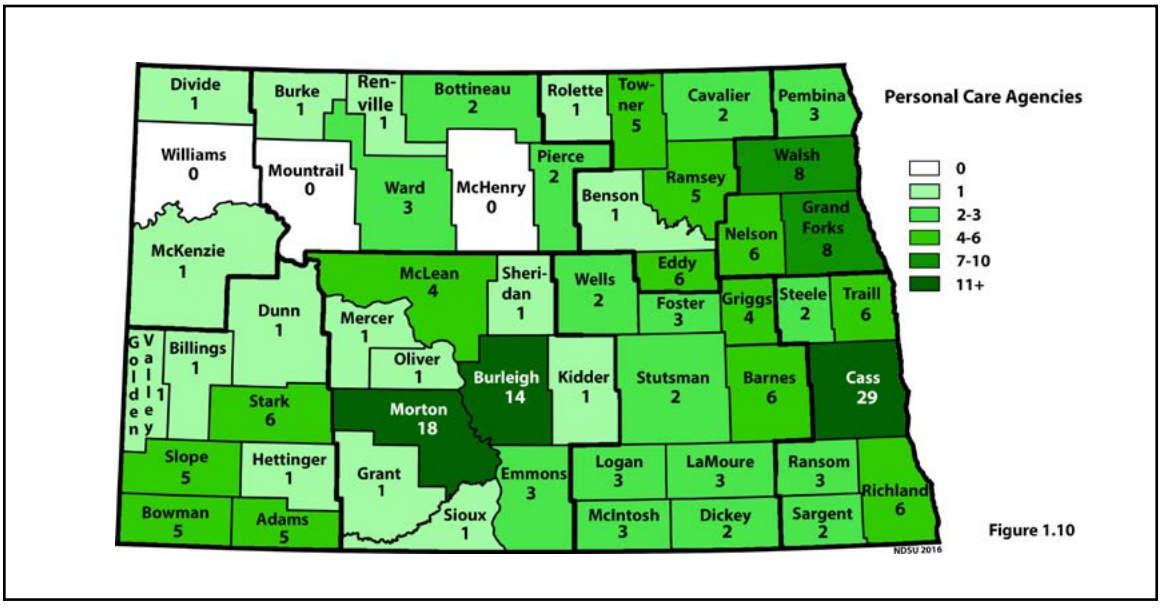
Personal Care Agencies

Definition: *Provide assistance to an individual with carrying out activities of daily living (e.g., bathing, grooming, toileting, preparing meals, laundry and errands) directly related to the individual's personal care needs.*

Three counties (6%), located in the northwest and north central areas of the state, reported having no personal care services. Another sixteen counties (30%) had only one personal care service listed, usually described as county social services or Easter Seals. These counties were primarily located in western North Dakota. Sixteen counties stated 2 to 3 services were available; twelve counties (22%) conveyed that 4 to 6 services were available; and three counties (6%) had 7 to 10 services. Three counties (Cass, Morton, and Burleigh) reported having 11+ services. This category of service had a wide range of service availability with two-thirds of the counties having 3 or fewer services.

The availability of personal care agencies is greater in urban versus rural areas. There is a clear need for additional personal care services in counties where county social services is the only provider. In these cases, the county social service agencies hire direct care professionals to provide services to their eligible clients. Local county social service agencies can determine if their staff members are available to private pay clients in the community. Again, the availability of services does not mean caregivers can get the services to meet their specific needs.

Figure 1.10: Personal Care Agencies



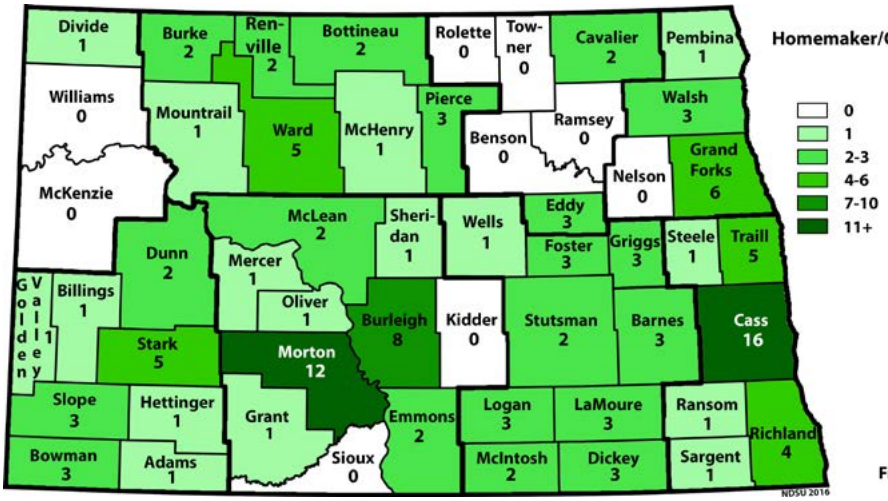
Homemaker/Chore

Definition: *Provide assistance with non-personal care tasks such as housekeeping, laundry, shopping, minor home maintenance, minor home repair, select installation, and walk maintenance.*

Ten counties (19%) reported no homemaker/chore services offered in their county. Another fifteen counties (28%) indicated only one homemaker/chore service available, and in most of these cases, the provider was listed as county social services. Twenty counties (38%) reported having 2 to 3 services available; five counties reported 4 to 6 services; one county reported 7 to 10 services; and two counties showed 11+ homemaker/chore service providers. The counties with the highest number of homemaker/chore providers were Cass, Morton and Burleigh.

This is a service that people may need to rely on if informal help (family, neighbors, or volunteers) is not available. Thus, a lack of professional services can increase caregiver stress/burden. The map indicates a great need for homemaker/chore services in rural areas.

Figure 1.11: Homemaker/Chore



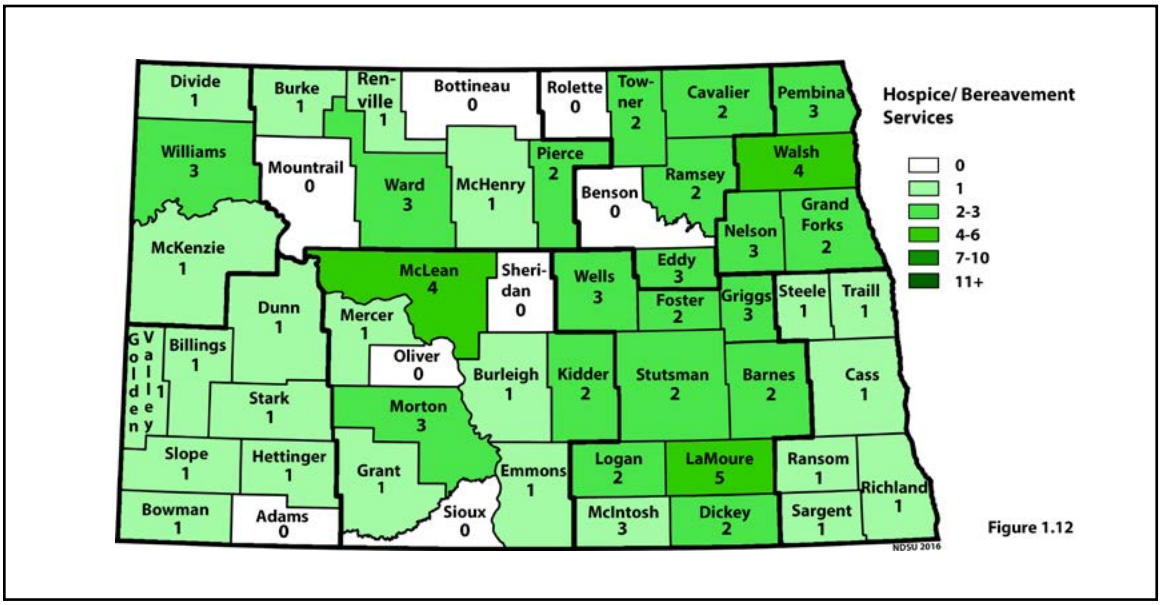
Hospice/Bereavement

Definition: *A type of care and philosophy of care that focuses on providing relief from the symptoms, pain, physical stress, and mental stress of a chronically ill, terminally ill or seriously ill patient. A primary goal of hospice is to provide support for the entire family, including anticipatory grief support for caregivers.*

Respondents listed both licensed hospice agencies serving their county and hospital and long-term care facilities that offer hospice services to their residents. Results showed eight counties (15%) not having hospice/bereavement services available with the majority of these counties located in the western part of the state. Twenty-two counties (42%) indicated at least one hospice service was available; twenty counties (38%) indicated 2 to 3 hospice services were available; and three counties (5%) showed 4 to 6 services available.

Older adults and their families generally prefer for the dying process to happen at home, rather than in a hospital or long-term care facility. This is important to consider when assessing the adequacy of coverage of hospice services, particularly in remote areas and rural regions where hospitals and long-term care facilities may be unable to provide hospice care.

Figure 1.12: Hospice/Bereavement



Information & Referral

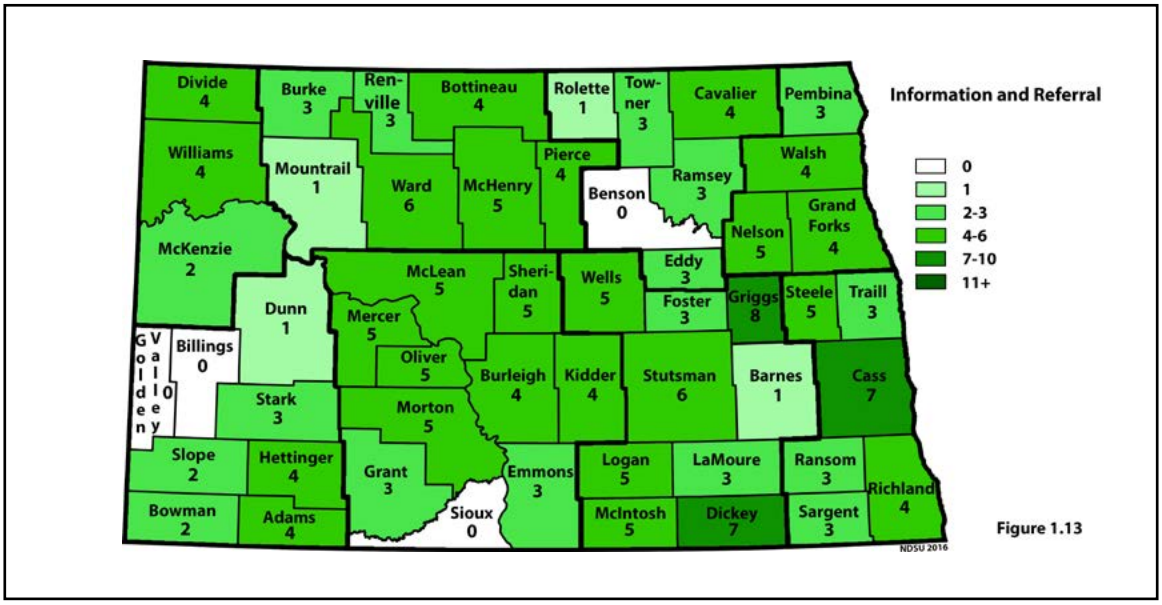
Definition: *Programs that direct caregivers to the necessary service agencies that help with counseling, support groups, education and training referrals. Also, may help the caregiver determine if the person they are caring for is receiving benefits they may be eligible for that could reduce the caregiver's costs including medications, home delivered meals, transportation and other necessities.*

Regarding this category of service, only four counties (8%) reported having no information and referral services available; another four counties reported having one information and referral service available; 17 counties (32%) indicated having 2 to 3 services; twenty-five counties (25%) indicated having 4 to 6 services; and three counties reported having 7 to 10 services present.

Many types of information and referral services were listed, such as Aging & Disability Resource LINK, Options Counseling, County Social Service Departments, Family Caregiver Support Program, Human Service Centers, Centers for Persons with Disabilities, and Public Health Departments. Other services mentioned included AARP, First Link, United Way, Valley Senior Services, and local senior centers.

Information and referral service seems to be well represented across the state, but there are concerns about counties who indicate they have no services, especially when a statewide resource service is available. The presence of these services does not guarantee that caregivers are aware of them or are utilizing them to find resources and help.

Figure 1.13: Information and Referral



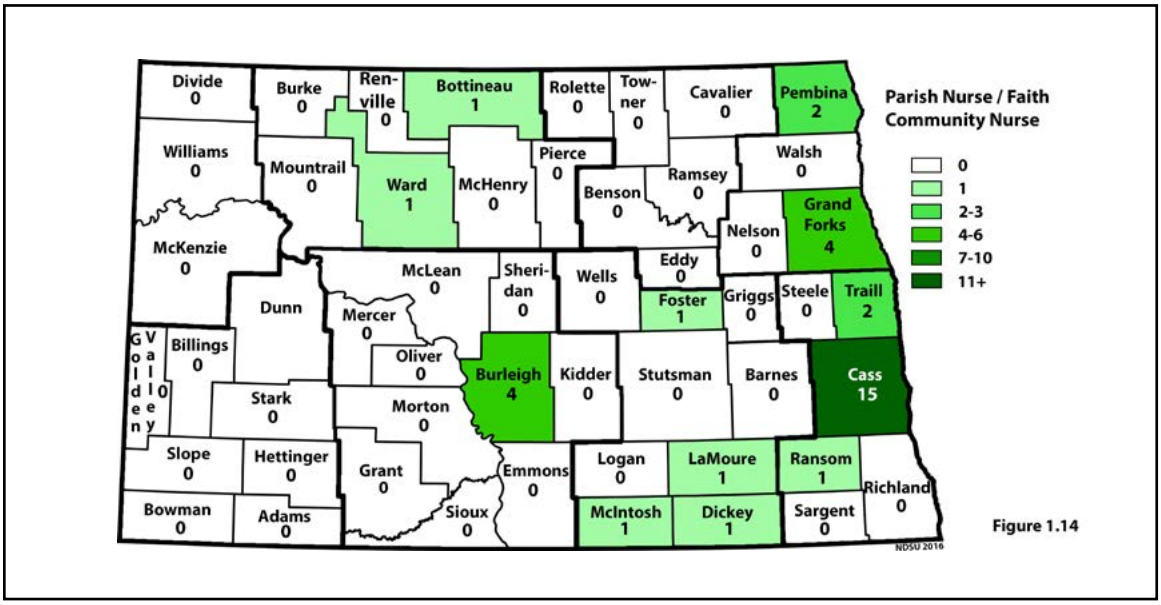
Parish Nurse/Faith Community Nurse

Definition: *A registered nurse with a minimum of 2 years of experience that works in a faith community to address health issues of its members as well as those in the broader community or neighborhood.*

There are 11 counties (21%) that reported having a parish nurse, now more commonly referred to as faith community nurse, functioning within a faith community or a broader community/ neighborhood-based setting. Cass County has the highest number of settings (16) with a parish nurse. The majority of the counties (6) reported only one faith community or community-based setting with a parish nurse.

Parish nursing is only available in a few areas and is more likely to exist in larger cities. Parish nurses can provide a range of services beneficial to caregivers. As an informal service, it could contribute in meeting the needs of caregiver without additional burden on public funds.

Figure 1.14: Parish Nurse/Faith Community Nurse



Public Health Nurse/Health Maintenance

Definition: *A nurse who works within the community to improve the overall health of the area by putting together plans that alleviate or eliminate health or safety issues in the community (e.g., immunizations, STDs, and obesity).*

There are 28 independent local health units working in partnership with the North Dakota Department of Health. Seventy-five percent of the units are organized into single county, city or combined city/county jurisdictions, while the other 25 percent serve multi-county jurisdictions. The majority of the multi-county jurisdictions are in the western part of the state.

In addition to the services provided by public health, North Dakota Division of Aging Services also provides health maintenance services in many communities located across the state. Services offered include blood pressure screening, home visits, medications set-up, and foot care. Health maintenance services are either contracted with the local public health unit or provided by a local nurse. The services are provided in senior centers, senior housing and many other community locations.

Figure 1.15: Public Health Nurse/Health Maintenance

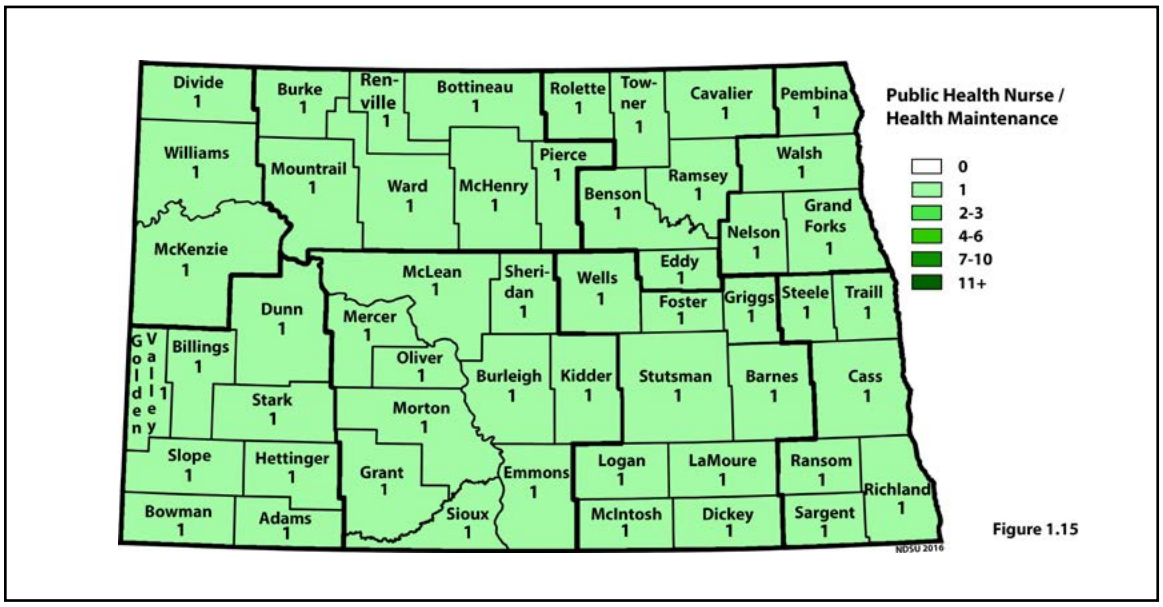


Figure 1.15

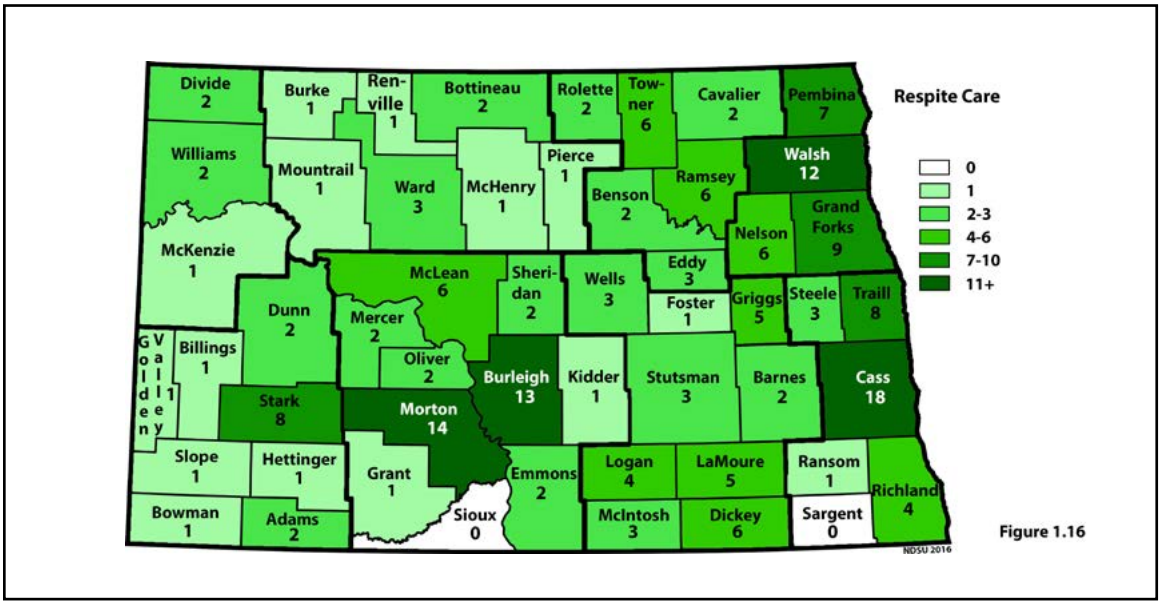
Respite

Definition: *Temporary relief of the stresses and demands associated with continuous daily care for a primary caregiver for a specified period of time. Respite care is provided by a trained individual in the home of the care recipient or in a health facility.*

There were two counties with no reported respite care services. Seventeen counties (32%) indicated having 1 respite care service; another seventeen counties reported having 2 to 3 respite care services; nine counties (17%) had 4 to 6 services; four counties (8%) had 7 to 10 services; and another four counties had 11+ respite care services. Overall, respite care services are more available in the eastern part of the state and more likely to be located in larger cities. County Social Services was frequently listed as the only provider of respite care services in many western counties. In-home respite care providers included Family Caregiver Support Services, home care agencies, Easter Seals, Community Options, a hospice agency and public health. Facility-based respite care providers included hospital and long-term care facilities.

Like adult day care, respite needs to be a local service for it to be accessible. In-home respite is preferable for family caregivers for various reasons and it is unknown if facility-based respite care is being utilized. Respite care is important to the well-being of the caregiver and the safety of the care recipient. The map indicates a need for additional respite care services, especially in rural areas.

Figure 1.16: Respite



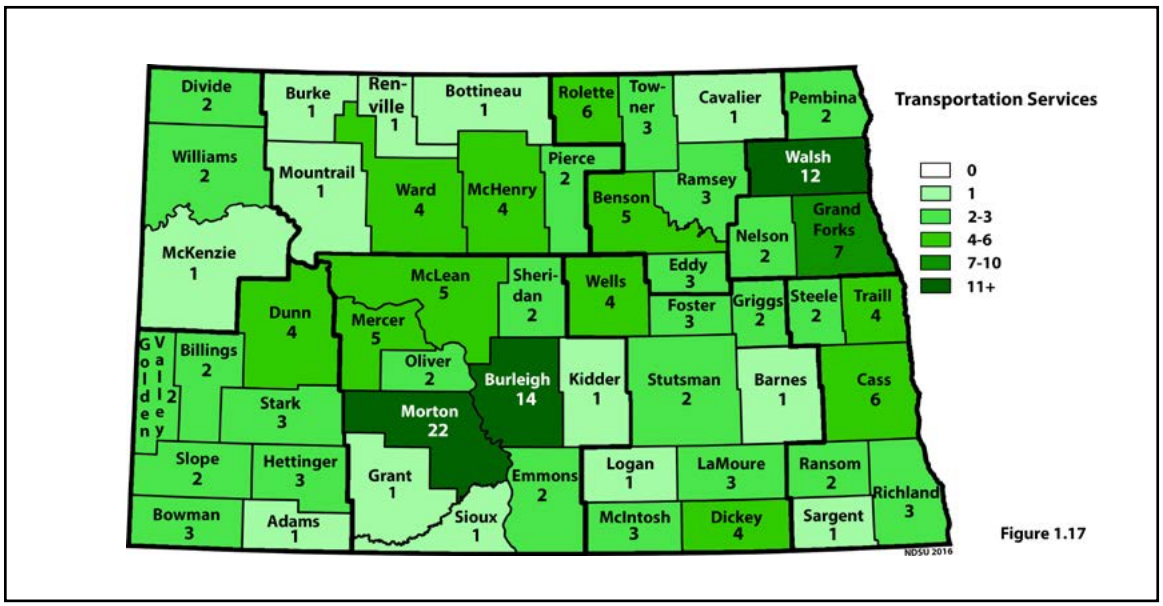
Transportation

Definition: *The availability of adequate transportation enables older persons to live independently in their communities and helps to prevent isolation and the possible need for long-term care placement. Types of transportation that may be available for older adults include individual door-to- door service, fixed route with scheduled services, and/or ridesharing with volunteer drivers.*

Nearly three-fourths of the counties reported having between 1 and 3 transportation services available. Three counties reported having 11+ services. For this category, there was more variation in the types of transportation services existing in each county. For example, some respondents included transportation provided by long term care facilities, home care providers, and county social service providers. Also, some counties listed senior citizen clubs as providing transportation services while others reported the county, multi-county or regional transit provider as the sole provider in the county. Several volunteer programs were also reported as providing transportation, especially for medical appointments in larger cities.

Transportation is a critical service for older adults to remain living independently. Access to transportation services is a key resource, especially in rural areas and it is often cited as a significant gap in service. Knowing only the types of transportation arrangements across the state, it is difficult to discern the actual accessibility, acceptability, and affordability of transportation options for residents. A closer examination is needed to better understand the gap between transportation resources and the needs of family caregivers.

Figure 1.17: Transportation



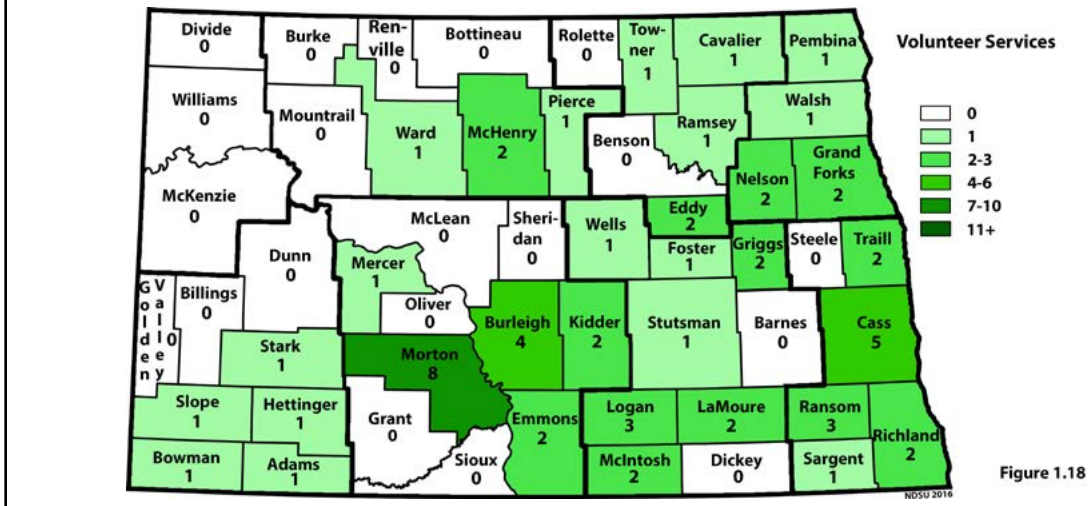
Volunteer Services

Definition: *Any caregiver service provided by unpaid volunteers.*

Twenty counties (38%) reported having no volunteer services available. Eighteen counties (34%) reported one volunteer service available. Twelve counties (22%) had 2 to 3 services. Two counties (4%) had 4-6 services. One county had 8 volunteer services present. Overall, western North Dakota had few volunteer services existing to serve its residents, whereas Eastern ND (especially urban areas) had greater services. Organizations listed as providing volunteer services were RSVP+, Senior Companions, local senior centers, senior service providers, Faith in Action programs, Community of Care, HEART, American Red Cross, Foster Grandparents, Volunteer Exchange Program, United Way, Helping Headings, Kiwanis, and SCORE.

Volunteer services can serve many purposes, and current services have different meaning and importance across the counties/regions. It is clear from the map that volunteer services are currently not a stable, dependable service for caregivers across the state.

Figure 1.18: Volunteer Services



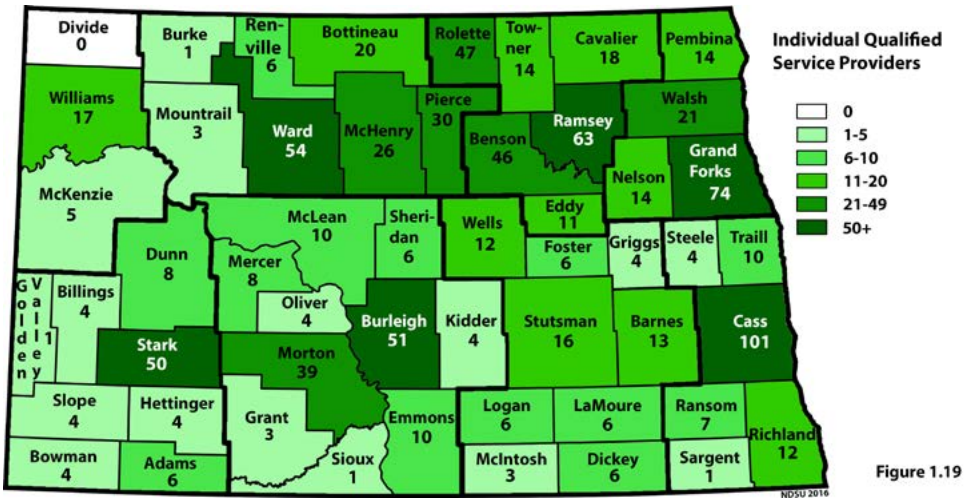
Individual Qualified Service Providers – Personal Care

Definition: *Qualified Service Providers (QSPs) are individuals that have agreed to provide services to clients who receive services funded by the North Dakota Department of Human Services. State law requires that people who are eligible for home and community-based services be free to choose among available QSPs that offer competitively priced services. QSPs are considered independent contractors that have met certain competency standards required to provide services to eligible clients.*

The ND Department of Human Services maintains a searchable database of QSPs who have been endorsed to provide a list of eligible services. For individual QSPs endorsed to provide personal care service, there was one county (Divide) with no reported QSPs. Twenty-three counties (43%) indicated having between 1 and 6 QSPs; seventeen counties (32%) reported having 7 to 20 QSPs); seven counties (13%) had 21 to 50 QSPs; and another four counties (Burleigh, Grand Forks, Ward and Ramsey) had 51 to 100 QSPs. One county (Cass) reported having 101 QSPs.

The database provides names, contact information and endorsements of individual QSPs for family members to assess as they look for this type of service. It is important to understand that there are individuals who become enrolled as a QSP to solely take care of a family member so the number of QSPs listed in a county may be misrepresentative of QSP availability.

Figure 1.19: Individual Qualified Service Providers – Personal Care



See Appendix A, starting on page 91, for a ND regional database of family caregiving resources, services, and supports.

C. Summary of Aim 1 Highlights

- The categories of services and resources identified cover areas of support related to: managing the logistics of caregiving, direct support in providing care, improving caregiver's ability to provide care, and fostering the well-being of the caregiver.
- Based on the resources identified across the state, services related to managing the logistics of caregiving seem to be more developed than many categories of services across ND. For instance, information and referral, assistive technology and equipment, and advocacy services seem to be evenly represented across the state. However, care management is one arena that would support managing the logistics of caregiving that seems to be lacking across the state.
- In terms of resources that provide direct support in the eldercare process, this is an area in which the rural/urban divide emerges quite clearly. In urban areas we find a strong representation of direct care services (such as adult day care, dementia care, hospice, home health care, homemaker and personal care), however these direct care services seem to be lacking in rural areas across the state.
- Some services (such as training and education, transportation, meal services, and volunteer services) indirectly help caregivers by improving the caregiver's ability to provide care him or herself. Of these, training and education, transportation, and volunteer services both seem to be lacking across the state.
- A few services have a primary aim of helping to foster the well-being of the caregiver, namely respite care and emotional support. These types of services seem to be under represented across North Dakota, which is concerning because if the well-being of the caregiver is not made a priority, seniors and their families may be put at risk.
- Despite these conclusions, however, a closer examination of all the key categories is required to fully identify gaps in service and to understand how these gaps can best be addressed because:
    - Examining the number or inventory of resources available to family caregivers provides only a partial picture of whether their needs are met for a particular category of service.
    - The existence of a service in a county does not guarantee that the service is available across the entire county.
    - In addition to availability, service delivery needs to include the underlying factors of accessibility (such as geographic distance), appropriateness (does service address actual needs), affordability, and awareness. Each of these factors present challenges and need to be addressed if the service needs of family caregivers are to be met.

Aim 2: Barriers and Challenges of Family Caregivers

Aim 2: Barriers and Challenges of Family Caregiving

Aim 2. Identify barriers and challenges family caregivers experience, which includes the need for training, respite care services, medical leave policies, and delegation of tasks to family members and nonmedical aides.

Part A: Family Caregivers' Perspectives

1. AARP-ND data 2015-16

- Data Summary
- Quantitative Findings
- Qualitative Findings

2. ND Family Caregiver Support Program Survey

- Data Summary and Findings from 2014
- Data Summary and Findings from 2015

Part B. Stakeholders' Perspectives

ND State Caregiving Stakeholder Survey (NDSU conducted)

- Data Summary
- Quantitative Findings
- Qualitative Findings
- Recommendations for Improving Services and Policies
- Focus on Special Groups

Part C. Summary of Aim 2 Conclusions

Part A. Family Caregivers' Perspective

1. AARP-ND Data 2015-16

Data Summary

AARP of North Dakota collected survey data related to the experiences of caregivers across the state of North Dakota. Survey participants were recruited via electronic and mailed newsletters to AARP members, in-person at AARP sponsored events targeting caregivers, and online via the AARP website.

A total of **103 current caregivers and 7 former caregivers completed surveys** online or in paper form from September 2015 to February 2016.

The sample included 68% urban and 32% rural caregivers (See Figure 2.1). Rural was defined as towns/communities with populations less than 5,000 people.

As displayed in Figure 2.2, the gender makeup of the sample was 82% female and 18% male.

Half of the sample (50%) was currently employed full-time. A total of 17% of the participants were employed part-time. Of these, 35% (6% of the total sample) stated that they had switched to working part-time as a result of their caregiving duties. A total of 33% of the sample were unemployed or retired. Of these, 38% (12% of the total sample) stated that they were no longer able to work outside of the home due to their caregiving responsibilities. See Figure 2.3.

Figure 2.1: Geographic Location

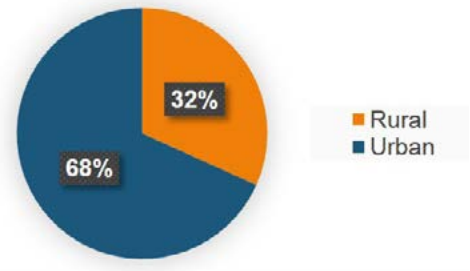


Figure 2.2: Gender

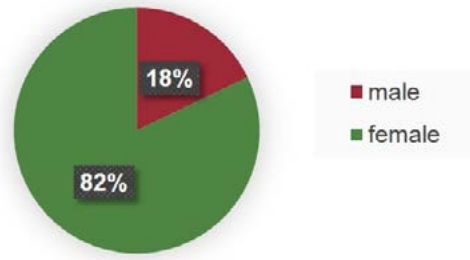
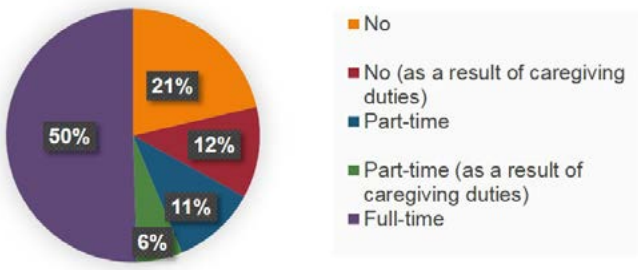


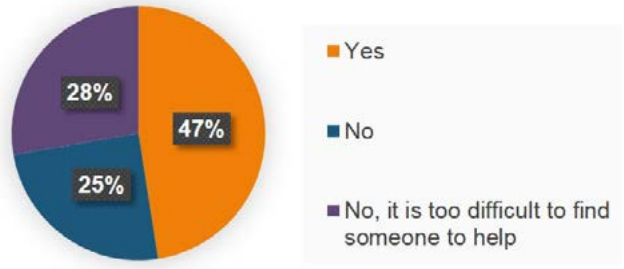
Figure 2.3: Current Employment



Quantitative Findings

The first question asked respondents: “As a caregiver, do you get enough breaks or respite from your caregiving duties?” (See Figure 2.4). Slightly fewer than half (47%) of the respondents responded that “yes”, they had enough breaks or respite from caregiving. The remaining 53% responded that “no” they did not get enough breaks or respite from caregiving. Of those that reported not having enough respite a majority (53%) reported that ‘it was too difficult to find someone to help’. Thus, more than a quarter of these caregivers reported having insufficient respite from caregiving duties because of lacking providers of respite care. An additional quarter of these North Dakota caregivers reported insufficient respite but did not specify why they lacked respite.

Figure 2.4: As a caregiver, do you get enough breaks or respite from your caregiving duties?



It is often expected that family caregivers are only providing non-medical cares (such as shopping, household, chores, etc.). However, of North Dakota caregivers, the majority (78%) reported providing medical or nursing cares (See Figure 2.5). Though 78% reported providing medical cares to their care recipient, only 51% reported receiving any instruction or training on how to provide those medical cares (See Figure 2.6). Thus, 27% of caregivers are providing medical cares without having received any prior instruction on how to do so.

Figure 2.5: Do you provide medical or nursing care?

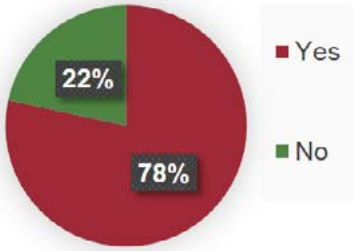
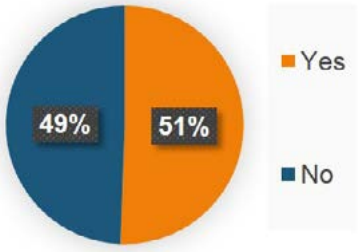
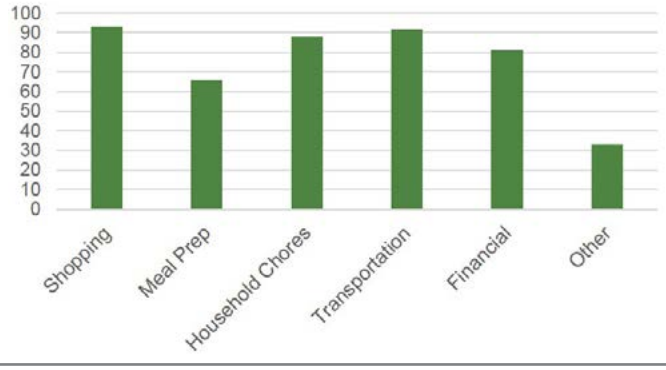


Figure 2.6: Did you receive any instruction or training on providing medical care?



Respondents were asked: “What types of non-medical cares do you provide?”. They could indicate as many types of help they provide and could select from: shopping, meal preparation, household chores, transportation, financial management, and other. As presented in Figure 2.7, the most common non-medical help provided were shopping and transportation, closely followed by household chores, then financial management, and finally meal preparations. Each of these types of non-medical help were quite common and were reported by more than 50% of caregivers.

Figure 2.7: Non-medical Help Provided



Qualitative Findings

The AARP-ND survey included two open-ended questions that were helpful in understanding the perspectives of caregivers. Responses from each open-ended question were analyzed to identify common themes and then coded to determine the prevalence of each theme. The first asked: "In your role as a caregiver, what do you find most rewarding?" The second asked: "Thinking about your caregiving experience and journey, what do you think the ND legislature should know as they look to improve supports for family caregivers like you? This is your opportunity to tell Legislators about your caregiving experience and what help would be of most value to you."

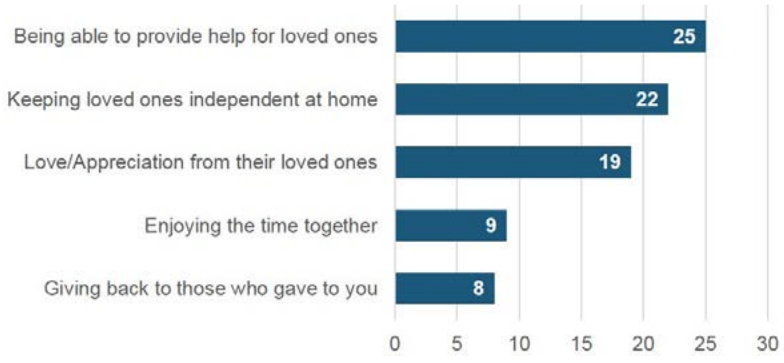
Question 1. In your role as a caregiver, what do you find most rewarding?

The following five themes emerged in response to this question:

1. Being able to provide help for loved ones
2. Keeping loved ones independent in their homes
3. Love/Appreciation from loved ones
4. Enjoying time together
5. Giving back to those who gave to you

The frequency of each theme is demonstrated in Figure 2.8 and the significance of each theme is described thereafter.

Figure 2.8: As a caregiver, what do you find most rewarding?



Theme 1. Being able to provide quality help for loved ones

The strongest perceived reward among caregivers was feeling rewarded by helping their loved ones. For some, the benefit of providing care was in knowing their loved ones are safe and secure. Caregivers also found satisfaction in knowing that their family members are healthy and are receiving the quality of care they deserve. These types of sentiments are demonstrated in the following quotes:

> *"Knowing my parents' life is better in my home than it would be at a facility."*
>
> *"Knowing that our loved ones are receiving BETTER care with us, than paid caregivers can provide, because paid caregivers do not see the whole person, only a small part of that person. Paid caregivers do not have continuity."*

Theme 2. Keeping loved ones independent in their homes.

Caregivers expressed high interest in the ability to keep their loved ones at home in comparison to placing them in long-term care facilities. The security of knowing their loved ones were happy and comfortable in a familiar setting was rewarding, as demonstrated by the following quotes.

> *"I found it rewarding to allow my mother to remain in her home until she passed. She was at peace and felt loved and cared for to the end."*
>
> *"Keeping my husband at home so he can be happy + content. I don't think he would be alive if he had to be in a care facility."*
>
> *"Making sure my husband is able to stay at home where he feels comfortable, and is surrounded by familiar surroundings and family."*

An important part of seeking to keep their loved ones at home was encouraging independence. Caregivers reported a sense of achievement in encouraging the independence of their loved ones. This was supported by the following responses by participants.

> *"Hoping that all I am doing for my husband is making a difference for him to regain some of the independence he has lost."*
>
> *"Keeping my parents independent as long as possible."*

Theme 3. Love/Appreciation from loved ones.

The next most common theme that emerged was related to the perception of being appreciated. Participants commented that providing care was worthwhile because they felt loved and appreciated. Caregivers feel caregiving is worth it when they know their loved ones appreciate the work that goes into providing care, as demonstrated in the quotes below.

> *"My husband expresses his appreciation for my efforts to help him. If something were to happen to me, he would have to go to a nursing home."*
>
> *"Mom is afraid of ending up in a nursing home because of the experience with her sister. She moved from Bismarck, her home, to Wahpeton and moved into an apartment for the elderly that is only 4 blocks from my home. She says daily how safe she feels and how happy she is to have me as her support. That is my reward."*

Hearing a simple 'thank you' made the hard work and dedication worth it to many caregivers.

> *"Both parents have Alzheimer's. I know they won't know me one day but it is wonderful when they call my name and every day they thank me for all I do for them. I know they are cared for."*

Seeing the smiles and hearing laughter from loved ones kept the caregiver motivated.

> *"Getting them to smile, laugh and tell stories."*

Theme 4. Enjoying time together.

Despite the challenges inherent in taking care of an elder family member, caregivers expressed enjoyment in spending quality time with the care recipients. Some did not view caring for loved ones as a job, but instead as time for family bonding. The quotes below demonstrate this theme.

> *"Finding the humor in each day."*
>
> *"I enjoy having time with my dear mother who is such a great woman."*

"Face time with my mom and dad"

"I loved both my parents and didn't consider it a "job". I was helping them as they would have helped me. There was joy in our time together."

Theme 5. Giving back to those who gave to you.

Many of the caregivers who participated in the AARP survey were the adult children of the care recipients. Adult child caregivers commonly responded that they felt it rewarding to be able to care for their parents in exchange for the care they received from them in childhood. Being able to provide what is needed to those who once gave to them was a common theme amongst respondents. These caregivers expressed gratitude in the "payback feeling" as demonstrated below.

"Knowing that I am giving back to my mom after she gave so much to me."

"Helping the mother who raised me years ago. She was most grateful for my care."

"Just being present or my mother as she has always been for all of her family. The love and attention she has given is now being returned."

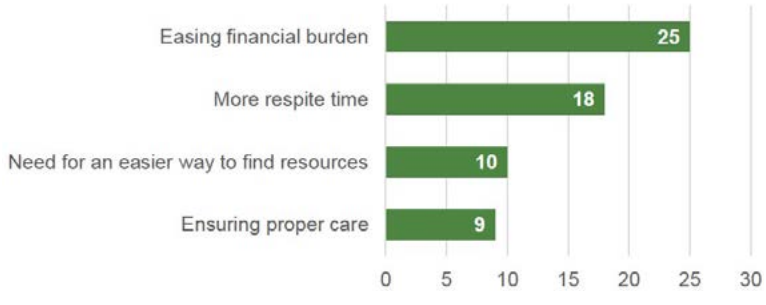
Question 2. Thinking about your caregiving experience and journey, what do you think the ND legislature should know as they look to improve supports for family caregivers like you? This is your opportunity to tell Legislators about your caregiving experience and what help would be of most value to you.

The following four themes emerged in response to this question:

1. Easing financial burden
2. More respite time
3. Need an easier way to find resources
4. Ensuring proper care

The frequency of each theme is demonstrated in Figure 2.9 and the significance of each theme is described thereafter.

Figure 2.9: What should the ND legislature know as they look to improve supports for family caregivers?



Theme 1. Easing financial burden

The largest concern of respondents was the need to increase financial supports for family caregivers. Caregivers expressed that social security is not enough to afford the necessary costs of caring for loved ones. This is demonstrated by the following participant responses:

> *"The pay I receive is not enough to make ends meet, perhaps some food and heating assistance would make a big difference, or increase pay per day, it's sad when you get to the age of 60's, your spouse suffers a stroke, so he can't work anymore, I had to quit my job to care for him, and also lost my health insurance, which has put us into poverty level existence."*

Caregivers also demonstrated a need for more flexibility in the work field, such as need for greater access to family medical leave.

> *"More home-health care allowed (better wages for those workers.) More "family" time allowed from employers, so employees don't fear losing their jobs."*
>
> *"Is there a way to have businesses give some time off (expand medical leave)."*

Some suggested specific avenues that could be explored to improve the financial situation of family caregivers. For instance, some expressed the need for tax breaks/tax deduction for caregiving expenses or other benefits to offset the income loss:

> *"Caregivers who are giving up work to care for their parents should receive some tax breaks or some other benefit to offset the income loss."*

Other respondents expressed concern for financial assistance to remodel houses so they are handicap accessible and to make medical equipment more available (walkers grab bars, shower assists, shower benches, etc.).

> *"Financial assistance to remodel bathrooms, bedrooms, entrances, etc. to be handicap accessible."*

Theme 2. More respite time

Caregivers expressed the need for increased access to respite from their caregiving duties. Caregivers reported needing a break mentally and emotionally. Additionally, caregivers reported needing time to run errands or to just get out of the house. These needs are expressed in the following quotes:

> *"It is exhausting to be a caregiver 7 days a week 24 hours a day. It is expensive to hire help and there is no time for yourself. You feel like you have no life."*
>
> *"We need more ways of giving a break to caregivers. It's a difficult, thankless job."*
>
> *"I would like to see more respite time available. As time went on and we were more homebound. I had to use my 2 hrs twice a week for grocery shopping etc. There was not time for personal pleasure."*

Theme 3. Need for an easier way to find resources.

Many caregivers reported being unsure of the resources that are available. They expressed feelings of being hidden or overlooked. Moreover, they stated that they were unsure of where to find resources when they need them:

"Where do you find help in rural ND?"

"North Dakota Legislature needs to know that resources need to be more readily available for the elderly and caregivers alike."

For those who were able to find resources, confusion of how to access those resources was expressed:

"The variety of care options and funding is confusing to anyone not educated in the "system". Even though social workers do a good job of providing information, it is still an overwhelming tasks to make decisions and find financial resources to deal with someone needing care."

In particular, caregivers expressed concerns about the ability to find transportation resources, suggesting limited availability of services to meet transportation needs, especially in rural areas of the state. One participant stated:

"Older people should not have to wait an hour or set up rides days ahead of time."

Theme 4. Ensuring proper care.

To ensure their loved ones are in the best hands possible, many reported wanting more training for caregivers and better screening of employees working with older adults. Moreover, caregivers also expressed wanting more access to reliable helpers due to the shortage of care. The following comments demonstrate some of these concerns:

"There needs to be more information and quality assurance ratings for agencies that provide home healthcare. Believe me, they are not all quality providers, even some that work as extension of large healthcare groups… There is also a huge difference in quality of care and information sharing services."

"Provide a center and funding for training people in what to do and what programs are available thru state and local agencies."

"The shortage of short-term medical care and home health nurses led my family member to an expensive facility rather than allowing him to remain in his apartment."

2. ND Family Caregiver Support Program Data 2014, 2015

Data Summary

The North Dakota Family Caregiver Support Program (FCSP) is a federally funded program administered by the Aging Services Division of the North Dakota Department of Human Services. The program offers support and services to family caregivers in the state of North Dakota. The types of services provided include assessment and care coordination, information provision, respite care, supplemental cost assistance, and counseling, support groups, and training. The FCSP program surveys its service recipients to assess caregiver experiences, needs and satisfaction. For the current study we draw upon data from the program's surveys of caregivers of individuals over 60 years of age for the past two years (2014 and 2015).

2014 Data and Findings

In the 2014 North Dakota Family Caregivers' Survey a total of 412 surveys were mailed with 196 returned completed. The returned surveys represented 31 of 53 counties in North Dakota.

As shown in Figure 2.10, the majority (78%) of caregivers participating in the FCSP were spousal caregivers. The next most common relationship type was children of the care recipient (sons and daughters represented 13% of caregivers). Gender differences were evident with women being more than 3 times as likely as men to be family caregivers.

As seen in Figure 2.11, most North Dakota caregivers are older adults themselves, with 79% of caregivers over the age of 65. Some caregivers fall into the 'oldest old' age group, with 13% of caregivers over the age of 85.

Figure 2.12 represents the ages of care recipients. About a quarter (24%) of care recipients are between the ages of 65 and 74. Forty percent of care recipients are between the ages of 75 and 84. Approximately a third (32%) of care recipients are part of the 'oldest old' age group, over the age of 85.

Figure 2.10: Relationship of Caregiver to Care Recipient

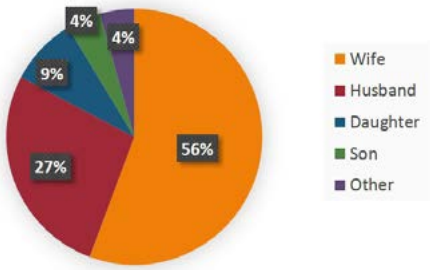


Figure 2.11: Age of Caregiver

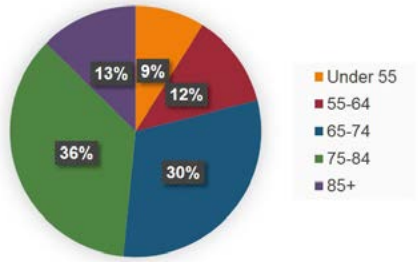
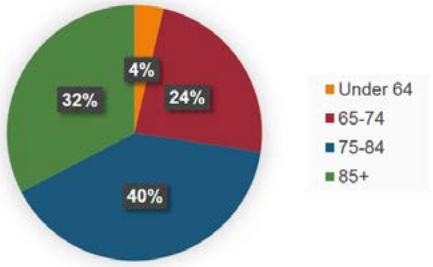


Figure 2.12: Age of Care Recipient



Qualitative Findings

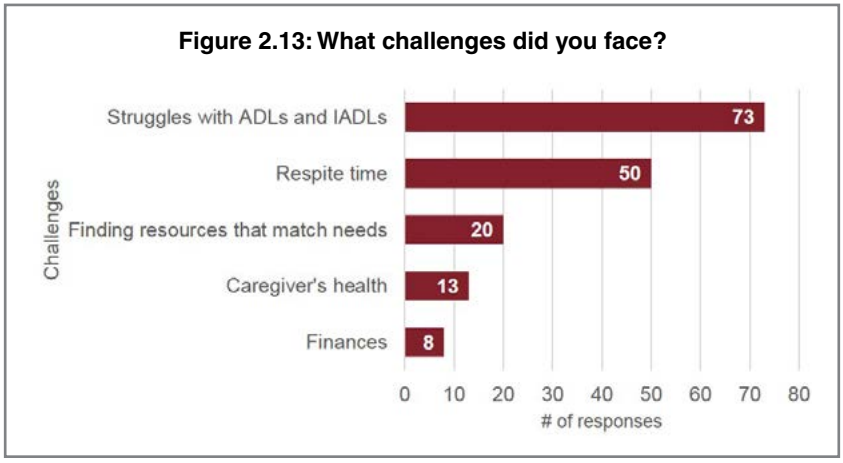
The FCSP survey included two open-ended questions that were helpful in understanding the perspectives of caregivers. Responses from each open-ended question were analyzed to identify common themes and then coded to determine the prevalence of each theme. The first asked: "What are the challenges you faced or are currently facing to providing care in your home?" The second asked: "Are there other services that you think could give or would have given you more help in meeting challenges of caregiving?". A description of the themes for each of these questions is provided below.

■ **Question 1. What are the challenges you faced or are currently facing to providing care in your home?** The following five themes emerged in response to this prompt:

1. Caregivers struggled with ADLs and IADLs
2. Respite time was very important
3. Helpers and services available do not always match needs.
4. Caregiver's own health was a concern
5. Care services are expensive

The frequency of each theme is demonstrated in Figure 2.13 and the significance of each theme is described thereafter.

Figure 2.13: What challenges did you face?



Theme 1. Caregivers struggled with ADLs and IADLs.

Assisting care recipients with their basic daily needs proves challenging for caregivers. Activities of daily living (ADLs), such as bathing and toileting, were primary concerns that challenged caregivers. Caregivers also report struggles with instrumental activities of daily living (IADLs), such as household chores like paying bills and cleaning. Performing seemingly simple day to day tasks were a challenge for many of the respondents and represented one of the greatest struggles reported.

> *"Person must be lifted & transferred, assisted with eating, going to bathroom, brushing teeth, toileting, bathing, changing catheter."*
>
> *"Transfers out of bed/chair. His confusion comes and goes."*

"Oxygen care – bathing – wheelchair care."

"To keep him from falling, watching so he doesn't eat what he should not – to keep him clean and clothes changed when needed."

Theme 2. Respite time was very important.

Caregivers valued time away from care recipients for errands, self-care, and renewal.

"My mother has dementia & can't be left alone & I am her only caregiver. Family & doctors have told me I need to care for myself too, so this program is just what I was looking for. I can for awhile."

"I was able to go get my hair fixed, get groceries & medicine. I had 3 hours a week."

"Time to get sleep!! Get away from situation and renew oneself. See doctors."

Some caregivers indicated an ongoing need for more respite than was provided.

"Not having enough time for me."

Theme 3. Helpers and services available do not always match caregiver's needs

Having access to helpers that are competent and capable of completing desired tasks was an ongoing issue. Qualified, compatible, and affordable caregivers were viewed as being in short supply. The following quotes demonstrate this perspective:

"Finding qualified caregiver. Paying for care."

"We have good programs again but at times the biggest challenge is finding compatible caretakers."

"Exhaustion, muscle aches, my challenges finding the right person, many are too old to do the work and others don't want to help with housework."

Moreover, service providers willing to perform the services needed could also be difficult to find.

"When I would call someone on my list to come and stay with him, they all had one excuse or another."

"Finding people that are willing to do this kind of work. There is a shortage of adequate help."

Theme 4. Caregiver's own health was a concern.

Respondents noted their own health was a challenge to their caregiving. Their physical capabilities, or lack thereof, presented a problem.

"He is harder to lift."

Physical health concerns related to the health of the caregiver sometimes resulted in an inability to properly care for the recipient.

"Had shoulder surgery – unable to help wife with dressing, personal care, showering, etc."

"Time limits. Physical stamina. My physical abilities. Financial resources."

"My own health."

Theme 5. Caregiver services are expensive

The cost of helpers was a significant and consistent concern for caregivers and families of care recipients. The money that caregivers and recipients were able to contribute in conjunction with stipends was not typically enough to meet the needs of these families.

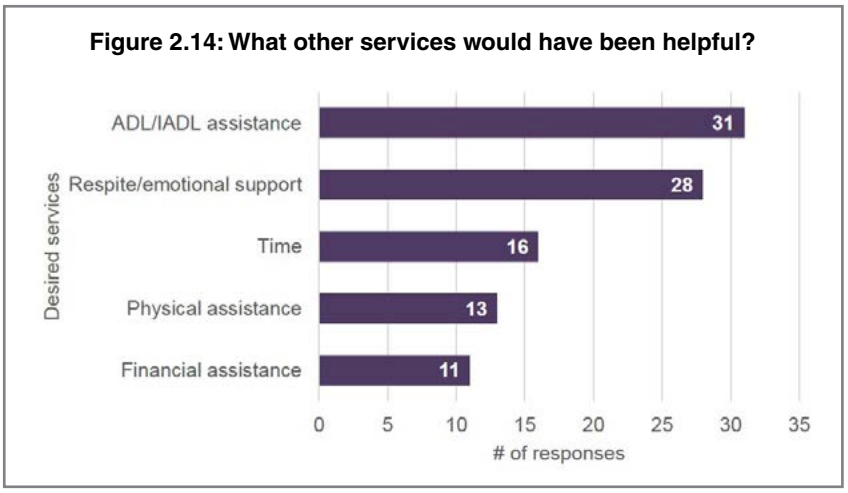
> *"When more help with his care was needed the finances weren't there for daily help – getting him up, dressed, bathed, etc. – and down at night."*
>
> *"Finding affordable and reliable help."*
>
> *"Age – cost of everything – but still doing okay on our own."*

■ **Question 2. Are there other services that you think could give or would have given you more help in meeting challenges of caregiving?** The following five themes emerged in response to this question:

1. ADL and IADL assistance
2. Respite or emotional support
3. Time
4. Physical assistance
5. Financial assistance and relief

The frequency of each theme is demonstrated in Figure 2.14 and the significance of each theme is described thereafter.

Figure 2.14: What other services would have been helpful?



Theme 1. ADL and IADL assistance

Services to assist with day-to-day care were important and lacking for some caregivers. Respondents identified assistance with daily routines and housekeeping chores as an opportunity for the Family Caregiver Support Program to provide additional services.

> *"At first, it took so much of my time caring for the person that my house cleaning got so far behind for about a month. Also, there was a lot more clothes & bed sheet washing."*
>
> *"Just general assistance, cooking, etc. Broken ankle."*
>
> *"Someone to visit her a couple times a week. Someone to assist her with some physical exercise 3 times a week."*

Theme 2. Respite and emotional support

There was a need for more emotional support as well as more respite from daily caregiving duties. Respite care services were appreciated and widely used but what was available to caregivers was not enough to meet their needs. More respite time would have been useful.

> *"We have discussed starting services for companionship – someone to sit and visit socially."*
>
> *"To be able to get away for more times so I would be emotionally healthy as well as physically. Family members are working, so can't get away from their jobs and families."*

Support groups and educational meetings would also have been helpful.

> *"I would have liked a support group closer than Grand Forks or Devils Lake. I would have needed another ½ day off to attend a meeting."*

Theme 3. Time

Respondents appreciated the services offered and expressed a need for more time with the professional caregivers with whom they worked. The time allotted for services was not adequate to meet the needs of the respondents and care recipients.

> *"More people available to come in to give me some free time."*
>
> *"I was not able to get help at night which would have been helpful a few times."*
>
> *"My support lady covers everything I need. BUT – it is a lot of time allowed for her to be here. And I do realize money is the factor and I DO appreciate the time I get from her. Unless you are in my position you can not realize what it means to have someone come in to help and I wish she could have more hours."*

At times, the hours that professional care providers were available were not useful to the family caregivers.

> *"I would have liked more options, i.e., providers to choose from for selecting in-home respite care services. I never utilized this service, due to unavailability of providers during the dates I needed them."*

Theme 4. Physical assistance

Physically demanding chores were an issue for some respondents who expressed a need for more help. As more family caregivers tend to be spouses, physical deterioration of the caregivers themselves became a concern.

> *"Help with cooking, shopping, cleaning and laundry – also lawn care & snow removal as I get older my energy and strength are decreasing."*
>
> *"Lifting device – back support"*
>
> *"The best help I could ask for is with getting her to appointments. With her arthritis & recovering from broken hip. It just so hard the hip was broken 9 or 10 years ago. She never adjusted well to it."*
>
> *"I am given 2 hours a week from the Veterans Admin for same services. I also hire private home care for 1 hour day/6 days week for mostly toileting and housekeeping. The help I have saves on my back & arm strength which is helpful at my age. I am thankful I am as strong as I am at my age to care for him and have him at home. I appreciate the services very much."*

Theme 5. Financial assistance and relief

Some caregivers expressed difficulties paying for needed services and indicated a need for financial assistance or reduced cost services. Respondents did not necessarily require free services, just more help finding affordable options or alleviating the financial burden.

> *"Possibly compiling lists of private individuals interested in doing health work full or part time. Possibly subsidizing some labor costs for independent home health assistance."*
>
> *"A lift van to be used (rented) on weekends or evenings. The Walsh co. van only is available certain days & weeks. I would love to buy one, but renting would be more economical."*
>
> *"Paying cost of nursing home is overwhelming. Is there anyway I can get some help?"*
>
> *"I would have liked to attend more support & educational meetings, but that would mean finding care for my father. Maybe while there is a meeting, there could be the option of an activity for the patients? Or more respite money to do so."*

2015 Data and Findings

In the 2015 North Dakota Family Caregivers' Survey a brief survey was sent only to caregivers who were no longer receiving services from the program. A total of 113 surveys were distributed and 92 were completed and returned. The returned surveys represented 28 of North Dakota's 53 counties.

As shown in Figure 2.15, the majority (82%) of caregivers formerly participating in the FCSP were spousal caregivers. The next most common relationship type was children of the care recipient (sons and daughters represented 14% of caregivers).

As seen in Figure 2.16, most North Dakota caregivers are older adults themselves, with 76% of caregivers over the age of 65. Some caregivers fall into the 'oldest old' age group, with 17% of caregivers over the age of 85.

Figure 2.17 represents the ages of care recipients. Forty percent of care recipients are between the ages of 75 and 84. An additional 39% of care recipients are part of the 'oldest old' age group, over the age of 85.

Figure 2.15: Relationship of Caregiver to Care Recipient

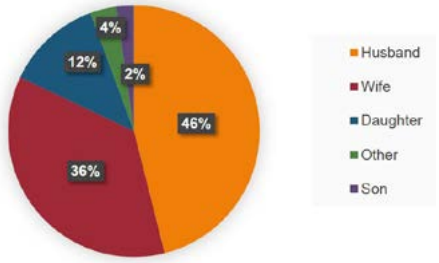


Figure 2.16: Age of Caregivers

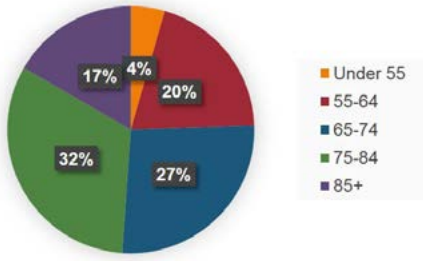
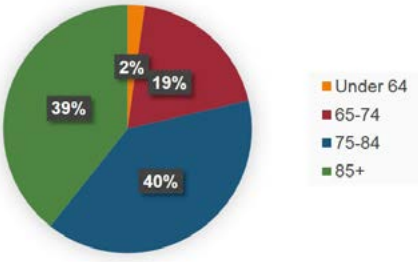


Figure 2.17: Age of Care Recipients

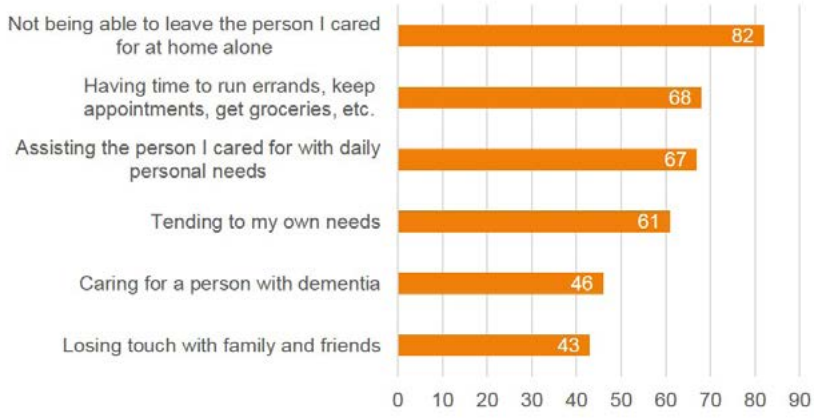


Caregivers were asked: “What were some of the challenges you faced as a full-time caregiver?”. Participants could select from the following responses and select all that applied:

1. Not being able to leave the person I cared for at home alone
2. Assisting the person I cared for with daily personal needs
3, Having the time to run errands, keep appointments, get groceries, etc.
4. Caring for a person with dementia
5. Tending to my own needs
6. Losing touch with family and friends

The frequency of each theme is demonstrated in Figure 2.18. The most frequently mentioned challenge was the inability to leave the care recipient home alone. Lack of time was commonly mentioned as a challenge both in terms of having time to run errands and keep appointments as well as having time to tend to the caregivers’ own needs. Caregivers also commonly indicated the challenge of providing the daily personal cares needed by the care recipient.

Figure 2.18: Challenges Faced as a Full-time Caregiver



Part B. Stakeholders' Perspectives

1. ND State Caregiving Stakeholder Survey (NDSU conducted)

Data Summary

In contrast to the caregivers' perspective, in which two recent, quality surveys of North Dakota caregivers already existed, data about family caregiving from North Dakota stakeholders did not exist prior to this study. Thus, NDSU's research team developed and conducted an online survey of stakeholders across ND. We aimed to recruit from the following groups of stakeholders: hospitals, social and clinical providers, advocacy organizations, veteran agencies, tribes, and state, local, and community agencies.

Participants were recruited via invitations sent to email list-serves of the following groups and associations: ND Senior Service Providers, Northland Care Coordination for Seniors, Northland PACE, Quality Health Associates of ND, RSVP+ ND, Sanford, Senior Medicare Patrol, ND Critical Access Hospital Quality Network, ND Hospice Organization, ND Board of Nursing, ND Nurses Association, Valley Senior Services, American Heart Association, Three Affiliated Tribes, Standing Rock Sioux Tribe, Sisseton Wahpeton Oyate, Spirit Lake Tribe, Turtle Mountain Band of Chippewa, Veteran Caregiver Support, Tribal Veterans Service Offices, Heart Springs, Aging Services Program Administrator, IPAT, ND Center for Rural Health, Community of Care, HEART (Enderlin), Faith in Action (Cavalier), Faith in Action (Carrington), Volunteer Exchange (Bismarck), Sanford-Health Ministries, American Cancer Association, ALS Association, ND Health Policy Consortium, ND Center for Nursing, Multiple Sclerosis Society, Alzheimer's Association, and Veteran Services Offices. Additionally, we asked each county social services representative (from Aim 1) to nominate and provide the contact information of up to five individuals in their community who they considered to be important stakeholders with regards to family caregiving; an email invitation was sent to each of the nominated individuals.

A total of **116 stakeholders completed surveys** online from March to April 2016.

To explore the stakeholders' role in family caregiving, we asked a series of questions related to the stakeholders' experience and role in working with family caregivers. First we assessed the length of time the stakeholder has worked with family caregivers. The stakeholders had worked with family caregivers for an average of 13.3 years, with total years ranging from less than 1 to 57. Additionally we asked whether the stakeholders were direct service providers or not (See Figure 2.19). More (58%) stakeholders were direct services providers to older adults and their families.

The stakeholders held a variety of different roles with regards to working with family caregivers (See Figure 2.20). The largest job role was program coordinator or supervisor, followed by social services providers and agency directors. These top three job roles represented nearly two-thirds of stakeholders. Less common job roles included healthcare professional, case manager, and community leader. Nearly twenty percent of stakeholders did not have a role that fit easily into the provided job role categories. This 'other' category included roles such as: Association President, Director of Nursing, Resource Coordinator, Senior Outreach Services, State Regional Aging Services Program Administrator, Advocacy Organization, Veteran Service Officer, Clergy, Lobbyist, and Consultant.

In addition to assessing the stakeholders' role, we asked some questions about the organization with which the stakeholder was affiliated. The stakeholders worked for organizations from governmental, non-profit, and for-profit sectors (See Figure 2.21). Non-profit organizations were the most common, followed by governmental organizations, and then for-profit organizations.

To ensure adequate representation of a variety of service sectors, we assessed the type of service sector for each stakeholder's organization. The sample consisted of stakeholders representing a wide range of service sectors (See Figure 2.22). The largest groups of stakeholders represented the sectors such as healthcare related services, long-term care facilities, and social service agencies. A moderate-to-good representation was included from aging services providers, community-based organizations, state and local governments, and advocacy agencies. The smallest groups of stakeholders represented sectors of faith-based organizations, Veterans organizations, and tribal agencies.

Figure 2.19: Are you a direct service provider?

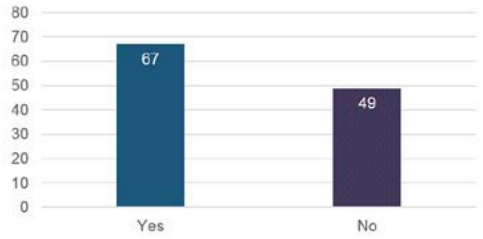


Figure 2.20: Which category best describes your job role/position?

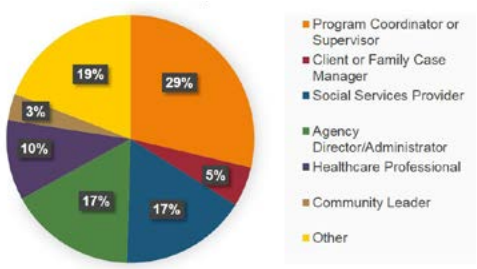


Figure 2.21: Which best describes your organization?

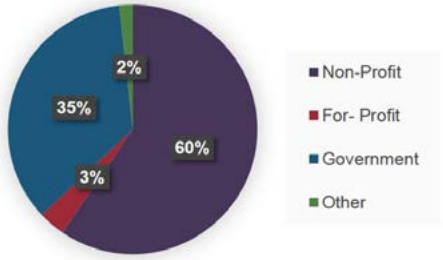
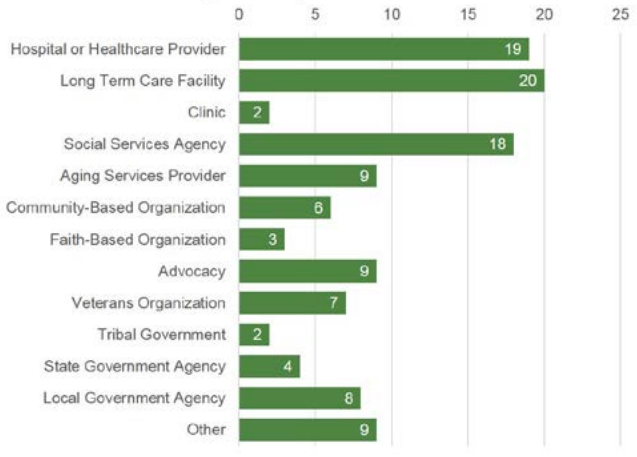
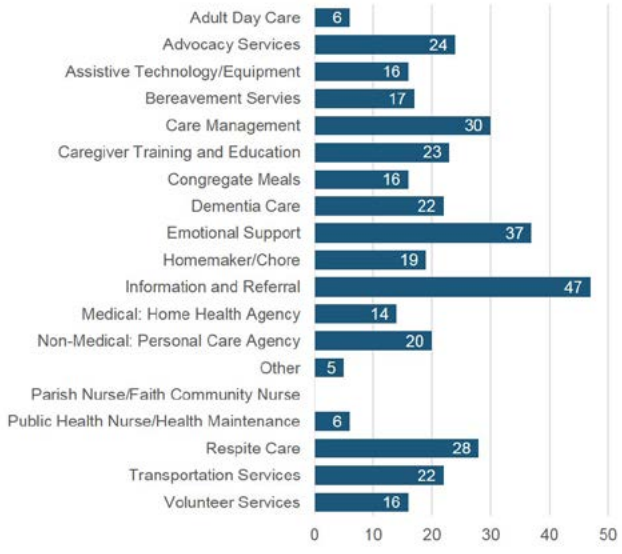


Figure 2.22: Which best describes the service sector of the organization you work for/with?



In addition to asking about the type of organization, we assessed the types of caregiver services and supports provided by each organization (See Figure 2.23). The most common service (provided by 39.8% of organizations) was the provision of information and referral services. Other common services included providing emotional support (31.4%), care management (25.4%), respite care (23.7%), and advocacy services (20.4%). Between 15% and 20% of organizations provided caregiver training and education (19.5%), dementia care (18.6%), transportation services (18.6%), and non-medical home care (16.9%). Between 10 to 15% of organizations provided bereavement services (14.4%), assistive technology/equipment (13.6%), congregate meals (13.6%), volunteer services (13.6%), and home health care (11.9%). Fewer than 10% of organizations provided adult daycare (5.1%) or parish/public health nurses (5.1%).

Figure 2.23: Caregiver supports and services provided by your organization



Quantitative Findings

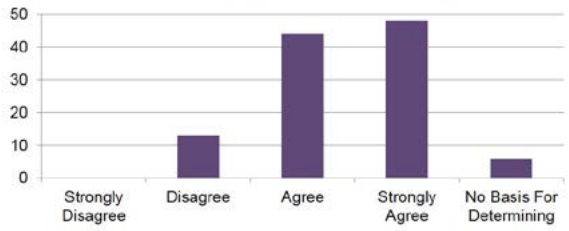
Participants were asked a series of questions about their perceptions of a) the challenges faced by family caregivers in their community, and b) the barriers to service utilization by family caregivers in their community.

Challenges faced by family caregivers in your community

The question posed was: “Do you believe the following represent challenges that family caregivers face in your community?” Seven statements were provided. For each statement participants were asked to rate their extent of agreement ranging from strongly disagree (1), disagree (2), agree (3), and strongly agree (4). A fifth option was ‘no basis for determination’.

As shown in Figure 2.24, the majority of stakeholders agreed or strongly agreed with the statement ‘Family caregivers have insufficient income/funds to pay for services and supports’. The mean score for this question was 3.33, indicating an average response in-between ‘agree’ and ‘strongly agree’.

Figure 2.24: Family caregivers have insufficient income/funds to pay for services and supports



As shown in Figure 2.25, the majority of stakeholders agreed or strongly agreed with the statement 'Services they need are not offered'. The mean score for this question was 3.00, indicating an average response of 'agree'.

As shown in Figure 2.26, the majority of stakeholders agreed with the statement 'lack of knowledge and training on how to best provide care'. The mean score for this question was 2.95, indicating an average response of 'agree'.

As shown in Figure 2.27, the majority of stakeholders agreed with the statement 'Unsupportive workplace policies (i.e. lack of access to family medical leave)'. The mean score for this question was 2.79, indicating an average response of 'agree'.

As shown in Figure 2.28, the majority of stakeholders agreed with the statement 'Insufficient support/help from family and friends'. The mean score for this question was 2.93, indicating an average response of 'agree'.

As shown in Figure 2.29, the majority of stakeholders agreed or strongly agreed with the statement 'Challenges of work/life balance (i.e. caregiving interferes with work and/or personal time)'. The mean score for this question was 3.32, indicating an average response in-between 'agree' and 'strongly agree'.

Figure 2.25: Services they need are not offered

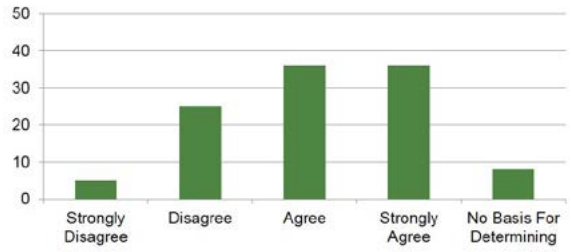


Figure 2.26: Lack of knowledge and training on how to best provide care

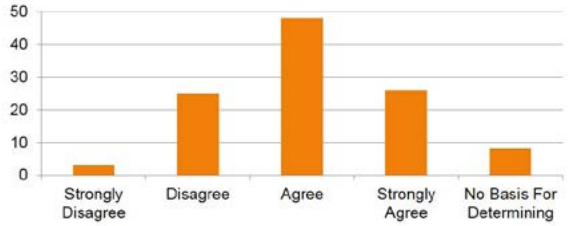


Figure 2.27: Unsupportive workplace policies (i.e. lack of access to family medical leave)

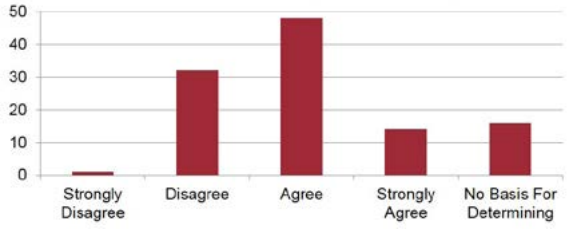


Figure 2.28: Insufficient support/help from family and friends

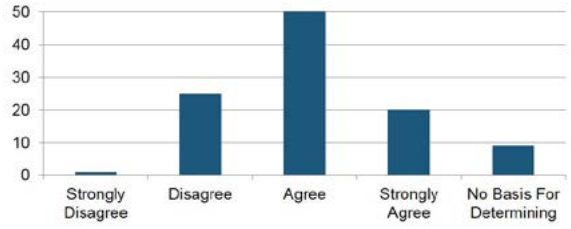
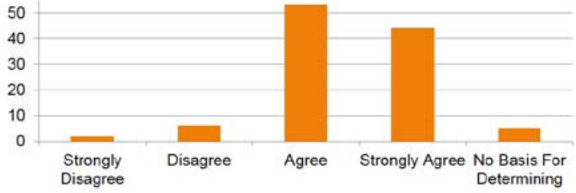
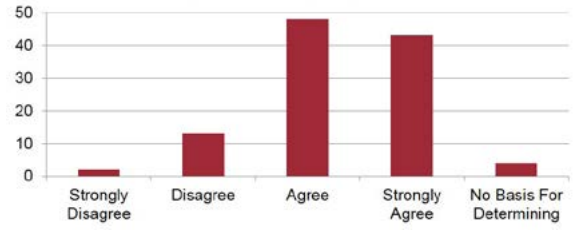


Figure 2.29: Challenges of work/life balance (i.e. caregiving interferes with work and/or personal time)



As shown in Figure 2.30, the majority of stakeholders agreed or strongly agreed with the statement 'Lack of community awareness and support for caregiving issues'. The mean score for this question was 3.25, indicating an average response in-between 'agree' and 'strongly agree'.

Figure 2.30: Lack of community awareness and support for caregiving issues

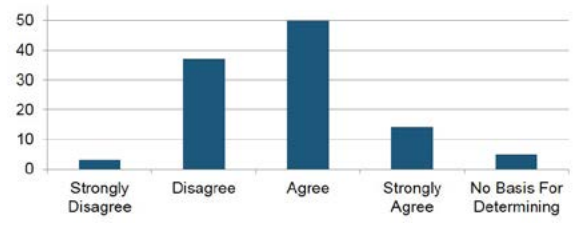


In sum, with regards to the challenges family caregivers face, on average stakeholders: a) strongly agreed that insufficient funds to pay, managing work/life balance, and lack of community awareness/support were challenges faced by family caregivers in their community, and b) agreed that needed services not being offered, lack of knowledge and training on how to provide care, unsupportive workplace policies, and insufficient support from family and friends were challenges faced by family caregivers in their community.

Barriers to the use of family caregiver services and supports in your community

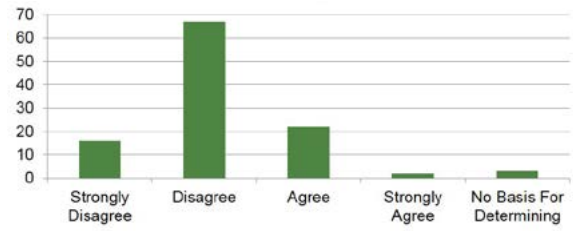
The question posed was: "Do the following represent barriers to the use of family caregiver services and supports in your community?". Eight statements were provided. For each statement participants were asked to rate their extent of agreement ranging from strongly disagree (1), disagree (2), agree (3), and strongly agree (4). A fifth option was 'no basis for determination'.

Figure 2.31: Family caregivers are reluctant to accept help



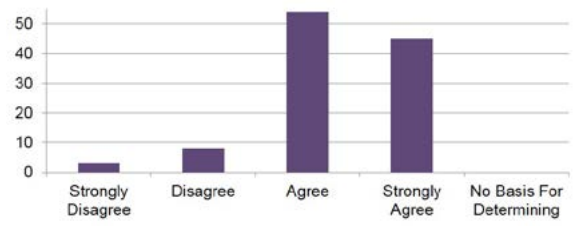
As shown in Figure 2.31, the most common response to the statement 'family caregivers are reluctant to accept help' was 'agree', followed by 'disagree'. The mean score for this question was 2.72, indicating though more people agreed, that there were mixed perceptions about this statement.

Figure 2.32: Family caregivers are not interested in services/supports



As shown in Figure 2.32, the majority of stakeholders disagreed or strongly disagreed with the statement 'family caregivers are not interested in services/supports'. The mean score for this question was 2.09, indicating an average response of 'disagree'.

Figure 2.33: Family caregivers are not aware of the services/supports or their benefits



As shown in Figure 2.33, the majority of stakeholders agreed or strongly agreed with the statement 'Family caregivers are not aware of the services/supports of their

benefits'. The mean score for this question was 3.28, indicating an average response in-between 'agree' and 'strongly agree'.

As shown in Figure 2.34, the majority of stakeholders agreed or strongly agreed with the statement 'Schedules of available services/supports do not match family caregiver needs'. The mean score for this question was 3.20, indicating an average response in-between 'agree' and 'strongly agree'.

As shown in Figure 2.35, the majority of stakeholders agreed or strongly agreed with the statement 'Locations of available services/supports do not match family caregiver needs'. The mean score for this question was 3.28, indicating an average response in-between 'agree' and 'strongly agree'.

As shown in Figure 2.36, the majority of stakeholders agreed or strongly agreed with the statement 'Workforce shortage (i.e., inability to hire qualified workers to provide caregiver services)'. The mean score for this question was 3.52, indicating an average response in-between 'agree' and 'strongly agree'.

As shown in Figure 2.37, the majority of stakeholders agreed with the statement 'Eligibility criteria are too restrictive'. The mean score for this question was 3.11, indicating an average response of 'agree'.

As shown in Figure 2.38, the majority of stakeholders agreed or strongly agreed with the statement 'Agencies lack funding to provide needed services'. The mean score for this question was 3.44, indicating an average response in-between 'agree' and 'strongly agree'.

Figure 2.34: Schedules of available services/ supports do no match family caregiver needs

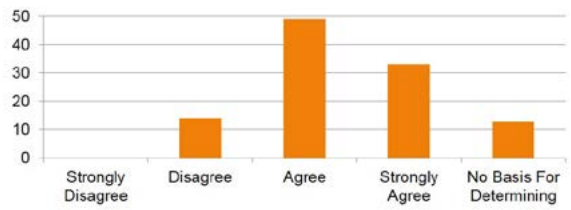


Figure 2.35: Locations of available services/ supports do not match family caregiver needs

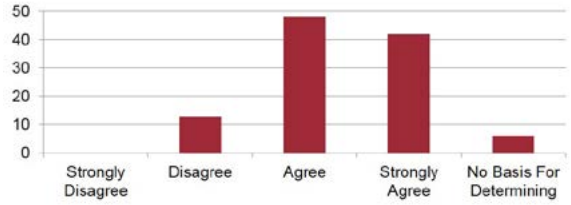


Figure 2.36: Workforce shortage (i.e. inability to hire qualified workers to provide caregiver services)

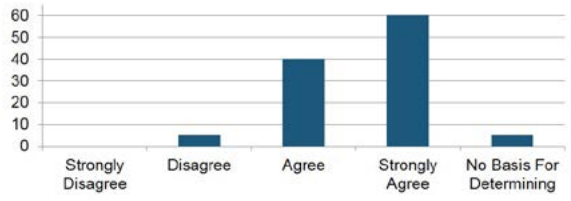


Figure 2.37: Eligibility criteria are too restrictive

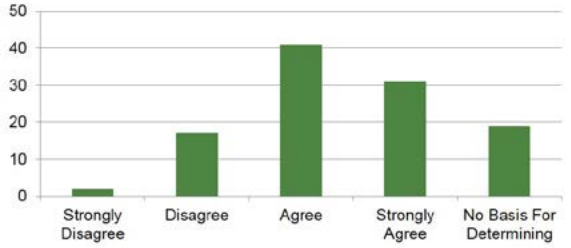
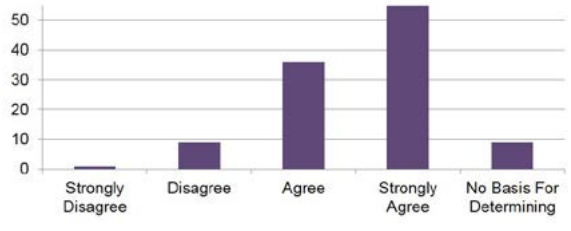


Figure 2.38: Agencies lack funding to provide needed services



In sum, with regards to the barriers organizations face in supporting family caregivers, on average stakeholders: a) strongly agreed that agencies' lack of funding to provide needed services, ND's workforce shortage, the location of services not matching caregiver's needs, and lack of awareness of services and supports were all challenges faced by family caregivers in their community, b) agreed that scheduling of services not matching caregivers' needs and too restrictive eligibility criteria were challenges faced by family caregivers in their community, c) were somewhat neutral with respect to the idea that family caregivers are reluctant to accept help, and d) disagreed that family caregivers are not interested in services.

Qualitative Findings

Participants were asked a series of open-ended questions about their perceptions of a) the challenges faced by families and organizations related to caregiving, and b) recommendations for improving services and policies related to family caregiving.

Challenges faced by families and organizations related to caregiving

Three distinct questions were posed to stakeholders that addressed issues of challenges related to caregiving faced by families and organizations.

1. In your opinion, what are the 3 greatest challenges facing family caregivers in caring for an older adult in the community?
2. In your opinion, what are the 3 greatest unmet needs of family caregivers within your community?
3. Please list the 3 greatest challenges facing organizations in providing services or supports to family caregiving of older adults.

Common themes emerged across these three questions and are presented in Table 2.1.

Table 2.1. Challenges related to caregiving faced by families and organizations.

Challenges faced by family caregivers		Unmet needs of family caregivers		Challenges facing organizations	
Financial costs of care	50	Lack of Support	44	Lack of available / compatible services	85
Difficulty connecting to / navigating services	49	Respite	38	Financial costs of programming	62
Lack of compatible services	41	Financial costs of care	38	Connecting to services	34
Respite	30	Education and training	31	Issues with policies and regulations	22
Work/life balance	24	Transportation	18	Location	15
Lack of Support	24	Difficulty connection to / navigating services	14	Time	4
Location (rurality)	20	Location (rurality)	7		
Education and Training	16	Safety	3		
Caregiver's Well-being	11	Work/life balance	2		
Time	5				
Safety	3				

Financial costs of care / programming

The most frequent caregiving-related challenge identified by stakeholders was the financial costs of care. Financing was reported as a struggle from the perspective of care recipients and their families as well as the service providers providing care. Caregivers and care recipients have trouble finding the money to pay for the services they need, while organizations struggle to pay for the programming and service provision in the face of uncertain budgets. Even when potential clients are able to qualify for services, organizations have issues with funding programs and clients have trouble paying for needed cares. For instance one stakeholder commented:

> *"Lack of funding (pending budget cuts will make it even harder)"*
>
> *"Insufficient funds to pay for services and supports"*

The middle class face pronounced cost challenges as they often do not meet requirements for financial assistance and care services are expensive. One stakeholder noted the challenge of:

> *"How to pay for [sic] services in the middle – not poor and not wealthy"*

Lack of available / compatible services

The second most common challenge identified related to the lack of availability of services. Stakeholders perceived a considerable lack of available services to meet the needs of caregivers and care recipients. Lack of compatible services refers not only to the actual shortage of facilities needed to serve caregivers and care recipients, but also the struggle involved with keeping such facilities staffed appropriately. Maintaining a good number of properly trained staff is a struggle for many organizations. Staffing shortages are crippling to organizations and have profound effects on not only the organizations, but care recipients and family caregivers as well. The following quotes demonstrate this theme:

> *"Nursing shortage"*
>
> *"Finding and retaining qualified/caring staff to provide services/supports…"*
>
> *"Qualified individuals to employ. Funds to pay these individuals a good wage. Finding individuals who are willing to keep up a schedule which requires traveling to homes, and to be physically able to do the lifting, etc. to provide personal cares in homes with a limited amount of equipment available to assist them."*

Difficulty connecting to / navigating services

A third common challenging issue related to family caregiving is connecting clients to the organizations and services that can be of use to them. Awareness of what services are available and navigation of the social services systems continue to be a gap between care seekers and care providers that needs to be bridged. For instance;

> *"It is challenging to get awareness of what organizations can do for caregivers to the people who could benefit from the information…"*

In some cases, those in need of care are reluctant to utilize available services due to the complexity of navigating the system. Disconnect between those in need of care and those who are capable of providing it is discouraging to some, as indicated in the following quote:

> *"Many family do not want to face the need/issues until it they have to (an uncomfortable topic) / Once they are willing to accept something needs to be done, many family members do not know what to do or who to reach out to get help to discuss options to take the next step."*

Other times, stakeholders perceived a reluctance from families and those in need of care to use services available or unwillingness to admit that they do actually need help in caregiving. This lack of connection in caregiving is an issue faced not only by caregivers themselves, but also by care organizations that are trying to provide services within a complex system.

Lack of support

The fourth most common challenge expressed by stakeholders was lack of support. Stakeholders mentioned that lack of support was a challenge as well as an unmet need for caregivers. Responses did not provide much elaboration to contextualize what kind of support was lacking. Some did clarify that the shortage of support was specific to support from the community and from family members. However, many stakeholders only responded simply 'lack of support' which could have various implications, in terms of social support, professional support, financial support, etc. Further exploration and analysis is needed to determine what types of support the stakeholders believe caregivers are lacking.

Respite needs

The fifth most common challenge expressed by caregivers was lack of access to respite care. Again, most respondents did not elaborate beyond identifying respite care as a challenge and unmet need. Stakeholders emphasized that respite care is challenging for service providers to deliver due to issues such as logistics, training, and cost. Another important perspective communicated was that respite care is frequently an unmet need for caregivers. Even in cases where caregivers were able to get some respite time, stakeholders perceived that there was still not enough and this was not a fully met need.

Lack of training and education

A sixth common challenge or unmet need identified by stakeholders was that caregivers faced a lack of training and education when it came to caring for their loved one as well. Caregivers would benefit from more training and education regarding the services they are trying to provide on their own as well as obtaining said knowledge proactively rather than reactively. For example, the following quote:

> *"Caregivers feel overwhelmed when they are not confident in providing care and treatment. There is sometimes a lack of education about the condition of the care recipient, and how to address their needs. They could use more education and reassurances from the medical providers to let them know if they are doing a good job. They need the medical providers to ask for their opinion more often – sometimes people are discharged even though the caregiver is not comfortable, because the caregiver isn't given the opportunity to talk about concerns, or doesn't feel comfortable doing so."*

Location (Rurality)

Seventh, the actual location of caregivers and care recipients poses a challenge and continues to be problematic in fully meeting their needs. Residents of rural communities faced the additional disadvantage of being too far from organizations offering services to be able to utilize them.

> *"Rural disparities for all services"*
>
> *"Lack of services for the very rural areas especially Hospice"*
>
> *"Unable to travel to rural areas as it is not reimbursed"*

Other challenges

Work / Life Balance. Stakeholders perceived that caregivers also face the added challenge of balancing work with caregiving responsibilities and, in some cases, caring for other members of their families. The following quote demonstrates this sentiment:

> *"Challenges of work/life balance. Caregivers are often working, have immediate family time commitments, as well as caring for their aging parents, etc."*

Policies and Regulations. A common challenge faced by organizations in providing services to families and older adults related to navigating the policies and regulations of governmental agencies, insurance programs, and organizations. Stakeholders expressed concern over restrictive policies and difficult to understand and navigate systems like Medicaid, as shown in the following quotes:

> *"Policies written too restrictively to provide adequate and realistic needed services to people in a variety of communities, sizes, and settings"*
>
> *"More and more regulations with less reimbursement"*
>
> *"Stricter guidelines from CMS; more insurance companies demanding notes on all cares provided: very taxing on the agency."*
>
> *"Eligibility criteria is too narrow"*

Transportation. Transportation was also identified an issue in terms of challenges and unmet needs faced by caregivers as well as organizations.

Caregiver's Well-being. Stakeholders identified caregiver's well-being overall is both a challenge and an unmet need. Not only was physical health of the caregiver a concern, but their mental health and opportunities for socialization were noted as a challenge or unmet need as well. The following quote expressed the burden of caregiver stress:

> *"Obviously, the stress of 24 [hour] caregiving – they are overwhelmed, can't sleep even though they are exhausted, patience levels become low, loneliness, etc."*

Time. According to stakeholders, time is a challenge faced by caregivers and organizations alike. Unfortunately, very little elaboration was given regarding what stakeholders meant by 'time'. Therefore, it is unclear if this is time with care providers from outside the home or simply more time needed by family caregivers to complete necessary cares.

Safety. Stakeholders mentioned safety of the care recipient as a concern in two distinct ways. First, they highlighted safety concerns related to the home environment and the provision of unskilled care by a family caregiver. Second, they mentioned the concern of practitioners of protecting older adults receiving care from elder abuse. These sentiments are demonstrated below:

> *"Safety of elder when home alone"*
>
> *"Protecting their family member from those who may try to take advantage of them"*

Recommendations for improving services and policies related to family caregiving

Two distinct questions were posed to stakeholders that addressed recommendations for improving services and policies related to family caregiving.

1. In your opinion, what are some ways to improve services and supports for family caregivers of older adults?
2. In your opinion, what initiatives or policies could improve the experiences of family caregivers of older adults in North Dakota?

Common themes emerged across these two questions. Major themes are presented in Figure 2.39 and Figure 2.40.

Figure 2.39: What are some ways to improve services?

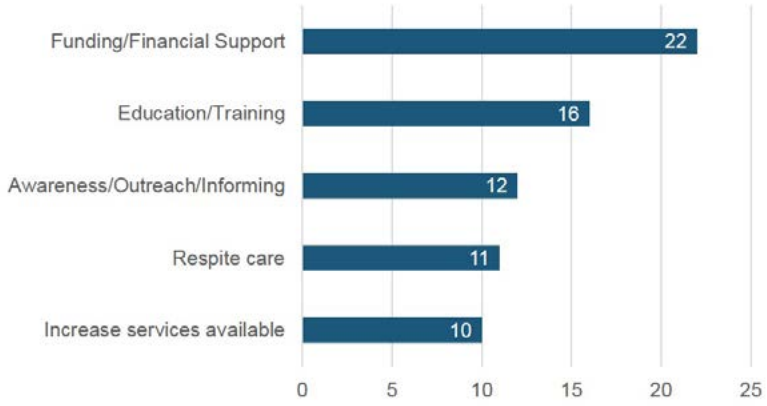
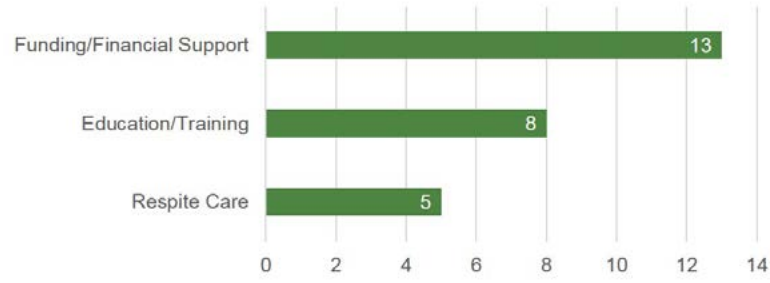


Figure 2.40: What initiatives or policies could improve the experiences of family caregivers?



Five major themes emerged with regards to stakeholders' recommendations for changes to services and policies.

Improve Funding/Financial Support

The most common recommendation provided by stakeholders was that the high need for funding/financial support for family caregivers should be addressed. Most respondents responded with comments suggesting a need for increased funding to meet family caregiver needs across the board. However, some did provide specific ideas on needed changes. These individuals offered specific examples or programs that they believe funding should be aimed towards.

For instance, some suggested the need to change regulations related to who can qualify to receive funding:

> *"Change some of the financial qualifiers."*
>
> *"I believe that there needs to be funding available or to have the knowledge of funding to assist caregivers and their families."*
>
> *"Raise Recipient Liability and SPED cost share limits to cover all low income persons."*

Others suggested specific types of services and supports that need to be better funded:

> *"More resources to get funds for items such as hospital beds or handicap vans so that willing family members have the necessary equipment to care for their loved ones at home if they are willing to do so."*
>
> *"Increase funding to HCBS types of services."*
>
> *"Increase the wage for family caregivers and quality service providers to make it highly desirable to care for aging family members."*

Finally, some stakeholders suggested that the sources of funding need to be considered and that policy-makers should consider making long-term investments in family caregivers.

> *"Funding could come from other areas, not just DHS, to ensure needs of seniors and their family caregivers are being met."*
>
> *"More government funding to support the needed resources."*
>
> *"Take state dollars away from unneeded entities like "Ducks Unlimited" and give it to care for humans!"*

Increase Education and Training

The second most common recommendation from stakeholders was that the provision of education and training related to family caregiving needs to be improved in the state of North Dakota. Many individuals stated their concern for caregivers not receiving the instruction they need in order to ensure loved ones are properly served. This is demonstrated by the quotes below.

> *"Education to family members before they need help — I am not sure how this would occur but I often hear from family members that they were unprepared for this role or never expected it to be so difficult. Many also do not realize that they are not alone—so many family members are experiencing the same thing."*
>
> *"Continue to repeat education and information as each generation enters retirement."*

"More education on the continuum of care, what it all entails, how the system work, etc. The problem is with offering education, people have to be willing to hear the message and this is not always the case."

"I think education versus enabling sometimes get lost. As healthcare providers/social workers we sometimes tend to "take over" instead of educating those how to provide/help themselves. We have identified in the last few months that be educating on process we can help many more people as our resources are not all used with a few people but rather helping a larger population."

Stakeholders also shared concern for lack of education in specific areas needed to care for loved ones, particularly with regards to dementia caregiving, as shown in the following quotes.

"Education of caregivers about diseases like dementia."

"Improve dementia screening and pursue accurate diagnosis so caregivers can receive more education and training and know more of what to expect."

Foster Outreach and Awareness of services available

A third recommendation made by stakeholders was to improve access to information about the caregiver services available. A lack of awareness and outreach to caregivers can lead to individuals not receiving the care they may need. Stakeholders felt that many of the family caregivers they work with are uninformed about the supports available to them, and moreover expressed concern that many current caregivers lack support due to lack of awareness. The following quotes from respondents demonstrate these concerns.

"Do outreach in places that family caregivers go to inform them of services. For example, they come to primary care for their own health or when they come with their loved one. Primary care is a good location."

"To increase the awareness of family caregiver services to community members."

"Make the rural areas aware of services available in the community."

"People don't know about services that are available until they need them and then they feel overwhelmed and don't know where to start."

Increase Respite Care

The fourth common recommendation was related to respite care. Stakeholders expressed a pervasive need to provide caregivers with a break from the tiring work of caring for an older family member. Many individuals stressed the need for greater availability of respite care services. Others mentioned the need for more funding in order to make these accommodations possible. The statements below demonstrated these concerns for respite care.

"Increase respite care and not have a waiting list."

"Coordination of care, including provision of respite care."

"Provide more funding for respite care services."

"Incorporate new financial guidelines for more to access respite care and adult day services."

"Increase available respite care hours through Family Caregiver Support Program."

Increase Services Available

Finally, stakeholders expressed a common theme in addressing the need to increase services available in general. Most frequently, this concern was targeted towards rural areas in the state of North Dakota. Some expressed concerns related to an insufficient workforce, suggesting that the state may be able to play a role in increasing incentives to train and work in family caregiving supports across the state. This sentiment of lack of services is demonstrated in the quotes below.

> *"Offer more programs for family caregivers."*
>
> *"Perhaps have service delivery from public health providers."*
>
> *"Expand services to rural caregivers."*
>
> *"More free services and support for families caring for an older adult."*
>
> *"Services need to be offered in rural setting and funded to provided them. We are very limited in this regard."*

Focus on Special Groups

Two groups were identified as potentially having unique needs: Veterans and American Indian older adults and their families. Though we were unable to identify the perspectives of these targeted special groups with the data from the perspective of family caregivers, we were able to evaluate the unique needs of these special groups from the stakeholders' perspective.

Veterans

Upon examining the quantitative data from stakeholders who work specifically with veteran elders and their families, no distinguishable patterns emerged. That is to say, the needs of family caregivers of veteran older adults appear to be similar to those of non-veteran older adults. However, the qualitative data revealed unique distinctions that need to be considered for family caregivers within the veterans' community.

Because veterans receive benefits through the Veteran's Affairs system, there are unique concerns related to working within this system. Some expressed concern that veterans face more 'red tape' than other seniors. For instance the following challenge:

> *""The constant politics of who is responsible," oh he is a veteran" that's a different criteria.""*

In particular, it is challenging for veterans in rural areas to access these services because they are often located in urban areas. These sentiments are demonstrated in the following quotes:

> *"We struggle to provide services to Veterans and Caregivers in our rural communities. Our inpatient respite care is only offered in Fargo which is impossible for many Caregivers to utilize due to distance. There are not resources within their communities to provide respite, home care assistance or even support groups."*
>
> *"Lack of options close to where the person in need lives, especially in rural areas. While the VA will pay for in-home respite, most of the rural home health care organizations are not staffed to provide this service so none are available to many caregiver in need"*

As suggested in this quote, Veterans may be eligible for benefits but unable to receive those benefits due to distance or issues of staffing. Stakeholders recommended initiatives that could help resolve some of these issues as shown in the following quotes:

"Expanding Veteran services to allow VA to utilize non contracted facilities for Adult Day Health Care and inpatient respite."

"[Increase] cross talk between agencies, for example, if social services has a family that needs help and they are a veteran, let the county VSO know and there are programs through the VA that can take over."

"Drop some of the "red tape" in programs. A veteran has to be a legal specialist to receive help. Vietnam Veterans especially suffer in their search for help. Our local hospitals are PA driven, maybe the VA service would be money ahead by allowing services [to] be provided locally by physicians without jumping through the hoops that currently exists."

American Indian Tribes

Similar to with the veterans, the quantitative data from stakeholders who work specifically with American Indian elders and their families did not show clear distinctions for this community. However, the qualitative data revealed unique distinctions that need to be considered for family caregivers with American Indian elders and specifically within Tribal communities.

Because American Indians have many programs and benefits administered through the Indian Affairs Commission, there are unique concerns related to working within this system. Moreover, within North Dakota there are five recognized Tribes, each with a distinct governing body, which means that the needs of family caregivers may vary quite greatly between tribes. Within four of these tribes, there is an Aging Services Program (that is coordinated at the tribal level but linked to state and federal programs (e.g. Older Americans Act), thus the programming within tribes may be similar yet distinct from programs across the rest of the state.

Stakeholders who work in tribal communities expressed many similar challenges in terms of rurality and access to services. A unique facet is the importance placed on delivering programs with cultural sensitivity. In particular, stakeholders focused on issues of family cohesiveness and emphasized the goal of caring for elders within the tribal community. Stakeholders focused on the cultural value of keeping elders in the home to be cared for by immediate family and other tribal kin/community, yet also did identify some challenges related to maintaining family cohesion yet also ensuring proper care. For instance, the following quotes:

"Need more help from family – usually recipient depends on just one family member. They need more family members to help."

"Monitoring – somebody should go into the home to monitor what is really going on between care recipient and caregiver. Sometimes proper care is not given because caregiver doesn't understand what they should be doing or how to do it. Going into home eve[r]y 3 to 6 months would be good."

"Elder abuse code needs to be in place."

A recommendation was to increase training within the community for family caregivers, yet also raise awareness of the needs of older adults within the tribes. Key to increasing training and education is ensuring that families can received culturally appropriate training, and moreover that workers are trained in a manner to encourage cultural competency. Such concerns extended beyond just increased proper awareness and education, but also in that there are significant challenges in terms of finding the qualified staff who could provide services to support family caregiving (i.e. respite care, or adult day care).

Part C. Summary and Conclusions of Aim 2

Highlights of North Dakota caregivers' perspective:

- Data were reviewed from 3 recent surveys of North Dakota caregivers: AARP-ND Family Caregiver Survey 2015 (N = 110), ND Family Caregiver Support Program Survey 2014 (N = 196) and 2015 (N = 92). In total, data were analyzed from **398 North Dakota Caregivers** from across the state (both rural and urban regions).
- **Caregiver characteristics:** 1) more likely women, 2) likely to be older adults themselves, 3) most common family relationship is spouses (second most common adult children), and 4) majority are working full or part-time though it is common to reduce/stop working as a result of caregiving duties.
- About 80% provide some type of medical or nursing cares, yet about half of caregivers report not receiving any training or instruction on providing medical cares.
- The most common non-medical help provided by family caregivers include shopping, transportation, and household chores.
- About 50% of caregivers feel they do not get enough respite (i.e., breaks) from caregiving, often because they cannot find someone to provide that respite care.
- **Common benefits of caregiving:** 1) satisfaction with being able to give back to and help loved ones, 2) value of helping maintain care recipient's independence, and 3) love and appreciation felt from care recipient.
- **Common challenges of caregiving:** 1) lack of sufficient respite time (providers), 2) need help finding available services and resources, 3) lack of knowledge, education, or training related to being a caregiver, 4) caregiver stress and impact on caregiver's well-being, and 5) financial burden of providing care

Highlights of North Dakota stakeholders' perspective:

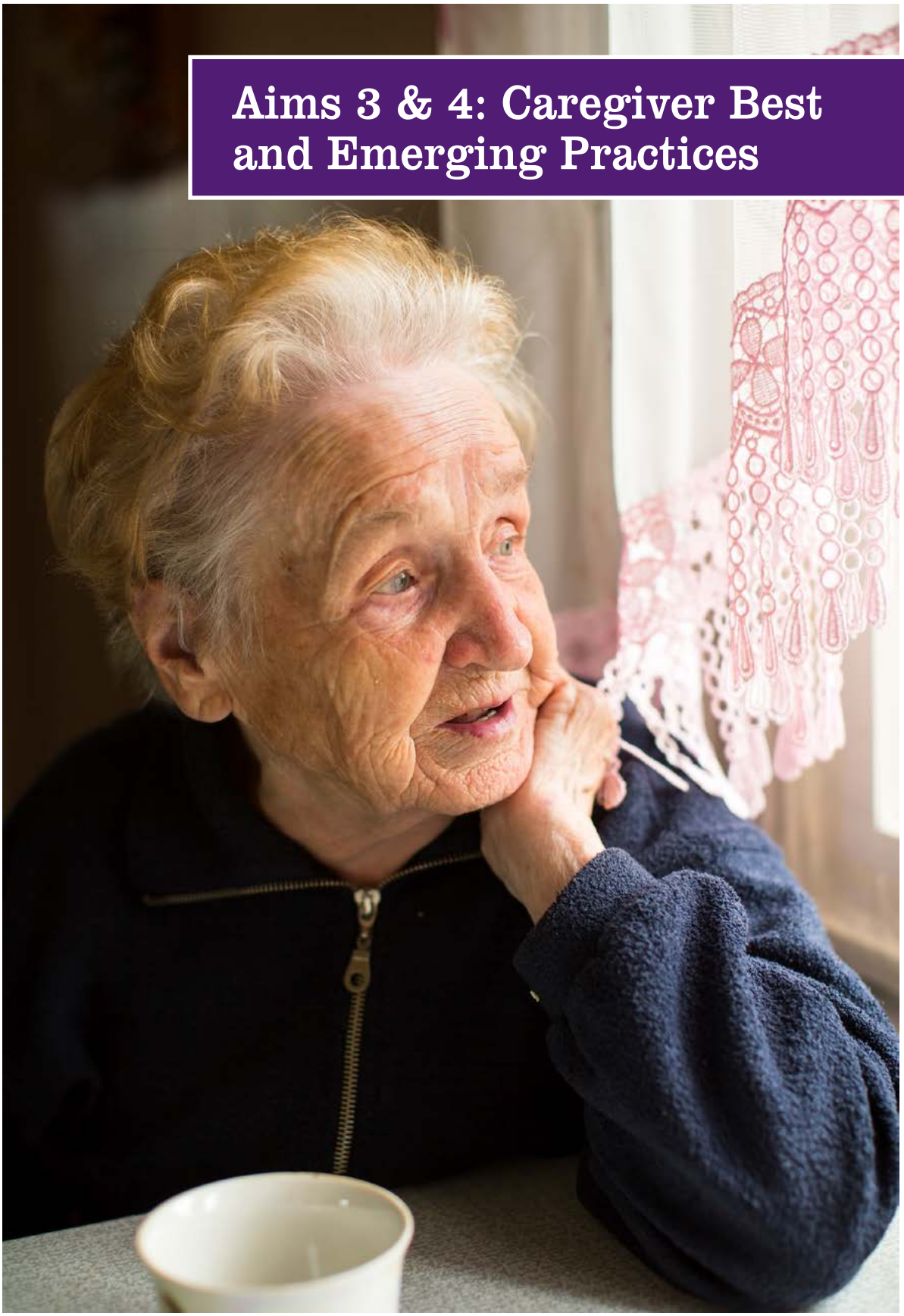
- Data were analyzed the NDSU conducted ND State Caregiving Stakeholder Survey (2016). In total, data were analyzed from **116 North Dakota Family Caregiving Stakeholders** from across the state (both rural and urban regions).
- **Stakeholder characteristics:** 1) Averaged 13 years working with family caregivers, 2) 58% were direct service providers, and 3) most common roles of program coordinator, social services provider, and agency directors,
- **Organization characteristics:** 1) organizations mostly non-profit and governmental, 2) service sectors (from most to least common): healthcare, long-term care, social services,

aging services, community-based organizations, state and local government, advocacy agencies, faith-based organizations, veteran's organizations, and tribal agencies, 3) caregiving-related services provided (from most to least common): information and referral, care management, respite, advocacy, training and education, dementia care, transportation, personal care, bereavement support, assistive equipment, congregate meals, volunteer services, home health care, adult daycare, and nursing.

- strongly agreed that insufficient funds to pay, managing work/life balance, and lack of community awareness/support were challenges faced by family caregivers in their community, and b) agreed that needed services not being offered, lack of knowledge and training on how to provide care, unsupportive workplace policies, and insufficient support from family and friends were challenges faced by family caregivers in their community.
- strongly agreed that agencies' lack of funding to provide needed services, ND's workforce shortage, the location of services not matching caregiver's needs, and lack of awareness of services and supports were all challenges faced by family caregivers in their community, b) agreed that scheduling of services not matching caregivers' needs and too restrictive eligibility criteria were challenges faced by family caregivers in their community, c) were somewhat neutral with respect to u the idea that family caregivers are reluctant to accept help, and d) disagreed that family caregivers are not interested in services.

- **Common challenges/unmet needs of families and service organizations:** 1) financial costs of care/programming, 2) lack of available/compatible services, 3) difficulty connecting to / navigating services, 4) lack of support, 5) respite, 6) lack of training and education, and 7) location (rurality).
- **Stakeholder recommendations:** 1) improve funding/financial support, 2) increase education and training, 3) foster outreach and awareness of services available, 4) increase respite care, and 5) increase services available.
- **Veterans' groups:** have special needs related to coordinated services with the VA, particularly challenging in rural North Dakota.
- **American Indian Tribes:** coordinating services between Tribal and state programs is a challenge. Special consideration needs to be made to support family caregivers in a culturally sensitive way.

Aims 3 & 4: Caregiver Best and Emerging Practices



Aims 3 & 4: Caregiver Best and Emerging Practices

Aims 3 and 4 both consisted of reviewing the extant research literature, relevant programs and practices across the U.S.

Aim 3. Identify best practice models for family caregiver support programs from other states.

We will review the scientific literature and relevant websites to identify successful models across the nation as well as internationally. We will then conduct an analysis of the key themes of success for caregiving models.

Aim 4: Identify emerging practices and technology that can enhance caregiver and patient home supports.

We will review the scientific literature and relevant websites to identify successful models across the nation as well as internationally. We will then conduct an analysis of the key themes of success for caregiving models.

Part A: Review of Literature and Programs

Part B. Examples of Best and Emerging Practices

Part C. Challenges to Applying Best and Emerging Practices

Part D. Summary of Best and Emerging Practices

Part E. Resources for Best and Emerging Caregiver Practices

Part A. Review of Literature and Programs

Determining service opportunities should be guided by what is known of best practices along with having an eye on emerging practices with strong potential. The application of best practices must be considered in the context of the costs, the culture, and the community. Programs that are successful in urban areas may need to be adapted or may simply not be feasible in a rural context. The challenges of identifying best and emerging practices in services to elders and their caregivers include the lack of standards and consensus related to specific services, the lack of adequate evaluation of existing programs, and a void in the research comparing different methods of service delivery and delivery methods most effective for rural areas. Further, caregivers and those receiving care represent a tremendous variety of situations influenced by age, health, distance from the caregiver, and available services making a one-size-fits all solution to supports unfeasible. Based on a review of the literature, we were able to identify pilot studies, examples of the use of technology, and recommendations for providing quality programs for some types of services. For the reasons mentioned above, these practices should not be applied without careful consideration.

Service coordination and collaboration is key.

With the often-stated challenge and cost of hiring professional care providers, use of volunteers can be effective in providing transportation, companionship, respite and other services. Professional providers usually direct finding, training, and coordination of volunteers. Coordination across service and health care providers can increase service access. Community nurses and mobile adult day care are examples of positive approaches to meeting rural service needs, but coordination and communication is needed to maintain program success through regular turnover of participants. Kelly, Reinhard, and Brooks-Danso (2008) suggested changing organizations to create a culture of collaboration that includes paraprofessionals, care recipients, and caregivers.

"The current evidence indicates that hospital discharge planning for frail older people can be improved if interventions address family inclusion and education, communication between health care workers and family, interdisciplinary communication and ongoing support after discharge. Interventions should commence well before discharge." (Bauer, Fitzgerald, Haesler, & Manfrin, 2008, p. 2539).

Combining in-person family therapy and a computer telephone integrated system to include family members unable to attend in person decreased caregiver depression to a greater extent than in-person therapy alone (Eisdorfer et al., 2003)

Technology offers extensive opportunities to overcome challenges of distances in rural areas.

In a recent study by AARP (2016), it was found that most (71%) caregivers were interested in technology to support caregiving, yet few (7%) use it to assist with caregiving. Caregivers were most frequently using technology to organize care schedules (19.5%), track caregiving activities (12.4%), and manage prescription refill and delivery (11.3%) (AARP). Knowledge and costs were the greatest challenges to using available technologies. Telehealth, e-health monitors, and tele-pharmacy applications are effective in providing health information and assessing care needs from a distance. Distant caregivers can utilize applications such as Skype and Facetime to obtain a visual connection with an elder providing more information on health status than from a telephone call. In addition, social media can be effective in providing emotional support for caregivers. The opportunities for using technology to enhance the lives of caregivers and the care of elders grow daily and are too numerous to mention here. Assessing and implementing the best technologies for rural North Dakota needs to build on careful assessment of best practices and testing of new devices and software. The notion that caregivers are unwilling to use technology is refuted by current research. In the AARP (2016) study, nearly 80% of caregivers indicated interest in using technology to support medication refill and pickup, making and overseeing medical appointments, assessing health, ensuring safety, and monitoring medication.

> *Telephone-based psycho-educational interventions have been proven to provide relief from caregiver burden, distress, and depression while allowing caregivers to remain in their homes. (Davis, Burgio, Buckwalter, et al., 2004)*

Training for service providers, volunteers, and caregivers is critical and technology can enhance the quality and reach of training efforts.

Even lower-tech applications such as the telephone have been used successfully to educate and support caregivers reducing caregiver burden. Higher tech solutions such as virtual learning can be used to train caregivers and professionals in formal settings such as hospitals and, in the near future, will become more accessible in homes. Role playing and interactive practice was found to be best practices for training and these methods could be adapted for use with distance technology. Although new technologies are often more user-friendly, training for all users needs to be part of the implementation plan.

> *Doody et al (2001) noted that research on short-term education programs have little impact on caregivers or elders. Longer-term, more intensive education, however, improved caregiver health ratings and delayed nursing home placement of the care receiver by a year or more.*

Best and emerging practices should be applied to informing caregivers, volunteers, and professional service providers of available caregiver supports.

Locating available services is inhibited by constant change in available providers. Tracking available services requires sustained effort. Knowledge of available services enhances caregiver feelings of competence but that information is often not available, is difficult to access, or is out of date.

Table 3.1 lists areas of best practices and emerging practices. In the discussion that follows, we will provide a broader overview of best and emerging practice themes most suitable to North Dakota and the challenges in applying these best practices followed by more detailed examples within these service areas.

Table 3.1. Best and Emerging Practices in Caregiving

Practices in Caregiving	Best	Emerging
Availability of Help / Support	• Telephone-based psycho-educational interventions • Virtual care • Community nurses	• Person-centered care (i.e., Money Follows the Person) • Mobile adult day care (especially in rural areas) • Working with college students • Technology (i.e., smarthomes, robotic applications, etc.) • Socially Assistive Robots • Smart Wear • Autonomous vehicles
Financial cost of care / Funding	• Sliding scales and vouchers • Increasing access to paid family medical leave • Long-term care planning	• Telemedicine reduced hospitalization • Co-op models • Tax credits for caregiving
Knowledge and ability to provide needed cares	• Interactive training (e.g. role playing) • Comprehensive discharge planning • Long-term education programming • Preventative care	• Home visits upon discharge • Virtual learning modules in hospital waiting rooms • Use social media to increase awareness • Trainings for employers about eldercare • Mobile apps for long distance care • Home monitoring devices
Respite / Well-being of Caregiver	• In-home care • Health education programs	• Respite provided by volunteers • Online emotional support groups • Employ Behavioral Risk Factor Surveillance System's (BRFSS) caregiver module to detect caregiver burden

Part B. Examples of Best and Emerging Practices

The examples below highlight the current best and emerging practices. Practices were considered best when they had a longer history of use and evaluation regarding their effectiveness. Emerging practices were more recently applied and held good promise of success based on initial evaluation.

Availability of help

Best

Telephone-based psycho-educational interventions have been proven to provide relief from caregiver burden, distress, and depression while allowing caregivers to remain in their homes. (Davis, Burgio, Buckwalter, et al., 2004).

Emerging

Person-centered care benefits the health and wellbeing of caregivers (Conor, Siebens, & Chodosh, 2015).

Socially assistive robots (SAR) have potential for enhancing the well-being of elders and reduces the workload for those providing care. SARs range from robotic cats, dogs, and rabbits to those with more humanoid qualities. Varied attempted outcomes in initial research include increasing engagement and activity through play, provide social interaction, accessing internet and TV, decreasing loneliness, and engaging elders cognitively (Kachouie, Sedighadeli, Khosia, & Chu, 2014).

Smart Wear refers to clothing such as vests, underwear and headbands with integrated monitoring devices that can be used to provide location and health information. Caregivers identified the ability to monitor location and vital signs as benefits that could improve care and reduce caregiver anxiety, but were concerned that Smart Wear might reduce direct interaction (Hall, et al., 2014).

Autonomous vehicles may be used to deliver caregivers to appointments without the need of volunteer or caregiver drivers (Delaware Family Caregiving Taskforce, 2015).

Cost/finances

Best

Coleman (2000) recommended using sliding scales for services for those whose income exceeds Medicaid or state-funded income eligibility criteria instead of eliminating those individuals from the program. Cash allowances or vouchers could be used to purchase the type of services or supplies unique to the caregivers needs.

Recommendations of best practices for employers included increasing paid time off. Employer flexibility reduces absenteeism rates, increases retention rates, and reduces health care costs of employee caregivers (Wagner, Lindemer, Yokum, & DeFreest, 2012).

Emerging

A study conducted in MA showed promise in reducing re-hospitalization when a telemedicine service was used in place of a traditional on-call medical professional (Grabowski and O' Malley, 2014).

Knowledge and ability to provide needed cares

Best

Using skills training, role-playing, and interactive practice were the most successful training methods in reducing caregiver burden (Lykens, Moayad, Biswas, Reyes-Ortiz, & Singh, 2014).

Health education programs can help caregivers reduce depression, increase knowledge of community services and how to access them, change caregivers' feelings of competence and how they respond to the caregiver situation. After 1 year, they felt the health education program helped them learn how to access community resources. (Toseland, McCallion, Smith, et al., 2004).

Emerging

Virtual learning modules in hospital waiting rooms show promise in improving options for service delivery and providing education and training to patients and caregivers (Conor, Siebens, & Chodosh, 2015).

Long distance caregivers desire mobile/web applications that provide medication regimens/ adherence, calendaring, cognitive health information, video calling, data on the elder's sleep and exercise, and other monitoring and communication opportunities (Williamson, Gorman, & Jimison, 2014).

Home monitoring technology can be used to help detect falls, the elder exiting the home, or changes in daily patterns. Likewise GPS can be used to monitor an elder's location outside the home (Delaware Family Caregiving Taskforce, 2015).

Respite

Best

It is important to have a variety of options while choosing respite services. Most families prefer in-home respite care because the care recipient may be more comfortable and would not have to adjust to a new environment, the home is already equipped for any special needs, the cost is relatively economical (especially if you hire and train your own provider), transportation barriers for the care recipient are eliminated. Volunteers who are carefully matched with program needs can provide respite care. Respite programs should plan for comprehensive orientation, training, ongoing support and supervision, as well as specific volunteer job roles (Silberberg & Caruso, 2001).

Arizona has a Respite Voucher program funded by a "collaborative partnership between the Arizona Caregiver Coalition and Arizona Department of Economic Security, Division of Aging and Adult Services, Arizona Association of Area Agencies on Aging and through the support of other public/private partnerships." (http://www.azcaregiver.org/).

Medicaid-eligible elders in Minnesota can utilize the Elderly Waiver program to fund respite care or adult day care. Those who are low income but not MA eligible can access the state-funded Alternative Care program. (http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=id_056766)

Oregon provides start-up and ongoing funds to build community networks to help families access respite care and find payment options. (Silberberg, 2001)

Emerging

Some programs have been successful in recruiting volunteers for respite programs. Suggestions for Caregiver Corps, etc. perhaps for student loan debt forgiveness, tax credits, stipends. (Rose, Noelker, & Kagan, 2015).

Part C. Challenges to Applying Best and Emerging Practices

Challenges for implementing quality practice include the lack of health professionals with geriatric expertise. This is especially a concern in rural areas of North Dakota but is relevant across the state. More generally, the lack of trained professionals has been identified as a problem in a number of service areas and again is an even greater challenge in rural areas.

> *Feinberg and Newman (2005) cited payment to family caregivers as a key solution to the problem of worker shortage and as a way to both improve outcomes and help family caregivers continue in that role.*

Considering the rapidly emerging possibilities for new caregiver practices, regular technology training updates are important for current service providers. Education programs must be accessible, should be updated regularly, and should not be prohibitive in terms of time.

> *Sterling (2014) noted that few technology tools are designed specifically for caregivers and their needs. Finding time to learn and apply technology into the caregiver routine is difficult.*

Lack of funding is a consistent challenge to applying best practices in rural areas or to keeping up with emerging practice and technologies. The purchasing, replacement, and upkeep expenses of some technologies are prohibitive or inconsistently available. Funding levels also influence the quality and number of available staff and severely limit the level of service available (such as respite) hours. With the growing numbers of elders needing support, current funding levels will reach a shrinking percentage of those in need.

Coordination, collaboration, and communication among service providers and with family caregivers are often lacking causing those in the care system to be less aware of needs and opportunities. Case management services can be effective in coordinating and communicating across a system of care, but case managers must be aware of local resources and know how to help elders and their caregivers access them.

Table 3.2. Challenges Related to Developing Best and Emerging Practices in Caregiving

Challenges	
Logistics and Implementation	**Limitations and Caveats**
• Balancing the needs of care recipient and caregiver • Increasing costs • Staffing shortage • Rurality	• Budget Cuts • Lack of flexibility in federal programs (i.e. Medicare) • Lack time to learn and implement technologies

Based on caregiver reports and the caregiver literature, the following specific challenges have been noted:

- Balancing the needs of the care recipient and the caregiver. For example, higher quality care for the recipient may create a greater challenge for the caregiver in terms of addressing their own needs, possibly increase time or expense giving care.
- Not enough staff to meet the demand of services. Rural locations are problematic for transportation/access to qualified providers. Ever rising costs make the help needed unaffordable.
- Grabowski & O'Malley (2014) identified concerns with determining who will pay for telemedicine delivery. Specifically, what would move the patient or care center/nursing home to pay for this service when it is Medicare receiving the cost benefit?
- Budget cuts continue to be an obstacle given the growing aging population. Many limited-resource aging adults are facing greater out of pocket expenses. Programs are trying to support more people than ever before. Guidelines can be strict and money runs out fast.
- Ever changing technology comes at a financial cost. Maintaining, updating, and creating technology is expensive (i.e., staff needed to build and maintain software, cost to access software, computers, servers, internet, etc.).
- There is rarely enough respite time even when it is available. Rural locations present barriers to access. Moreover, family caregivers are sometimes reluctant to accept help.

Part D. Summary of Best and Emerging Practices

Best and emerging practices frequently but not always include applications of the latest technology. These practices may provide more frequent and higher quality care at a lower cost. For example, telemedicine can provide more frequent checks on health of vulnerable rural elders with lower personnel and transportation costs. Such checks can result in the ability to respond to minor health needs before they become major (and more expensive) problems. Online education and support can help caregivers provide better care and experience reduced stress resulting in better quality of life for both the elder and caregiver. In addition, as a result of the available technology, this can be done without the need to travel or use difficult to access respite care.

Best practices do not always require the latest technology. Programs such as a mobile adult day service can reach rural areas where a full-time on-site program would not be cost effective. Consideration should be given to implementing programs to serve multiple functions. A mobile adult day service could provide health monitoring and social interaction for elders while also giving respite and training/education opportunities for caregivers. Schulz and Martire (2004) highlighted numerous interventions for specific risks. For example, interventions to impact caregiver health should include respite, education, monitoring, and facilitating access to services.

Challenges to implementing best practices include cost of technology purchase, upkeep, replacement, and training. Cost of personnel and locating qualified professionals or willing volunteers can be especially difficult in rural areas. Needed training can cut into time for direct service, especially if that training requires considerable travel. Sustainability requires updated training materials, a successful financial model, and the flexibility to adapt programs according to evaluation results and new technologies.

Implementing what seems to be a best practice or the latest idea in caregiving needs to be done with careful consideration and analysis. Standards of best practice are not well established in many areas of care. The generalization of what is reported as a model program to specific settings in rural North Dakota may not be appropriate because of distance, culture, availability of trained professionals, etc. Organizations developing new programs need in include an evaluation expert from the beginning of the project development. Programs developed in North Dakota must be carefully evaluated. Evaluation will create opportunities to adjust elder and caregiver supports to result in the best outcomes. Because of the unique needs, resources, and culture of the area, the most appropriate setting for developing best practices is in the communities where we are providing services.

Part E. Resources for Best and Emerging Caregiver Practices

ARCH National Respite Network and Resource Center (2011) National Respite Guidelines: Guiding Principles for Respite Models and Services. http://archrespite.org/productspublications
- This booklet provides a description of respite and various respite models.

Levine, C. Halper, D., Peist, A., and Gould, D. (2010). Bridging troubled waters: Family caregivers, transitions, and long-term care. Health Affairs, 29, 116-124. http://www.healthaffairs.org/
- Reviews transition care and the outcome of studies of transitional care programs.

MetLife National Study of Adult Day Services: Providing Support of Individuals and their family caregivers (2010). https://www.metlife.com/assets/cao/mmi/publications/studies/2010/mmi-adult-day-services.pdf
- This manuscript describes adult day services centers, services offered, funding, and implications for consumers, providers, and policy makers.

AARP (2016). Caregivers & Technology: What they Want and Need. http://www.aarp.org/content/dam/aarp/home-and-family/personal-technology/2016/04/Caregivers-and-Technology-AARP.pdf
- This report highlights the interest of caregivers in using technology and the areas for technology caregiver innovations.

Sterling, M. (2014). What family caregivers need from health IT and the healthcare system to be effective health managers. Connected Health Resources. www.connectedhealthresources.com
- Discusses the effective use of caregiver technology especially in the area of health information.

Adler, R. & Mehta, R. (2014) Catalyzing technology to support family caregiving. National Alliance for Caregiving. http://www.caregiving.org/wp-content/uploads/2010/01/Catalyzing-Technology-to-Support-Family-Caregiving_FINAL.pdf
- Discusses caregiving and maximizing technology to support family caregivers.

Aim 5: Conclusions and Recommendations

Aims 5: Conclusions and Recommendations

Aim 5. Provide recommendations to the interim committee

Objective: Synthesize the information gathered in Aims 1-4 to develop conclusions and inform recommendations to present to the committee. Recommendations will include best practices for community supports and technology opportunities, policy needs, and top priorities for family caregiver supports and services.

Part A: Overview

Part B. Research Conclusions

Part C. Recommendations

Part A. Overview

As services and policies related to family caregiving are developed and implemented, consideration should be given to the following:

- There is tremendous savings and economic value of informal caregivers over formal care options. Supporting informal caregivers is a low cost option that has the potential to create outcomes including reduced hospital admissions, delayed entry into formal long term care, and decreased amount of time spent in long term care.
- Actions by the state need to address sustainability of programs. Projects are often short-term with no plans beyond for maintenance and sustainability. In particular, programs such as resource and referral and education are funded once (i.e., to create a curriculum or a database), yet it is key that sustainable funding is put in place to keep these services up-to-date, accessible, and user-friendly.
- There is great potential in strengthening public, community, and family partnerships. Many successful family caregiving programs and supports (both within ND and nationally) are grassroots, community-level programs that are able to tailor services to local needs. However, such programs are best able to function and thrive when public policies and programs provide support and avenues for sustainability.
- As new and emerging supports for caregiving are developed and implemented, serious attention must be paid to implementing supports that are research-based and continuing only services that are determined to be successful through professional evaluation.
- Policy considerations should include supporting industry that provides new technologies for eldercare such as big data, virtual care strategies, robotics, and technology for smart homes.

Part B. Research Conclusions

The primary goal of family caregiving is to help older adults to maintain their independence and well-being. This study concludes that though family caregiving is rewarding, North Dakota family caregivers are vulnerable due to lack of support. The following conclusions have resulted from this study:

1. High costs of care and lack of funding are a significant problem

The high costs of care and lack of funding for services to support caregiving prove enormously challenging for North Dakota caregivers. The majority of caregivers are working full-time or part-time as ongoing income is central to providing care. However, given the pervasive concerns related to work-life balance, it is evident that balancing paid work and care creates a major burden to family caregivers. Repeatedly, caregivers cite the high costs of providing care. The stakeholders, who were most often service providers, cited difficulty paying for and sustaining programs. This lack of funding is compounded by the fact that a great deal of family caregiver support is currently being provided in the non-profit sector. These obstacles for service-providers in funding their programs meant that in many cases needed programs could not be created or sustained. In fact, both stakeholders and caregivers report that not enough services are being offered across our state.

2. Insufficient access to Respite Care

Both caregivers and stakeholders clearly indicated that one of the most salient gaps in the services provided to North Dakota family caregivers is related to respite. About 50% of caregivers felt they do not get enough respite from caregiving, often because they cannot find someone to provide that respite care. These issues were especially salient in rural areas of the state. The issue of insufficient access to respite care is in part an issue of funding, but also an issue of the availability of respite care workers. This gap is indicative of a major risk to caregiver well-being, as it is well documented that caregiver stress and burden (which can be partially alleviated by respite care) is a major predictor of declining physical and mental health and even mortality among caregivers, not to mention the potential negative repercussions for the care recipients (i.e., premature admission to nursing home).

3. Difficulty finding, connecting to, and navigating available services and resources

Caregivers reported difficulty finding services and programs, indicating there is a gap in access to information about available supports. Moreover, they discussed the challenges of navigating available services even when they felt they had found the appropriate services. Stakeholders

reported a lack of community awareness about both the needs of family caregivers and the programs available to help those caregivers. Though not technically an outcome of this study, many of the challenges experienced by our research team were quite telling. As we worked with various entities across the state to navigate these information systems it became clear that budget cuts and a lack of funding create major limitations to ensuring information is comprehensive, accessible, and current. In some instances, lack of staffing poses a challenge to accessing information (i.e., vacancies in social services or other aging services positions). Similarly, in some programs that are state-wide or regional, a lack of staffing sometimes limited those programs from being able to actually deliver services across the state or intended region. Sometimes, key stakeholders were unaware of services available in their region, suggesting a lack of communication and outreach between systems. Websites were often outdated and difficult to navigate. There is not a 'one stop' comprehensive resource to access to find all needed information related to family caregiving supports in ND (i.e., to find the needed information we need to piece together an array of different sources). Moreover, the databases that do exist are not kept up-to-date on a regular basis.

4. Education and training

Lack of education about caregiving was evident throughout the data components of this study. Family caregivers lacked training related to the logistics and financial management of caregiving as well as best practices for providing support in activities of daily living. Of particular salience, stakeholders felt that caregivers lack knowledge and training on how to provide care. The caregiving data indicated that though about 80% of family caregivers provide some type of medical or nursing cares, only half of caregivers report receiving any training or instruction on providing these medical cares. These findings suggest a major gap in training for family caregivers in the provision of nursing cares, which is a great concern because empirical research has documented that caregiver education programs can reduce healthcare costs and delay nursing home placement (Toseland, 2004).

5. Supports for eldercare in rural regions of ND is scant

Both caregivers and stakeholders reported the challenge of lack of available and appropriate services. This sentiment was especially strong for eldercare in rural North Dakota. An examination of the key categories revealed several services to be underrepresented in rural regions, such as care management, training and education, transportation, and volunteer programs. Respite care and emotional support, both important for fostering the well-being of the caregiver, were found to be lacking in the state, as well. Direct care services, such as adult day care, dementia care, personal care, and homemaker/chore services were significantly lacking in rural areas. Findings from this study highlight the unique needs and challenges of family caregiving in rural areas of the state.

Part C. Recommendations

Based on these conclusions, we have developed a series of recommendations. We begin by discussing a few overarching recommendations that cut across the various conclusions, and then discuss recommendations based on each of the core study conclusions.

Overarching Recommendations

- Develop family caregiving taskforce consisting of caregivers, service providers, and community leaders. The taskforce would develop recommendations regarding support for caregivers addressing the service gaps noted in the studies, issues related to distance, population density of those needing service, culture, and other caregiving challenges. Considering current, best, and emerging practices, the taskforce could make recommendations regarding closing service gaps in area noted. A particular focus of this taskforce should be the unique concerns related to rural caregiving in North Dakota.
- Foster marketing and outreach to increase awareness of current programs and services.
- Explore ways to lift restrictive eligibility criteria and cut the red tape, or expand funding opportunities to include those not currently financially eligible.
- Increase service availability for respite care, care management, training and education, emotional support, volunteer programs and a range of direct care supports (adult day care, homemaker/chore, dementia care, and personal care).
- Resources to address caregiver well-being (including preventative, screening, and intervention care).
- Develop supports and guidelines for the streamlined integration of state-sponsored services and specialized programs for Veterans and American Indian Tribes. Study findings suggest challenges to navigating these multiple systems, indicating the need to support families to understand the ropes of each program and how they align.

Recommended goals, along with strategies, resulting from study's core conclusions:

1. Improve avenues for sustainable funding for family caregivers and programs that support them

Funding/costs related to caregiver supports need to consider both opportunities for additional resources and collaborations for care supports and for services that reduce costs by reducing re-hospitalization or premature entry into a higher level of care. These opportunities include:

a) Explore legislation that would provide tax credits for private sector employers who offer a 12-week paid family medical leave. This would support employees who need to take a leave from work to care for a spouse, child, or parent who has a serious health condition.

b) Expand the minimum requirements of the Family and Medical Leave Act (FMLA) to increase the number of people who can access the FMLA by altering the eligibility requirements, expanding the range of family caregiving relationships, or increasing the amount of unpaid leave than can be taken.

c) Re-evaluate the proposed budget cuts that will drastically affect the Homemaker Services authorized by county social service agencies. The proposed budget cut will reduce the reimbursements agencies and individual QSPs receive by nearly 50% starting in July 2016, having the potential to impact the availability of QSP services across the state.

d) Evaluate the use of and potential reimbursement options for telemedicine and other technologies that have been shown to reduce re-hospitalization and allow long-distance caregivers to join in health care visits.

e) Consider adjusting the sliding fee scale for the state-funded Service Payments for the Elderly and Disabled (SPED) Program which provides services that help older adults or physically disabled persons who have difficulty completing tasks to live at home independently. Adjusting the sliding fee scale based on similar models, in order to account for cost of living and inflation, would ease the financial burden on lower-income older adults.

f) Educate employers about the special needs of family caregivers and the importance of developing policies and strategies to support, retain, and reduce the burden and stress of employees who are engaged in caregiving.

g) Create a plan to expand long- term care (LTC) insurance coverage across the state. This plan could include educating citizens on the benefits of LTC insurance, expanding tax credits for individuals who purchase LTC insurance and employers who provide some level of benefit toward the insurance, and providing state employees with a subsidized LTC insurance plan.

2. Increase access to respite care across the state

Respite support (including adult day care services) can be provided in various forms such as in-home and facility-based programs. Whereas the ideal program for a community might be one that offers a variety of respite choices, implementation and coordination costs may be prohibitive. One best practice that could be applied as a new approach in North Dakota would be a planning process that engages caregivers, professionals, and communities to work together to determine a local option that would be most effective and user-friendly. Such an effort could follow the Oregon model cited under best practices that provides support to build community networks (Silberberg, 2001)

Another new approach would be enacting legislation that could provide a mechanism for licensing respite workers for older adults similar to respite providers connected to the foster care system. Licensing could be a first step in insurance coverage for respite care. Elevating the status of respite care providers and strengthening or adding funding mechanisms could help address the challenge of inadequate numbers of respite providers.

Mechanisms by which current respite care services could be made more accessible and affordable include:

a) Investigate the feasibility of applying for a federal grant from the Lifespan Respite Care Program. The Lifespan Respite Care Program advances the following objectives:
   - Expand and enhance respite services in the states
   - Improve coordination and dissemination of respite services
   - Streamline access to programs;
   - Fill gaps in service where necessary
   - Improve the overall quality of the respite services currently available (http://www.acl.gov/Programs/CIP/OCASD/LifespanRespite/Index.aspx)

b) Expand available respite care by training college students (i.e., nursing, social work students) and volunteers to give family caregivers a break.

c) Evaluate best-practice training, such as REST (Respite Education and Support Tools training) that could be made available to North Dakota Family Caregivers. It is an original, professionally designed model for individuals wishing to train or be trained to become trained respite volunteers. It is appropriate for use within many settings, such as schools, veterans' organizations, hospitals, senior centers, and faith communities.

d) Promote awareness of the Family Caregiver Support Program to ensure it is fully utilized across the state.

e) Create directory of local respite care available to family caregivers. This directory should be easy to navigate and available online and in print. Moreover, it should be updated on a regular-basis.

f) Assess the utilization of facility-based respite care to determine awareness and acceptance by family caregivers.

3. Improve resources to help family caregivers find, connect to, and navigate available services

Family caregivers, stakeholders (who are skilled professionals), and our very own research team struggled to find and navigate available resources across the state. Excellent models exist across the nation for improving awareness of caregiving programs, particularly using online platforms. Moreover, tools to organize and manage computerized databases grow increasingly more accessible and user-friendly. Mechanisms by which the resources to help family caregivers find, connect to, and navigate available services could be improved include:

a) Identify marketing and communication strategies to promote awareness and benefits of the Aging & Disability Resource LINK and state-wise options counseling system to increase referrals and connect family caregivers with needed services. These services are available to North Dakotans of all income levels, but many are not aware of this.

b) Create a Caregiver Resource Center, within the Aging & Disability Resource LINK or other appropriate organization, to increase access to existing programs and services for caregivers. The Caregiver Resource Center, organized around family caregiver needs, could house or connect family caregivers with relevant online resources, training, support, respite, and planning tools. It could be a caregiver portal that hospitals, clinics, and other caregiver stakeholders promote.

c) Create a comprehensive guide to caregiving for North Dakota caregivers similar to publications created in other states (e.g., United Way Caregivers Coalition Pathways for Caregivers, Northern New Jersey).

d) Explore current care coordination improvement efforts within the state to determine if there are ways to better support the needs of family caregivers as the care recipient transitions from hospital to home, rehabilitation, and/or hospice. Public and private care coordination programs should be encouraged to use evidence-based care coordination programs, along with caregiver assessments.

e) Identify ways to increase communication, awareness of services, and collaboration among entities (health care, social services, aging services, etc.) at the county and regional levels to identify local family caregiver resources and increase referrals by all likely points of contact to appropriate resources.

f) Target public awareness to increase involvement in caregiving beyond the primary caregiver and to enhance greater understanding of family caregiving issues by the public at large.

4. Increase training and education for informal and professional caregivers

Support for training and information has been provided in the past but sustainability is a challenge. With rapid changes in available technology, service providers, and community resources, information quickly is outdated. Funding for education and training should take a longer-term approach with initial development funding followed by funds for annual updates and dissemination to new family members who join the ranks of caregivers on a daily basis.

Opportunities for training and education include:

a) Provide in-person instruction about medical/nursing tasks that the caregiver will need to provide at home, such as medication management, injections, wound care and transfers (for example, movement from bed to wheelchair). This instruction needs to be inclusive of both care recipients discharged from a facility and those who have not been discharged from a facility but still need this type of education.

b) Ensure training is available in-person and online to meet the variety of family caregiver training needs, including, but not limited to:

- Caregiving basics
- Managing care of others
- Financial caregiving
- Legal issues
- Medical/mental health support
- Communication
- Physical tasks of caregiving
- Caregiver self-care
- End-of-life issues

Explore partnerships with agencies that could collaborate to develop and deliver this family caregiver track training (e.g., universities, healthcare systems).

c) Broaden the availability of the *Powerful Tools for Caregivers Program* statewide, as well as other evidence-based training programs proven to be effective.

d) Ensure that information, including schedules for training programs, is aggregated and made easily accessible for family caregivers (especially new caregivers).

e) Create opportunities for family caregiver peer support, including a mentoring program with former caregivers, training events, and outings for both caregiver and care recipient to participate together.

f) Foster the development of in-person and online support groups for caregivers of older family members who are declining not due to a single, specific disease.

g) Explore the feasibility of developing a professional training track for employees delivering care. The training could include a small fee that could help cover the costs of sustaining and updating the training program and providing the professionals with required CEUs.

5. Closing the gaps in caregiver support services in rural areas

North Dakota is both an aging state and a rural state. The needs of rural seniors and their families (who may not reside rurally) are unique and thus warrant special consideration. Access to resources and staffing is a greater challenge in rural areas meaning that creative solutions need to be explored. Multiple options to close the gaps in caregiver support services in rural areas emerged as a result of the current study. These options include:

a) Support the statewide direct care workforce initiative in an effort to increase the number of individuals interested in caregiving professions, particularly in rural areas.

b) Explore the potential ways telehealth may address the needs of rural family caregivers and their care recipients. Such initiatives must include plans for sustainable funding.

c) Research the potential of developing and piloting a mobile adult day care model for rural communities.

d) Foster the development of volunteer networks to support the needs of rural caregivers, recognizing that seed money to get started and an administrative host is needed to recruit, orient, train, supervise and coordinate the volunteers.

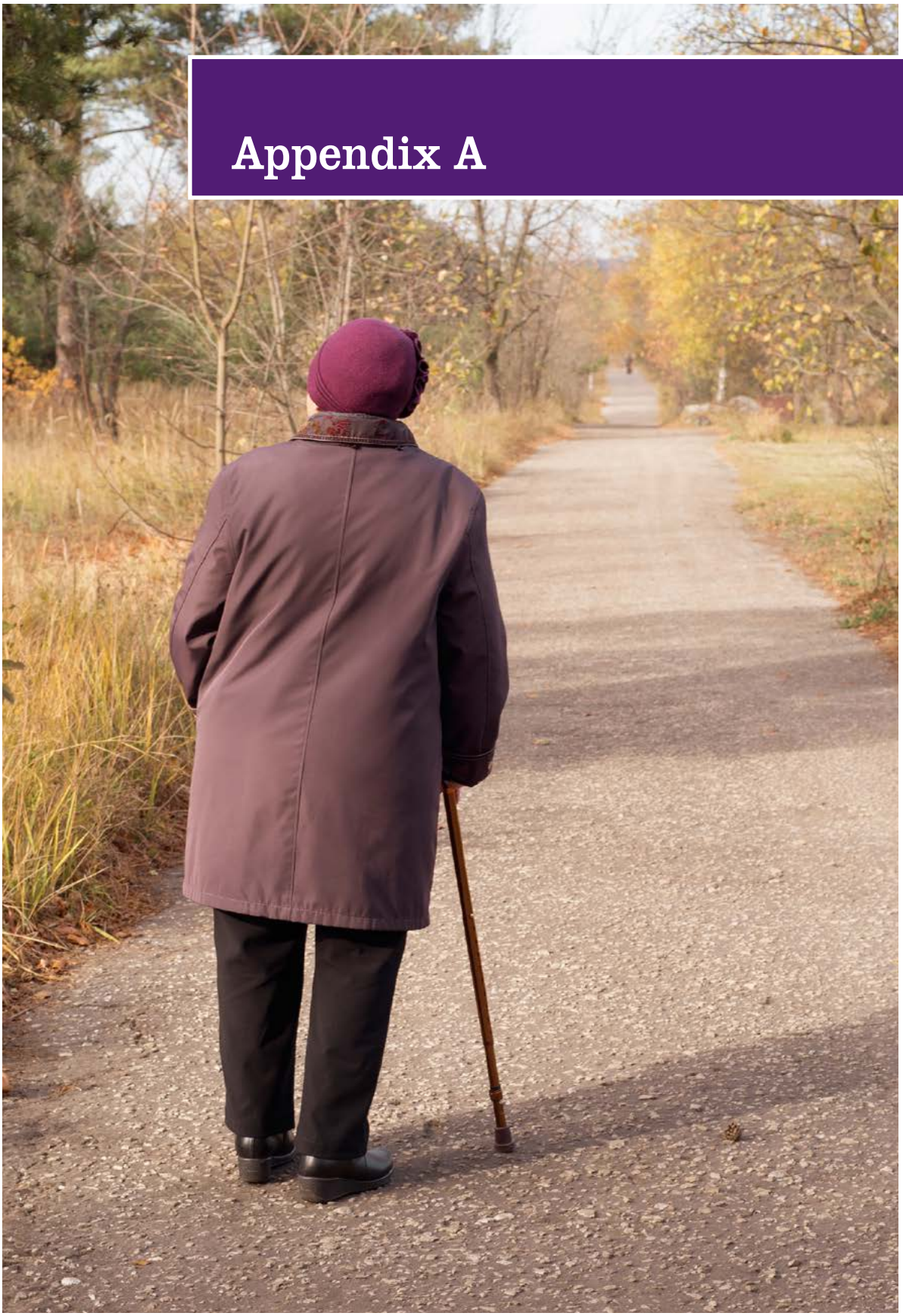
e) Promote programs that help family caregivers "organize" caregiving tasks through platforms such as *"Lots Helping Hands,"* a social media website which allows caregivers to calendar a care recipients task needs and family/friends to sign up for performing specific tasks. *"Share the Care"* is a similar program that can be adopted by caregivers and friends, health professionals, faith communities and businesses.

f) When county social services are the only provider of a key service (such as respite or personal care), determine ways to provide assistance so that they can continue to provide services to eligible clients and to expand services, if possible, to private pay clients.

g) Make funding available for pilot projects that include careful evaluation studies. Piloting best practices for caregiver services targeting rural areas could lead to effective and cost efficient solutions.

h) Make funding available for innovative technologies that make it possible for older adults to live independently for longer periods of time. In particular, foster technologies that support virtual caregiving from a distance given the preponderance of seniors living in rural areas while their (caregiving) children live in urban regions or out-of-state.

Appendix A



Appendix A: ND Regional Database of Family Caregiving Resources, Services, and Supports

Region I (Divide, Williams, and McKenzie counties)

Services	Counties Where Available
Adult Day Care	
Good Shepherd Home	McKenzie
Bethel Lutheran Nursing and Rehabilitation	Williams
Advocacy Services	
Easter Seals Goodwill ND	Williams
Family Crisis Shelter	Williams, McKenzie
Williston Council for the Aging	Divide, Williams
Assistive Technology / Equipment	
American Legion	Divide
Easter Seals Goodwill ND	Williams
Great Plains Rehabilitation Services	McKenzie
IPAT	Divide, Williams, McKenzie
MedQuest Home Medical Equipment	Williams, McKenzie
ND Association for the Disabled	McKenzie
Vocational Rehabilitation	Divide, Williams, McKenzie
Emotional Support (support groups, geriatric mental health)	
Alzheimer's Association of Minot	Williams
Divide County Social Services	Divide
Family Caregiver Support Program	Williams, McKenzie
McKenzie County Health Care Systems	McKenzie
Solutions	Divide
William County Social Services	Williams, McKenzie
Caregiver Training and Education	
Alzheimer's Association	Divide
Family Caregiver Support Program	Williams, McKenzie
Dementia Care	
Alzheimer's Association	Williams
Care Management	
Divide County Social Services	Divide

Region I continued

Services	Counties Where Available
Home Delivered Meals / Congregate Meals	
Alexander Senior Citizens	McKenzie
Horizon	McKenzie
Purfoods LLC Mom's Meals	Divide, Williams
SNAP	McKenzie
Williston Council for the Aging	Divide, Williams, McKenzie
Home Health Agencies	
McKenzie County Healthcare Visiting Nurse Service	McKenzie
Mercy Home Care and Hospice	Williams
Personal Care Agencies	
Divide County Social Services	Divide
Horizon	McKenzie
Homemaker / Chore	
Divide County Social Services	Divide
Hospice/ Bereavement Services	
Bethel Lutheran Nursing & Rehabilitation Center	Williams
McKenzie County Health Care Systems	McKenzie
Mercy Home Care and Hospice	Divide, Williams
Mercy Medical Center	Williams
Information and Referral	
Aging and Disability Resource LINK ND	Divide, McKenzie
Center for Persons with Disabilities ND	Divide, Williams
Divide County Social Services	Divide
Family Caregiver Support Program	Divide, Williams
McKenzie County Social Services	McKenzie
NorthWest Human Services Center	Williams
Williams County Social Services	Williams
Parish Nurse / Faith Community Nurse	
N/A	
Public Health Nurse / Health Maintenance	
Upper Missouri District Health	Divide, Williams, McKenzie
Respite Care	
Divide County Social Services	Divide
Good Shepherd Home	Williams
Family Caregiver Support Program	McKenzie
Transportation Services	
Divide County Social Services	Divide
Williston Council for the Aging	Williams
Mercy Rider Program	Williams
Watford City Young @ Heart Club	McKenzie
Northwest Dakota Public Transit	Divide
Volunteer Services	
N/A	

Region II (Burke, Renville, Bottineau, Mountrail, Ward, McHenry and Pierce counties)

Services	Counties Where Available
Adult Day Care	
Brentmoor	Renville, Ward
Advocacy Services	
Community Options	Burke, Renville, Bottineau, Mountrail, Ward, McHenry, Pierce
Easter Seals Goodwill ND	Burke, Renville, Bottineau, Ward, Pierce
Kenmare Wheels & Meals	Burke, Renville, Ward,
Minot Commission on Aging	Burke, Renville, Mountrail, Ward, McHenry, Pierce
Tri County Senior Meals & Services	Bottineau, Pierce
Independence Inc.	Bottineau
Money Follows the Person Program	Bottineau
Assistive Technology / Equipment	
Great Plains Rehabilitation Services	Burke, Renville, McHenry
IPAT	Burke, Renville, Bottineau, Mountrail, Ward, McHenry, Pierce
Vocational Rehabilitation	Burke, Renville, Bottineau, Mountrail, Ward, Pierce
Easter Seals Goodwill ND	Bottineau, Ward, Pierce
Independence Inc.	Bottineau, Ward, Pierce
Key Care Medical	Ward, McHenry, Pierce
Minot Commission on Aging	Ward, McHenry, Pierce
ND Association for the Disabled	Bottineau, Ward, Pierce
Sanford Health Care Accessories	Ward
Adaptive Equipment Services	McHenry
Disability Services Division	Pierce
Emotional Support (support groups, geriatric mental health)	
Family Caregiver Support Program	Bottineau, Mountrail, Ward
Mountrail County Social Services	Mountrail
Bottineau County Social Services	Bottineau
Burke County Social Services	Burke
Good Samaritan Society	Burke
McHenry County Social Services	McHenry
Pierce County Social Services	Pierce
Prairie Rose Home Services	Ward
ProHealth Home Care	Ward
Renville County Social Services	Renville
Ward County Social Services	Ward
Heart of America Medical Center	Pierce
Caregiver Training and Education	
Family Caregiver Support Program	Bottineau, Mountrail, Ward

Region II continued

Services	Counties Where Available
Dementia Care	
Dementia Care Services Program	Burke, Renville, Bottineau, Ward, Pierce
Trinity Care	Ward
Heart of America Medical Center	Pierce
Care Management	
Northland Care Coordination for Seniors	Ward
Northland PACE Services	Ward
Ward County Social Services	Ward
Home Delivered Meals / Congregate Meals	
Bowbells Senior Center	Burke
Glenburn Senior Citizens	Renville
Kenmare Wheels & Meals	Ward
Lignite Senior Center	Burke
Minot Commission on Aging	Burke, Renville, Ward
Powers Lake Senior Citizens	Burke
Purfoods LLC Mom's Meals	Burke, Renville, Ward, Pierce
Golden Age Senior Citizens Club	Mountrail, Ward
SNAP	Burke, Renville, Ward, Pierce
Anamoose Senior Center	McHenry
Bottineau Senior Center	Bottineau
Burlington Senior Centers	Ward
Carpio Senior Citizens	Ward
Deering Senior Citizens Club	McHenry
Granville Senior Citizens Club	McHenry
Haaland Estates Basic Care	Pierce
Heart of America Medical Center	Pierce
Independent Living Centers LLC	Ward
Kenmare Senior Citizens	Ward
Lakeside Senior Citizens of New Town	Mountrail
Makoti Pioneer Senior Citizens	Ward
McHenry County Commission on Aging	McHenry
Milton Young Towers	Ward
Newburg Area Senior Citizens Club	Bottineau
Oak Manor - Bottineau	Bottineau
Plaza Senior Center	Mountrail
Rugby Senior Center	Pierce
Somerset Court	Ward
St. Andrew's Health Center	Bottineau
Towner Senior Citizens VIP Club	McHenry
Tri County Senior Meals & Services	Bottineau, Mountrail, Pierce
Velva Star City Senior Citizens	McHenry
Willow City Senior Citizens	Bottineau
Mom's Meals	Ward
Westhope Senior Meals	Bottineau

Region II continued

Services	Counties Where Available
Home Health Agencies	
Easter Seals Goodwill ND	Burke, Renville, Pierce
Trinity Home Health and Hospice	Burke, Renville, Ward, McHenry, Pierce
St. Alexius Home Care and Hospice	Pierce
Rolette County Home Health	Bottineau
Personal Care Agencies	
Easter Seals Goodwill ND	Burke, Renville, Bottineau, Ward, Pierce
Prairie Rose Home Services	Ward, Pierce
ProHealth	Ward
Bottineau County Social Services	Bottineau
Homemaker / Chore	
Burke County Social Services Board	Burke
Renville County Social Services Board	Renville
Mountrail County Social Services Board	Mountrail
Kenmare Wheels & Meals	Burke, Renville
Bottineau County Social Services Board	Bottineau
Easter Seals Goodwill ND	Bottineau, Ward, Pierce
Pierce County Social Services Board	Pierce
Prairie Rose Home Services	Ward
ProHealth Home Care	Ward
REM North Dakota Inc.	Ward, Pierce
Ward County Social Services	Ward
Community Action	McHenry
Hospice / Bereavement Services	
Trinity Home Health and Hospice	Burke, Renville, Ward, McHenry
Heart of America Medical Center	Pierce
Heart of Hope Hospice	Ward
ManorCare Health Services	Ward
Haaland Estates	Pierce
Information and Referral	
Aging and Disability Resource LINK ND	Burke, Renville, Bottineau, Ward, McHenry, Pierce
Burke County Social Services	Burke
Renville County Social Services	Renville
Options Counseling	Burke, Renville, Bottineau, Ward
Mountrial County Social Services	Mountrail
Bottineau County Social Services	Bottineau
Center for Persons with Disabilities ND	Ward, McHenry, Pierce
Family Caregiver Support Program	Bottineau, Ward, McHenry, Pierce
FirstLink	Ward, McHenry
McHenry County Social Services	McHenry
Pierce County Social Services	Pierce
Ward County Social Services	Ward

Region II continued

Services	Counties Where Available
Parish Nurse / Faith Community Nurse	
Our Lady of Grace Catholic Church	Ward
First Lutheran Church in Bottineau	Bottineau
Public Health Nurse / Health Maintenance	
Burke County Public Health	Burke
Ward Co. First District Health Unit	Ward
Mountrail County Public Health	Mountrail
Renville County Public Health	Renville
Bottineau County Public Health	Bottineau
McHenry County Public	McHenry
Pierce County Public Health	Pierce
Respite Care	
Burke County Social Services	Burke
Renville County Social Services	Renville
Mountrail County Social Services	Mountrail
Easter Seals Goodwill ND	Bottineau, Ward
Prairie Rose Home Services	Ward
ProHealth Home Care	Ward
McHenry County Social Services	McHenry
Haaland Estates	Pierce
Bottineau County Social Services	Bottineau
Transportation Services	
Souris Basin Transportation	Burke, Renville, Bottineau, Ward, McHenry
Community Action Partnership	Ward
ProHealth Home Care	Ward
Lakeside Senior Citizens	Mountrail
Drake Senior Citizens Club	McHenry
Granville Senior Citizens Club	McHenry
Velva Star City Senior Citizens	McHenry
Tri-County Meals & Services	Pierce
Kenmare Senior Citizens	Ward
Pierce Senior Citizen Center	Pierce
Volunteer Services	
RSVP+	Ward, McHenry
Lutheran Social Services Senior Companions Program	McHenry
Heart of America Medical Center	Pierce

Region III (Rolette, Towner, Cavalier, Ramsey, Benson and Eddy counties)

Services	Counties Where Available
Adult Day Care	
GSS Devils Lake	Ramsey
Lutheran Home of the Good Shepherd	Eddy
Maddock Memorial Home	Benson
Advocacy Services	
Hearts of Hope	Rolette
Spirit Lake Victim Assistance Program	Towner, Ramsey, Benson,
Options for Independent Living	Towner, Ramsey, Eddy
Adult Protective Services	Towner, Ramsey
Assistive Technology / Equipment	
IPAT	Rolette, Towner, Cavalier, Ramsey, Benson, Eddy
Options for Independent Living	Towner, Ramsey
Hero	Towner, Ramsey
North Dakota School for the Deaf	Towner, Ramsey
Altru Specialty Services Inc	Cavalier, Eddy
Vocational Rehabilitation	Cavalier, Benson
Emotional Support (support groups, geriatric mental health)	
Family Caregiver Support Program	Towner, Cavalier, Ramsey
FirstLink HelpLine	Towner, Ramsey
Caregiver Training and Education	
Family Caregiver Support Program	Cavalier
Dementia Care	
Dementia Care Services Program	Cavalier, Eddy
Eventide Care Center	Ramsey
Care Management	
Cavalier County Social Services	Cavalier
Ramsey County Social Services	Ramsey
Towner County Social Services	Towner
Family Caregiver Program	Towner, Ramsey
Aging Life Care Management Lutheran Social Services of ND	Eddy
Lakes Social Services District	Eddy
Home Delivered Meals / Congregate Meals	
Minnewaukan 55 Club	Benson
New Rockford Golden Age Club	Eddy
Rocklake Cornerstone Club	Towner
Senior Meals and Services	Towner, Ramsey, Eddy
Spirit Lake Senior Meals & Services	Benson
Cando Senior Citizens	Towner
Cavalier County Senior Meals & Services	Cavalier
Devils Lake Community Senior Center	Ramsey

Region III continued

Services	Counties Where Available
Home Delivered Meals / Congregate Meals (continued)	
Leeds 55 Club	Benson
Maddock 55 Club	Benson
Nutrition United Inc.	Rolette
Peace Garden Senior Center (Dunseith)	Rolette
Rolette County Senior Meals and Services	Rolette
Turtle Mountain Nutrition & Support Services	Rolette
Mom's Meals	Rolette, Towner, Cavalier, Ramsey, Eddy
Home Health Agencies	
Altru's Home Care	Towner, Cavalier, Ramsey, Eddy
Tri Care Home Health Inc.	Rolette, Eddy
Good Samaritan Society	Towner, Ramsey, Eddy
Personal Care Agencies	
Benson County Social Services	Benson
Cavalier County Social Services	Cavalier
Community Options	Towner, Ramsey, Eddy
Easter Seals Goodwill ND Inc.	Towner, Ramsey
Park View Manor Assisted Living	Rolette
Eddy County Social Services	Eddy
Good Samaritan Society Home Care	Towner, Ramsey, Eddy
Ramsey County Social Services Board	Ramsey
REM North Dakota Inc.	Towner, Cavalier, Ramsey, Eddy
Towner County Social Services Board	Towner, Eddy
Lake Region Lutheran Home Inc	Eddy
Homemaker / Chore	
Cavalier County Social Service Board	Cavalier
REM North Dakota Inc.	Cavalier, Eddy
Community Options	Eddy
Lakes Social Services	Eddy
Hospice / Bereavement Services	
Altru's Hospice	Towner, Cavalier, Ramsey, Eddy
Heart of America Hospice	Towner, Ramsey
Maple Manor Care Center	Cavalier
Heartland Care Center	Eddy
Lutheran Home of the Good Shepherd	Eddy
Information and Referral	
Aging and Disability Resource	Rolette, Towner, Cavalier, Ramsey, Eddy
Options Counseling	Towner, Cavalier, Ramsey, Eddy
Ramsey County Social Services	Ramsey
Towner County Social Services	Towner
Center For Persons with Disabilities	Cavalier
FirstLink	Cavalier, Eddy

Region III continued

Services	Counties Where Available
Parish Nurse / Faith Community Nurse	
N/A	
Public Health Nurse / Health Maintenance	
Eddy County Public Health	Eddy
Cavalier County Health District	Cavalier
Rolette County Public Health District	Rolette
Benson County Public Health Services	Benson
Lake Region District Health Unit	Ramsey
Towner County Public Health	Towner
Respite Care	
Benson County Social Services Board	Benson
Cavalier County Social Services	Cavalier
Community Options	Towner, Ramsey
Easter Seals Goodwill ND Inc	Towner, Ramsey
Family Caregiver Support Program	Towner, Ramsey, Eddy
GSS Devils Lake	Ramsey
Lake Social Service District	Ramsey
Osnabrock Community Living Center	Cavalier
REM North Dakota Inc.	Towner, Ramsey, Eddy
Towner County Living Center	Towner
Towner County Social Services Board	Towner
Maddock Memorial Home	Benson
Rolette County Social Services	Rolette
Rolette Community Care Ctr	Rolette
Eddy County Social Services	Eddy
Transportation Services	
Benson County Transportation	Benson, Eddy
Cando Senior Citizens	Towner
Devils Lake Transit	Ramsey
Ramsey County Social Services Board	Ramsey
Seniors Meals & Services Inc.	Towner, Ramsey, Eddy
Spirit Lake Senior Meals & Services	Benson
Towner County Social Services Board	Towner
Dunseith Community Nursing Home	Rolette
Park View Manor Assisted Living	Rolette
Rolette County Senior Meals & Services	Rolette
Turtle Mountain Nutrition & Support Services	Rolette
Turtle Mountain Band of Chippewa Tribal Transit Program	Rolette
Rolette County Transit	Rolette
Cavalier County Senior Meals & Services	Cavalier
Leeds 55 Club	Benson
Maddock 55 Club	Benson
Minnewaukan 55 Club	Benson
Devils Lake Community Senior Center	Eddy

Region III continued

Services	Counties Where Available
Volunteer Services	
Lutheran Social Services	Towner, Ramsey
Cavalier Senior Center	Cavalier
RSVP	Eddy
Eddy Senior Center	Eddy

Region IV (Pembina, Walsh, Grand Forks and Nelson counties)

Services	Counties Where Available
Adult Day Care	
GSS Park River	Pembina
Aneta Park View	Nelson
Wedgewood Manor Cavalier	Pembina
Borg Memorial Home	Pembina
Northwood Deaconess Health	Grand Forks
Edgewood Park Place	Grand Forks
Maple View	Grand Forks
Advocacy Services	
Pembina County Memorial Hospital	Pembina
Options	Pembina, Grand Forks
Grand Forks County Social Services	Grand Forks
Arc Upper Valley	Nelson
Options Counseling	Nelson
Assistive Technology / Equipment	
Altru Specialty Services Inc.	Pembina, Walsh, Grand Forks
HERO	Pembina, Walsh
IPAT	Pembina, Walsh, Grand Forks
Vocational Rehabilitation	Pembina, Walsh, Grand Forks
Adaptive Equipment Services	Walsh
Disability Services Division	Walsh
Grand Forks Senior Center	Nelson
Options Independent Living	Nelson
Emotional Support (support groups, geriatric mental health)	
Altru Health System	Pembina, Walsh, Grand Forks, Nelson
Family Caregiver Support Program	Pembina, Walsh, Nelson
Lutheran Social Services	Pembina, Walsh, Nelson
Northeast Human Service Center	Pembina
Alzheimers Association	Grand Forks
Caregiver Training and Education	
Family Caregiver Support Program	Pembina, Walsh, Grand Forks, Nelson
Dementia Care Services	Nelson
Grand Forks Senior Center	Nelson
UND Nursing Dept.	Nelson
Altru Health Systems	Nelson
Dementia Care	
Dementia Care Services Program	Pembina, Walsh, Grand Forks, Nelson
Maple View	Grand Forks
Aneta Park View	Nelson
Northwood Deaconess	Grand Forks
Grafton Nursing Home	Walsh
Memory Café	Grand Forks

Region IV continued

Services	Counties Where Available
Care Management	
Pembina County Social Services	Pembina
Northland Care Coordination for Seniors	Walsh
Grand Forks County Social Services	Grand Forks
Home Delivered Meals / Congregate Meals	
Pembina County Meals & Transportation	Pembina
Mom's Meals	Pembina
Great Plains Food Bank	Walsh, Nelson
Home Delivered Meals Inc.	Walsh, Grand Forks
Lankin Senior Citizens Club	Walsh
Red River Valley Community Action Agency	Walsh, Nelson
Walsh County Nutrition Program	Walsh
Altru Health Systems	Grand Forks
Grand Forks Senior Center	Grand Forks, Nelson
Greater Grand Forks Senior Citizens Associtation Inc	Grand Forks, Nelson
McVille Young Hearts	Nelson
Tolna Friends & Neighbors Café	Nelson
Home Health Agencies	
Altru	Pembina, Walsh, Grand Forks, Nelson
Comfort Keepers	Walsh
Easter Seals Goodwill ND Inc	Walsh, Nelson
Home Care Companions	Walsh
Home Helpers	Walsh
Unity Medical Center	Walsh
Good Samaritan Society	Grand Forks, Nelson
Sanford	Grand Forks
Nelson County Health System	Nelson
Personal Care Agencies	
Friendship Inc.	Pembina, Walsh
Pembina County Social Services	Pembina
REM North Dakota Inc	Pembina, Walsh
Comfort Keepers Peterson TCS LLC	Walsh, Grand Forks
Community Options	Walsh
Developmental Homes Inc	Walsh, Grand Forks
Easter Seals Goodwill ND Inc.	Walsh, Grand Forks, Nelson
Home Care Companions	Walsh, Grand Forks
Walsh County Social Services	Walsh
Good Samaritan Society Home Care	Grand Forks, Nelson
Grand Forks Social Services	Grand Forks
Integrity Homecare and Counseling	Grand Forks
Sanford Home Care	Grand Forks
Altru Home Services	Nelson
Nelson County Social Services	Nelson

Region IV continued

Services	Counties Where Available
Personal Care Agencies (continued)	
Northwood Deaconess Health Center	Nelson
Support Systems Inc.	Nelson
Homemaker / Chore	
Pembina County Social Services	Pembina
Community Options	Walsh
REM North Dakota Inc.	Walsh
Support Systems Inc.	Walsh
Development Home Inc	Grand Forks
Integrity Homeware and Counseling	Grand Forks
Home Care Companions	Grand Forks
Comfort Keepers	Grand Forks
Good Samaritan Society	Grand Forks
Sanford	Grand Forks
Hospice / Bereavement Services	
Altru's Hospice	Pembina, Walsh, Grand Forks, Nelson
Pembiller Nursing Center	Pembina
Wedgewood Manor-Cavalier	Pembina
Hospice of the Red River Valley	Walsh, Grand Forks, Nelson
Lutheran Sunset Home	Walsh
Unity Medical Center	Walsh
Nelson County Health Care System	Nelson
Information and Referral	
FirstLink	Pembina, Walsh, Nelson
Options Counseling	Pembina, Walsh, Grand Forks, Nelson
United Way Answer Line	Pembina, Nelson
Arc Upper Valley	Walsh, Grand Forks, Nelson
Center for Persons with Disabilities	Walsh, Nelson
Grand Forks County Social Services	Grand Forks
Grand Forks Senior Center	Grand Forks
Parish Nurse / Faith Community Nurse	
Immanuel Lutheran Church	Grand Forks
United Lutheran Church	Pembina
Walhalla Lutheran Church	Pembina
Calvary Lutheran	Grand Forks
Turtle River Ministries	Grand Forks
Holy Family	Grand Forks
Public Health Nurse / Health Maintenance	
Pembina County Health Department	Pembina
Walsh County Public Health	Walsh
Grand Forks Public Health Department	Grand Forks
Nelson/Griggs District Health	Nelson

Region IV continued

Services	Counties Where Available
Respite Care	
Borg Pioneer Memorial Home	Pembina
Family Caregiver Support Program	Pembina, Walsh, Grand Forks, Nelson
Friendship Inc.	Pembina, Walsh
Pembiller Nursing Center	Pembina
Pembina County Social Service	Pembina
REM North Dakota Inc.	Pembina, Walsh
A Spectrum of Care	Walsh
Comfort Keepers Peterson TCS LLC	Walsh, Grand Forks
Community Options	Walsh
Development Homes Inc.	Walsh
Easter Seals Goodwill ND Inc.	Walsh, Nelson
Home Care Companions	Walsh, Grand Forks
Hospice of the Red River Valley	Walsh
Support Systems Inc.	Walsh
Walsh County Social Services Board	Walsh
Good Samaritan Society	Grand Forks
Integrity Homecare and Counseling	Grand Forks
Maple View	Grand Forks
Northwood Deaconess Health Center	Grand Forks
Altru Home Services	Nelson
Valley Elder Care	Grand Forks
Nelson County Health Systems	Nelson
Wheatland Terrace	Grand Forks
GSS Lakota	Nelson
Wedgewood Manor	Pembina
Nelson County Social Services	Nelson
Transportation Services	
Faith in Action Health Coalition	Pembina
Pembina Senior Meals & Transportation	Pembina, Walsh
Comfort Keepers	Walsh, Grand Forks
Community Options	Walsh
Development Homes Inc	Walsh
Friendship Inc.	Walsh
Home Care Companions	Walsh, Grand Forks
Lutheran Sunset Home	Walsh
Red River Valley Community Action (Grand Forks)	Walsh
REM North Dakota Inc	Walsh
Walsh County Nutrition Program	Walsh
Walsh County Social Services Board	Walsh
Northwood Deaconess Health Center	Grand Forks
Parkwood Senior Living	Grand Forks

Region IV continued

Services	Counties Where Available
Transportation Services (continued)	
Tufte Manor	Grand Forks
Senior Rider	Grand Forks
Cities Area Transit	Grand Forks
Lankin Senior Citizens	Walsh
Tolna Friends & Neighbors Club	Nelson
Nelson County Health Care System	Nelson
Volunteer Services	
Faith in Action Health Coalition	Pembina
Lutheran Social Services Senior Companions	Walsh, Grand Forks, Nelson
Grand Forks Senior Center	Grand Forks
RSVP+	Nelson

Region V (Steele, Traill, Cass, Ransom, Sargent and Richland counties)

Services	Counties Where Available
Adult Day Care	
Bethany Home Health Care	Cass
Maple View Fargo	Cass
Rosewood On Broadway	Cass
St Catherines Living Center	Richland
Villa Maria Health Care	Cass
Johnson Eldercare	Cass
All Health Home Day Care	Cass
Luther Memorial Home	Traill
Hatton Prairie Village	Traill
Advocacy Services	
Aging Life Care Management, Lutheran Social Services of ND	Cass
Lutheran Social Services- Services for Elder Refugees	Traill, Cass
Valley Senior Services	Steele, Traill, Cass, Ransom, Sargent, Richland
Freedom Resource Center in Fargo	Cass, Ransom
Community Care in Casselton	Cass
Protection and Advocacy	Cass
Steele County Social Services	Steele
Assistive Technology / Equipment	
Altru Specialty Services Inc	Steele, Traill, Cass
Lincare	Traill, Cass, Richland
Sanford Healthcare Accessories	Steele, Traill, Cass, Ransom, Sargent, Richland
Assistive Safety Devices Distribution Program	Traill, Cass
HealthCare Accessories	Traill, Cass, Sargent
HERO	Steele, Traill, Cass, Ransom, Sargent, Richland
IPAT	Steele, Traill, Cass, Ransom, Sargent, Richland
Steele County Public Health	Steele
Emotional Support (support groups, geriatric mental health)	
HeartSprings	Cass
Caregiver Support Coordinator VA	Traill, Cass, Richland
Catholic Family Service	Cass, Richland
Community of Care	Cass
FirstLink HelpLine	Cass, Sargent, Richland
Family Caregiver Support Program	Traill, Cass, Ransom, Richland
Fargo VA Medical Center	Cass, Ransom, Richland
Lost & Found Ministry	Cass
Lutheran Social Services of North Dakota	Cass, Ransom, Richland
Mental Health Association	Cass

Region V continued

Services	Counties Where Available
Emotional Support (support groups, geriatric mental health) continued	
Solutions	Cass, Sargent, Richland
Southeast Human Service Center	Traill, Cass, Ransom, Sargent, Richland
Alzheimer's Association	Cass
Community Options	Cass
Multiple Sclerosis Society	Cass
Caregiver Training and Education	
Family Caregiver Support Program	Steele, Traill, Cass, Ransom, Richland
NDSU Extension	Traill, Cass, Ransom, Sargent, Richland
Train ND	Cass
Alzheimer's Association	Cass
Coalition of Elderly Service Providers	Cass
Dementia Care	
Dementia Care Services Program	Cass
Mapleview Memory Care Unit	Cass
Elim	Cass
Edgewood Vista	Cass
Bethany	Cass
Rosewood on Broadway	Cass
Evergreen's	Cass
Care Management	
Aging Life Care Management, Lutheran Social Services of ND	Cass
Community of Care	Cass
Valley Senior Services	Cass
Cass County Social Services	Cass
Dignity Care	Traill
Traill County Social Services	Traill
Home Delivered Meals / Congregate Meals	
Mom's Meals	Steele, Traill, Cass, Ransom, Richland
Senior Commodities- SENDCAA	Traill, Sargent
SNAP	Ransom, Sargent, Richland
Valley Senior Services (Congregate Meals)	Steele, Traill, Cass, Ransom, Sargent, Richland
Valley Senior Services (Meals on Wheels)	Steele, Traill, Cass, Ransom, Sargent, Richland
Home Health Agencies	
Prairieland Home Health	Cass
Accra Home Care	Cass
All Health Home Care	Traill, Cass
Arise Home Health Care	Cass
Essentia Health Home Care West	Cass
Experience Health ND	Cass, Richland
Fargo Cass Public Health	Cass

Region V continued

Services	Counties Where Available
Home Health Agencies (continued)	
Good Sam of Fargo	Cass
Hospice of the Red River Valley	Traill, Cass, Ransom, Sargent, Richland
Sanford Home Health Care	Steele, Traill, Cass, Sargent
Comfort Keepers	Cass
Easter Seals	Cass
Altru Home Health	Steele, Traill
Benedictine Living Communities Inc	Ransom, Richland
Richland County Home Health Agency	Richland
Personal Care Agencies	
A Spectrum Of Care	Traill, Cass, Ransom
Accent Multi Services	Cass
Access, Inc.	Cass
Active At Home Helpers	Cass
All Health Home Care	Traill, Cass
Bethany Home Health Care	Cass
Cass County Social Service	Cass
Cathy's Caretakers LLC	Cass
Change is Good	Cass
Comfort Keepers Peterson TCS LLC	Cass
Community Living Services Inc.	Traill, Cass
Continental Home Health-Aide Inc	Cass
Dakota Estates Retirement Center	Richland
The Dove	Cass
Easter Seals Goodwill ND Inc	Traill, Cass, Richland
Fargo Cass Public Health	Cass
Friendship Inc	Cass
Good Samaritan Home Care	Cass
Griswold Home Care	Cass
Home Instead Senior Care	Cass, Richland
Home Helpers And Direct Link	Cass
Kind-er Care	Cass
LifeSort	Cass
Lutheran Social Service Caregiver Respite	Cass, Ransom
Ransom County Social Services	Ransom
Rem North Dakota Inc	Cass
Richland County Health Department	Richland
Richland County Social Services	Richland
Rosewood On Broadway	Cass
Sanford Home Care Fargo	Steele, Traill, Cass, Sargent
Sargent County Social Services	Sargent
Spectrum Home Care	Cass
St Catherines Living Center	Richland

Region V continued

Services	Counties Where Available
Personal Care Agencies (continued)	
Tami's Angels/ Specialty Care, Inc.	Cass
Traill County Social Services	Traill
Ultimate Senior Home Care	Cass
Steele County Social Services	Steele
Homemaker / Chore	
A Spectrum Of Care	Traill, Cass
Active At Home Helpers	Cass
AllHealth Home Care	Traill, Cass
Bethany Home Health Care	Cass
Cathy's Caretakers LLC	Cass
Comfort Keepers Peterson TCS LLC	Cass, Richland
Community Living Services Inc.	Traill, Cass
Continental Home Health-Aide Inc	Cass
Dakota Estates Retirement Center	Richland
Easter Seals Goodwill ND Inc	Richland
Fargo Cass Public Health	Cass
Friendship Inc	Cass
Good Samaritan Home Care	Cass
Griswold Home Care	Cass
Home Helpers And Direct Link	Cass
Ransom County Social Services	Ransom
Richland County Social Services	Richland
Sanford Home Care Fargo	Traill, Cass
Sargent County Social Services	Sargent
Traill County Social Services	Traill
Ultimate Senior Home Care	Cass
Steele County Social Services	Steele
Hospice / Bereavement Services	
Hospice of the Red River Valley	Steele, Traill, Cass, Ransom, Sargent, Richland
Information and Referral	
AARP	Steele, Cass, Ransom, Sargent, Richland
ADRLink	Cass
Valley Senior Services	Cass
Family Caregiver Support Program	Steele, Traill, Cass, Ransom, Richland
FirstLink	Steele, Traill, Cass, Sargent, Richland
Options Counseling	Steele, Traill, Cass, Ransom, Sargent, Richland
Cass County Social Services	Cass
Steele County Social Services	Steele

Region V continued

Services	Counties Where Available
Parish Nurse / Faith Community Nurse	
Blessed Sacrament Catholic Church	Cass
Messiah Evangelical Lutheran	Cass
Faith Lutheran West Fargo	Cass
HeartSprings	Cass
Hope Lutheran Church	Cass
Olivet Lutheran Church	Cass
Atonement Lutheran	Cass
Holy Cross Catholic Church	Cass
Calvary United Methodist	Cass
Sanford Health Fargo Parish Nurse	Cass
Church of the Nativity	Cass
Community Health Ministry	Cass
First Lutheran Church	Cass
First Prebyterian Church	Cass
First United Methodist	Cass
Parish Nurse Mayville	Traill
United Methodist	Ransom
Our Saviors Church	Traill
Public Health Nurse / Health Maintenance	
Fargo Cass Public Health	Cass
Steele County Public Health Department	Steele
Traill County District Health Unit	Traill
Ransom County Public Health	Ransom
Sargent County District Health Unit	Sargent
Richland County Public Health and Home Health	Richland
Respite Care	
A Spectrum Of Care	Traill, Cass
Active At Home Helpers	Cass
AllHealth Home Care	Traill, Cass
Cathy's Caretakers LLC	Cass
Comfort Keepers Peterson TCS LLC	Cass
Community Living Services Inc.	Traill, Cass
Easter Seals Goodwill ND Inc	Steele, Traill, Cass
Family Caregiver Support Program	Steele, Cass, Richland
Friendship Inc	Cass
Good Samaritan Society Home Care	Cass
Griswold Home Care	Cass
Home Helpers And Direct Link	Cass
Johnson Eldercare	Cass
Maple View Fargo	Cass
Richland County Health Department	Richland
Richland County Social Services	Richland

Region V continued

Services	Counties Where Available
Respite Care (continued)	
Rosewood on Broadway	Cass
Sanford Home Care Fargo	Cass
St Catherines Living Center	Richland
Traill County Social Services	Traill
Ultimate Senior Home Care	Cass
Villa Maria Health Care	Cass
Sanford Health Hillsboro Care	Traill
Luther Memorial Home	Traill
Prairie Village	Traill
Parkside Lutheran Home	Ransom
Steele County Social Services	Steele
Transportation Services	
Valley Senior Services	Steele, Traill, Cass, Ransom, Sargent, Richland
Anytime	Cass
Handi Wheels	Cass
Hillsboro Senior Citizens	Traill
Mat Paratransit	Cass
Care-a-van	Cass
Steele County Social Services	Steele
Lidgerwood Friendship Club	Richland
Mayville Senior Center	Traill
Wahpeton Senior Center	Richland
Community of Care	Cass
HEART	Ransom
Traill County Social Services	Traill
Volunteer Services	
Community of Care	Cass
HEART Program	Cass, Ransom
Lutheran Social Services Senior Companions	Cass, Ransom
Valley Senior Services	Steele, Traill, Cass, Ransom, Sargent, Richland
RSVP+	Cass, Richland
Kiwanis Club	Traill

Region VI (Wells, Foster, Griggs, Stutsman, Barnes, Logan, LaMoure, McIntosh and Dickey counties)

Services	Counties Where Available
Adult Day Care	
GSS- Oakes	Dickey
Napoleon Care Center	Logan
Advocacy Services	
Stutsman Public Health	Stutsman
Dickey County Social Services	Dickey
Freedom Resource Center	Dickey
Community Care	Dickey
Dickey Senior Centers	Dickey
Family Caregiver Services	Dickey
Aging Life Care Management, Lutheran Social Services of ND	McIntosh
Valley Senior Services	McIntosh
Assistive Technology / Equipment	
Assistive Safety Devices Distribution Program	Wells, Foster, Griggs, Stutsman, Logan, McIntosh
HealthCare Accessories	Griggs, Stutsman, Logan, LaMoure, McIntosh,
IPAT	Wells, Foster, Griggs, Stutsman, Barnes, Logan, LaMoure, McIntosh, Dickey
HERO	Stutsman, McIntosh, Dickey
Oaks Senior Center	Dickey
Dickey County Health District	Dickey
NDAD	Dickey
Freedom Resources	Dickey
Project Hero	McIntosh
Emotional Support (support groups, geriatric mental health)	
Family Caregiver Support Program	Wells, Griggs, Stutsman, Logan, LaMoure, McIntosh, Dickey
Griggs County Care Center	Griggs
Alzheimer's Association	Dickey
Dickey County Counselors	Dickey
Caregiver Training and Education	
Family Caregiver Support Program	Wells, Foster, Griggs, Stutsman, Logan, LaMoure, McIntosh, Dickey
Dementia Care	
Eventide at Jamestown	Stutsman
Prince of Peace Center	Dickey
Griggs County Care Center	Griggs
Alzheimer's Association	Griggs, Dickey
Dementia Care Services Program	Barnes, McIntosh
Sheyenne Care Center	Barnes

Region VI continued

Services	Counties Where Available
Care Management	
Griggs County Social Services	Griggs
Senior Adult Services	Griggs
Logan County Social Services	Logan
Northland Care Coordination for Seniors	Dickey
Dickey County Social Services	Dickey
Dickey County Senior Centers	Dickey
Nelson County Social Services	McIntosh
McIntosh County Social Services	McIntosh
Home Delivered Meals / Congregate Meals	
Fessenden Specialist Club	Wells
Harvey Senior Citizens	Wells
Moms Meals	Wells, Griggs, Logan, LaMoure
Wells County Aging	Wells, Foster
Carrington Senior Citizens	Foster
Eddy County Social Services	Foster
Cooperstown Golden Age Club	Griggs
Griggs County Care Center	Griggs
Hannaford Friendly Fun Makers	Griggs
James River Senior Citizens	Stutsman
South Central Adult Services	Griggs, Barnes, LaMoure, McIntosh
Ashley Senior Center	Stutsman, McIntosh
Wishek Senior Citizens	Stutsman, McIntosh
Barnes County Housing Authority	Barnes
Barnes County Senior Center	Barnes
Gackle Senior Citizens Club	Logan
Glenfield Senior Citizens	Logan
Independent Living Centers LLC	Logan
Lehr Senior Citizens	Logan, McIntosh
Napoleon Golden Age Meal Site	Logan
Dickey Adrian Friendly Folks	LaMoure
Jolly Seniors Inc. Edgeley	LaMoure
Jud Senior Citizens Club	LaMoure
Kulm Friendship Club	LaMoure
LaMoure Senior Center	LaMoure
Manor St. Joseph	LaMoure
Rosewood Court Assisted Living	LaMoure
Ellendale Senior Center	Dickey
Oakes Senior Center	Dickey

Region VI continued

Services	Counties Where Available
Home Health Agencies	
Chi Health Connect at Home	Wells, Barnes, LaMoure
City-County Health District	Wells, Griggs, Barnes
St. Aloisius Medical Center	Wells, Foster
Nelson County Health	Griggs
Griggs County Health	Griggs
Altru Home Care	Griggs
Carrington Home Care	Griggs
Easter Seals Goodwill Inc.	Stutsman, LaMoure, McIntosh, Dickey
St. Alexius Home Care	Stutsman, Logan, McIntosh
Hospice of the Red River Valley	Barnes, LaMoure, Dickey
Wishek Community Hospital	Logan, LaMoure
Jamestown Reg Medical Center	Stutsman, LaMoure
St. Rose Care Center	LaMoure
Avera at Home	Dickey
Mercy Home Health and Hospice	Dickey
Ashley Home Health	McIntosh
Personal Care Agencies	
Hav-It Services	Wells
Wells County Social Services	Wells, Foster
Foster County Social Services	Foster
Eddy County Social Services	Foster
A Spectrum of Care	Griggs
Griggs County Social Services	Griggs
McVille Home Care	Griggs
Carrington Home Care	Griggs
Easter Seals Goodwill ND Inc.	Stutsman, Barnes, Logan, LaMoure, McIntosh, Dickey
St. Alexius Home Health Care	Stutsman, Logan, McIntosh
Barnes County Social Services	Barnes
City County Health District Home Care	Barnes
Dickey County Social Services	Barnes, Dickey
Guardian Angels Inc.	Barnes
Open Door Center	Barnes
Wishek Community Hospital	Logan, McIntosh
Community Options	LaMoure
LaMoure County Social Services	LaMoure
Homemaker / Chore	
Wells County Social Services	Wells, Foster
Foster County Social Services	Foster
Eddy County Social Services	Foster
A Spectrum of Care	Griggs
Easter Seals Goodwill Inc.	Griggs, Stutsman, Barnes, Logan, LaMoure, McIntosh, Dickey

Region VI continued

Services	Counties Where Available
Homemaker / Chore (continued)	
Griggs County Social Services	Griggs
St. Alexius Home Care	Stutsman, Logan, McIntosh
Barnes County Social Services	Barnes
Guardian Angels Inc.	Barnes
Wishek Community Hospital Home Health	Logan
Community Options	LaMoure
LaMoure County Social Services	LaMoure
Dickey County Social Services	Dickey
Dickey Senior Companion Services	Dickey
Hospice / Bereavement Services	
Carrington Health Center	Wells
CHI Health Connect at Home	Wells, Barnes, LaMoure
Presentation Hospice	Foster
Griggs County Care	Griggs
Hospice of the Red River Valley	Griggs, Stutsman, Barnes, LaMoure, McIntosh, Dickey
Altru Hospice	Griggs
St. Alexius Hospice	Logan
Wishek Community Hospice	Logan, LaMoure, McIntosh
Jamestown Reg Medical Center	Stutsman, LaMoure
St. Rose Care Center	LaMoure
Mercy Home Health and Hospice	Dickey
Carrington Medical Center	Wells, Foster
Ashley Home Health	McIntosh
Information and Referral	
AARP	Wells, Griggs, Stutsman, Logan, LaMoure, McIntosh
ADRLink	Wells, Griggs, Stutsman, Logan, McIntosh, Dickey
Family Caregiver Support Program	Wells, Foster, Griggs, Stutsman, Logan, LaMoure, McIntosh, Dickey
FirstLink	Wells, Foster, Griggs, Stutsman, Barnes, Logan, LaMoure, McIntosh, Dickey
Options Counseling	Wells, Foster, Griggs, Stutsman, Logan, McIntosh
Griggs County Social Services	Griggs
South Central Adult Services	Griggs
Nelson-Griggs District Health	Griggs
Stutsman Public Health	Stutsman
Dickey County Social Services	Dickey
Community Care	Dickey
Dickey County Health District	Dickey
Dickey County Senior Centers	Dickey

Region VI continued

Services	Counties Where Available
Parish Nurse / Faith Community Nurse	
Dickey/LaMoure County Parish Nurse	LaMoure, Dickey
Trinity Lutheran Church	Foster
Public Health Nurse / Health Maintenance	
Wells County Public Health	Wells, Foster
Foster County Public Health	Foster
Nelson-Griggs District Health	Griggs
McIntosh County District Health	McIntosh
Barnes County Health Department	Barnes
Central Valley Health Unit	Logan
LaMoure County Public Health	LaMoure
Dickey County Health District	Dickey
Respite Care	
Family Caregiver Support Program	Wells, Griggs, Stutsman, LaMoure, McIntosh, Dickey
Hav-It Services	Wells
Wells County Social Services	Wells
GSS Oakes	Dickey
Napoleon Care Center	Logan
St. Aloisisus Medical Center	Foster
A Spectrum of Care	Griggs
Easter Seals Goodwill ND Inc.	Griggs, Stutsman, Logan, LaMoure, McIntosh, Dickey
Griggs County Social Services	Griggs
South Central Adult Services	Griggs
St. Alexius Home Health Care	Stutsman, Logan, McIntosh
City County Health District Home Care	Barnes
Hospice of the Red River Valley	Barnes, LaMoure, Dickey
LaMoure County Social Services	Logan, LaMoure
St. Rose Care Center	LaMoure
Dickey County Social Services	Dickey
Mercy Home Health and Hospice	Dickey
Transportation Services	
Faith in Action Health Coalition	Wells
Wells County Aging	Wells, Foster
Benson County Bus	Wells
Carrington Senior Citizens	Foster
Eddy County Seniors	Foster
South Central Adult Services	Griggs, Stutsman, Logan, McIntosh
Valley Senior Services	Barnes
Dickey Adrian Friendly Folks	LaMoure
Kulm Friendship Club	LaMoure
LaMoure Senior Center	LaMoure

Region VI continued

Services	Counties Where Available
Transportation Services (continued)	
Dickey County Social Services	Dickey
Dickey County Senior Citizens	Dickey
Oakes Senior Center	Dickey
Ellendale Senior Center	Dickey
Ashley Senior Center	McIntosh
James River Senior Citizens	Wells, Stutsman
Hannaford Friendly Fun Makers	Griggs
Wishek Senior Citizens	McIntosh
Volunteer Services	
Faith in Action Health Coalition	Wells, Foster
Sutton Senior Citizens	Griggs
South Central Adult Services	Griggs
American Red Cross	Stutsman, Logan, McIntosh
Napoleon Golden Age Meal Site	Logan
RSVP+	Logan
Dickey Adrian Friendly Folks	LaMoure
Kulm Friendship Club	LaMoure
Wishek Senior Citizens	McIntosh

Region VII (McLean, Sheridan, Mercer, Oliver, Burleigh, Kidder, Morton, Emmons, Sioux and Grant counties)

Services	Counties Where Available
Adult Day Care	
Graceful Aging	Burleigh
Garrison Memorial Hospital	McLean
Turtle Lake Community Memorial Hospital	McLean
Missouri Slope Lutheran Care	Burleigh
Dacotah Alpha	Morton
Maple View	Burleigh
Hit Inc	Morton
Advocacy Services	
Protection and Advocacy	McLean, Sheridan, Mercer, Oliver, Burleigh, Kidder, Morton, Emmons, Sioux, Grant
Dakota Center for Independent Living	Burleigh
Guardian and Protective Services	Burleigh, Morton, Emmons
Adult Protective Services	Burleigh
Ombudsman	Burleigh
Vulnerable Adult Services	Morton
Assistive Technology / Equipment	
Great Plains Rehab Services	McLean, Mercer, Burleigh, Morton, Emmons, Sioux, Grant
HealthCare Accessories	McLean, Burleigh, Morton, Grant
IPAT	McLean, Sheridan, Mercer, Oliver, Burleigh, Kidder, Morton, Emmons, Grant
Home and Community Based Services Program	McLean
Assistive Safety Devices Distribution Program	Kidder, Morton
Linton Hospital	Emmons
Emotional Support (support groups, geriatric mental health)	
Benedictine Living Center	McLean
Family Caregiver Support Program	McLean, Mercer, Kidder, Morton, Emmons, Grant
Knife River Care Center	McLean, Mercer
St. Alexius Medical Center	Burleigh, Morton
Sanford Health	Morton
Caregiver Training and Education	
Family Caregiver Support Program	McLean, Mercer, Oliver, Burleigh, Kidder, Morton, Emmons, Grant
NDSU Extension	Mercer, Morton, Emmons
Alzheimer's Association	Oliver

Region VII continued

Dementia Care	
Alzheimer's Association	McLean
Dementia Care Services Program	Mercer, Kidder, Morton, Grant
Mapleview	Burleigh
Sanford Health St. Vincents	Burleigh
Knife River Care Center	Mercer
Edgewood Vista	Burleigh
Care Management	
Northland Care Coordination for Seniors	McLean, Mercer, Burleigh, Morton
Dakota Central Social Service District	McLean, Sheridan, Oliver
Northland PACE Services	Burleigh, Morton, Grant
Burleigh County Social Services	Burleigh
Kidder County Social Services	Kidder
Home and Community Based Services	Emmons
Home Delivered Meals / Congregate Meals	
Burleigh County Council on Aging	McLean, Burleigh, Morton
Burleigh County Senior Adults Program	Burleigh
Butte Senior Citizens	McLean
Center/Oliver County Golden Age Club	McLean, Mercer, Oliver
Hazen Senior Citizens	McLean, Mercer
Mandan Golden Age Services	McLean, Morton
Mercer/McLean Counties Commission on Aging	McLean
Underwood Senior Citizens	McLean
Wilton Pioneer Activity Center	McLean
Sheridan Senior Center	Sheridan
Mercer Golden 50s	Mercer
Bismarck Meals on Wheels	Burleigh
Marillac Manor	Burleigh
PACE	Burleigh, Morton
Purfoods LLC Mom's Meals	Burleigh, Kidder, Morton, Emmons
Terrace	Burleigh
Kidder Emmons Senior Services	Kidder, Emmons
Robinson Senior Center	Kidder
Tuttle Senior Center	Kidder
Almont Prairie Rose Senior Citizens	Morton
Elm Crest Manor and Assisted Living	Morton
Flasher Nutrition Program	Morton
Glen Ullin Senior Center	Morton
Hebron Brick City Seniors	Morton
New Salem Pioneer Club	Morton
Linton Hospital	Emmons
Linton Senior Citizens	Emmons
Grant Count Senior Meals Program	Grant
Strasburg Care Center	Emmons

Region VII continued

Services	Counties Where Available
Home Delivered Meals / Congregate Meals (continued)	
Selfridge Silver and Gold Seniors	Sioux
Standing Rock Nutrition Program	Sioux
Home Health Agencies	
Custer District Health	McLean, Mercer, Oliver, Morton
Sakakawea Medical Center Home Health	McLean, Mercer
Sanford Home Health	McLean, Burleigh, Kidder, Morton, Grant
St. Alexius Home Care	McLean, Burleigh, Kidder, Morton, Grant
Trinity Home Health	McLean
First District Public Health	Sheridan
Bismarck / Burleigh Public Health	Burleigh
Good Samaritan Home Care	Burleigh
Pride	Morton
Emmons County Public Health	Emmons
Linton Hospital	Emmons
Grant County Public Health	Grant
KOLA	Sioux
Personal Care Agencies	
Dakota Central Social Service District	McLean, Sheridan, Mercer, Oliver
PRIDE	McLean, Morton
Redwood Village	McLean
Extended Personal Care	McLean
Comfort Care Inc	Burleigh, Morton
Comfort Keepers	Burleigh, Morton
Community Options	Burleigh, Morton, Emmons
Easter Seals Goodwill ND Inc	Burleigh, Morton
Enable Inc	Burleigh, Morton
Extended Life Home Care Co	Burleigh, Morton
Loving Hearts Home Care LLC	Burleigh, Morton
PACE	Burleigh, Morton
Sanford Home Care	Burleigh, Morton
Smiling Angel Home Care Service LLC	Burleigh, Morton
Spectrum Home Care Inc	Burleigh, Morton
St. Alexius Home Health Care	Burleigh, Morton
Support Systems Inc	Burleigh, Morton
Visiting Angels	Burleigh, Morton
Kidder County Social Services	Kidder
Circle of Life Kola Home Care Inc	Morton, Sioux
Edgewood Mandan LLC	Morton
Personal Home Care	Morton
Linton Hospital	Emmons
Prairie Rose Assisted Living	Emmons
Grant County Social Services	Grant

Region VII continued

Services	Counties Where Available
Homemaker / Chore	
Dakota Central Social Service District	McLean, Sheridan, Mercer, Oliver
Extended Personal Care	McLean
Community Options	Burleigh, Morton
Easter Seals Goodwill Inc	Burleigh, Morton
Loving Hearts Home Care LLC	Burleigh, Morton
Sanford Home Care	Burleigh, Morton
Smiling Angel Home Care Service LLC	Burleigh, Morton
Spectrum Home Care Inc	Burleigh, Morton
Support Systems Inc	Burleigh, Morton
Visiting Angels	Burleigh, Morton
Hit Inc	Morton
Personal Home Care	Morton
PRIDE	Morton
St. Alexius Home Health Care	Morton
Linton Hospital	Emmons
Grant County Social Services	Grant
Prairie Rose Assisted Living	Emmons
Hospice / Bereavement Services	
Garrison Memorial Hospital	McLean
Sanford Hospice	McLean, Kidder, Morton
St. Alexius Hospice	McLean, Burleigh, Kidder, Morton, Grant
Trinity Hospice	McLean
Golden Manor	Mercer
Linton Hospital	Emmons
Comfort Keepers	Morton
Information and Referral	
AARP	McLean, Sheridan, Mercer, Oliver, Burleigh, Kidder, Morton, Grant
ADRLink	McLean, Sheridan, Mercer, Oliver, Burleigh, Kidder, Morton
Family Caregiver Support Program	McLean, Sheridan, Mercer, Oliver, Burleigh, Kidder, Morton, Emmons, Grant
Options Counseling	McLean, Sheridan, Mercer, Oliver, Burleigh, Kidder, Morton, Emmons, Grant
Dakota Central Social Services	McLean
FirstLink	Sheridan, Mercer, Oliver, Morton
Emmons County Social Services	Emmons
Parish Nurse / Faith Community Nurse	
Good Shepherd Lutheran	Burleigh
Faith Lutheran	Burleigh
Trinity Lutheran	Burleigh
McCabe United Methodist	Burleigh

Region VII continued

Services	Counties Where Available
Public Health Nurse / Health Maintenance	
First District Health Unit	McLean, Sheridan
Sioux County Public Health	Sioux
Custer District Health Unit	Mercer, Oliver, Morton, Grant
Kidder County District Health Unit	Kidder
Burleigh/Bismarck Public Health	Burleigh
Emmons County Public Health	Emmons
Respite Care	
Dakota Central Social Service District	McLean, Sheridan, Mercer, Oliver
Extended Life Home Care CO	McLean, Morton
Family Caregiver Support Program	McLean, Burleigh, Kidder, Morton
Grant County Social Services	Grant
Missouri Slope Lutheran Care Center	Burleigh
Maple View Memory Care	Burleigh
Garrison Memorial Hospital	McLean
McLean County Social Services	McLean
Mercer County Social Services	Mercer
Oliver County Social Services	Oliver
Sheridan County Social Services	Sheridan
Turtle Lake Community Memorial Hospital	McLean
Community Options	Burleigh, Morton, Emmons
Easter Seals Goodwill ND Inc	Burleigh, Morton
Hit Inc	Burleigh, Morton
Loving Hearts Home Care LLC	Burleigh, Morton
Morton County Social Services	Burleigh, Morton
PRIDE	Burleigh, Morton
Sanford Home Care	Burleigh, Morton
Smiling Angel Home Care Service LLC	Burleigh, Morton
Spectrum Support Services	Burleigh, Morton
St Alexius Home Health Care	Burleigh, Morton
Support Systems Inc	Burleigh, Morton
Visiting Angels	Burleigh, Morton
Linton Hospital	Emmons
Transportation Services	
Mercer/McLean Counties Commission on Aging	McLean, Mercer
Beulah Senior Citizens	McLean, Mercer
Max Over 55 Club	McLean
Lewis & Clark Senior Center	Morton
Hazen Busing	McLean, Mercer
West River Transportation Council	McLean, Mercer, Oliver, Burleigh, Morton, Grant
Dakota Central Social Service District	Sheridan, Mercer, Oliver
Bis-Man Transit	Burleigh, Morton

Region VII continued

Services	Counties Where Available
Transportation Services (continued)	
Community Options	Burleigh, Morton
Loving Hearts Home Care LLC	Burleigh, Morton
Maple View East Inc, North	Burleigh
PACE	Burleigh
Smiling Angel Home Care Service LLC	Burleigh, Morton
Spectrum Home Care Inc	Burleigh, Morton
Support Systems Inc	Burleigh, Morton
Touchmark	Burleigh
Visiting Angels	Burleigh, Morton
Volunteer Caregivers for the Elderly	Burleigh, Morton
Kidder Emmons Senior Services	Kidder, Emmons
Aid Inc	Morton
Almont Prairie Rose Senior Citizens	Morton
Edgewood Mandan LLC	Morton
Elm Crest Manor and Assisted Living	Morton
Flasher 55+ Club	Morton
Hebron Brick City Seniors	Morton
Hit Inc	Morton
Mandan Golden Age Services	Morton
Wells/Sheridan Counties Aging Council	Sheridan
Metro Plains Management	Morton
Northland Care Coordination for Seniors	Morton
James River Senior Citizen Center	Burleigh
Personal Home Care	Morton
Southeast Burleigh Golden Age Club	Burleigh
PACE	Morton
Emmons County Transit	Emmons
Standing Rock Transit	Sioux
Volunteer Services	
Beulah Senior Citizens	Mercer
Burleigh County Senior Adults	Burleigh
Missouri Slope United Way	Burleigh, Morton
RSVP+	Burleigh, Kidder, Morton, Emmons
Volunteer Caregiver Exchange	Burleigh, Morton
SCORE	Kidder, Morton
Almont Prairie Rose Senior Citizens	Morton
Flasher 55+ Club	Morton
St. Alexius Volunteer Services	Morton
United Way- First Call for Help	Morton
Foster Grandparent Program	Emmons

Region VIII (Dunn, Billings, Golden Valley, Stark, Slope, Hettinger, Bowman and Adams counties)

Services	Counties Where Available
Adult Day Care	
Spring Creek Senior Citizens Dodge	Dunn, Bowman
Halliday Senior Citizens	Dunn
Good Samaritan Society Mott	Hettinger
Advocacy Services	
Aging Life Care Management, Lutheran Social Services of ND	Dunn, Slope, Bowman
ND Protection and Advocacy	Stark
Veterans Advocacy	Slope, Bowman
Assistive Technology / Equipment	
Assistive Safety Devices Distribution Program	Dunn, Stark, Slope, Bowman
Great Plains Rehab Services	Dunn, Billings, Golden Valley, Hettinger
IPAT	Dunn, Billings, Golden Valley, Stark, Slope, Hettinger, Bowman, Adams
HealthCare Accessories	Adams
West River Health Service	Adams
Emotional Support (support groups, geriatric mental health)	
BGVCCOA	Billings, Golden Valley
Dakota Center for Independent Living	Stark
Badlands Human Services	Slope, Bowman
Family Caregiver Support Program	Hettinger
Caregiver Training and Education	
Family Caregiver Support Program	Stark, Slope, Hettinger, Bowman, Adams
NDSU Extension	Slope, Hettinger, Bowman, Adams
Dementia Care	
St. Benedict's Health Center	Stark
Dementia Care Services Program	Stark, Slope, Hettinger, Bowman
Care Management	
Aging Life Care Management, Lutheran Social Services of ND	Dunn
Northland PACE Services	Dunn, Stark, Hettinger
Care Connection	Hettinger
Home Delivered Meals / Congregate Meals	
Dunn County Council on Aging	Dunn
Beach Senior Center	Golden Valley
Elder Care	Golden Valley, Stark, Slope, Hettinger, Bowman
Moms Meals	Billings, Golden Valley, Stark, Slope, Hettinger, Bowman
Metro Plains Management	Stark
Richardton Senior Citizens	Stark

Region VIII continued

Services	Counties Where Available
Home Delivered Meals / Congregate Meals (continued)	
CannonBall Senior Citizens of Mott	Hettinger
New England Senior Citizens	Hettinger
Regent Senior Citizens	Hettinger
Hettinger Second 40 Club	Adams
Western Horizons Assisted Living	Adams
Home Health Agencies	
Hill Top Home of Comfort	Dunn
Southwest Health Care Services	Billings, Golden Valley, Slope, Bowman
St. Joseph Hospital Home Health	Billings, Golden Valley, Stark, Hettinger
St. Alexius Home Care	Stark
West River Regional Medical Center	Hettinger, Adams
West River Visiting Nurses	Hettinger, Adams
Easter Seals Goodwill Inc.	Adams
Personal Care Agencies	
Dunn County Social Services	Dunn
Golden Valley / Billings County Social Services	Billings, Golden Valley
Community Options	Stark
Easter Seals Goodwill ND Inc.	Stark, Adams
Loving Hearts Home Care LLC	Stark, Slope, Bowman
PACE	Stark
Stark County Social Services	Stark
Support Systems Inc.	Stark, Slope, Bowman
Bowman County Social Services	Slope, Bowman
Dakota Prairie Helping Hands	Slope, Bowman, Adams
Western Horizons Living Center	Slope, Bowman, Adams
Hettinger County Social Services	Hettinger
Adams County Social Service Board	Adams
West River Visiting Nurses	Adams
Homemaker / Chore	
Dunn County Social Services	Dunn
Hill Top Home of Comfort	Dunn
Golden Valley / Billings County Social Services	Billings, Golden Valley
Community Options	Stark
Easter Seals Goodwill ND Inc.	Stark
Loving Hearts Home Care LLC	Stark, Slope, Bowman
Stark County Social Services	Stark
Support Systems Inc.	Stark
Bowman County Social Services	Slope, Bowman
Western Horizons Living Center	Slope, Bowman
Hettinger County Social Services	Hettinger
Adams County Social Services	Adams

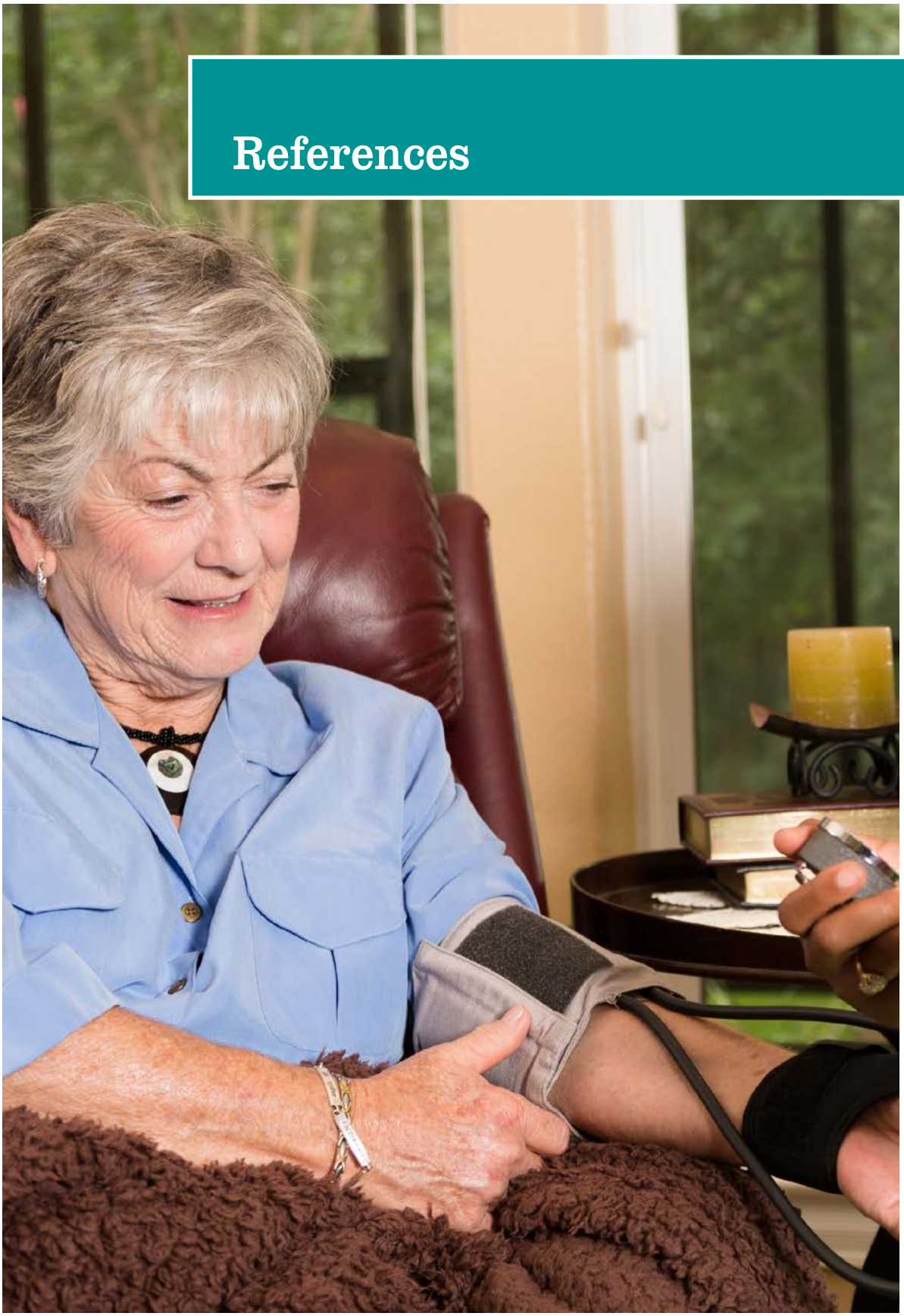
Region VIII continued

Services	Counties Where Available
Hospice / Bereavement Services	
St. Joseph Hospice	Dunn, Billings, Golden Valley, Stark, Hettinger
Southwest Health Care Visiting Nurse Services	Slope, Bowman
Information and Referral	
AARP	Dunn, Hettinger, Adams
Family Caregiver Support Program	Stark, Slope, Hettinger, Bowman, Adams
Options Counseling	Stark, Slope, Hettinger, Bowman, Adams
Stark County Social Services	Stark,
FirstLink	Hettinger, Adams
Parish Nurse / Faith Community Nurse	
N/A	
Public Health Nurse / Health Maintenance	
Dunn County Public Health Department	Dunn
Billings / Golden Valley County Public Health	Billings, Golden Valley
Southwestern District Health Unit	Stark, Slope, Bowman
Hettinger County Public Health Department	Hettinger
Adams County Public Health	Adams
Respite Care	
Dunn County Social Services	Dunn
St. Joseph Hospital Home Health	Dunn
Golden Valley / Billings County Social Services	Billings, Golden Valley
St. Luke's Home	Stark
Dickinson Country House	Stark
Community Options	Stark
Easter Seals Goodwill ND Inc.	Stark
Family Caregiver Support Program	Stark
Loving Hearts Home Care LLC	Stark
Stark County Social Services	Stark
Support Systems Inc.	Stark
Bowman County Social Services	Bowman
Slope County Social Services	Slope
Hettinger County Social Services	Hettinger
Adams County Social Services	Adams
Dakota Prairie Helping Hands	Adams
Transportation Services	
Dunn County Council on Aging	Dunn
Elder Care / Public Transit	Dunn, Stark, Adams
Hill Top Home of Comfort	Dunn
CCOA	Billings, Golden Valley
PACE	Stark
Stark County Social Services	Stark

Region VIII continued

Services	Counties Where Available
Transportation Services (continued)	
Bowman County Social Services	Bowman
Loving Hearts Home Care LLC	Slope, Bowman
Southwest Transportation Services	Slope, Hettinger, Bowman
West River Transportation Council	Dunn
Golden Valley/Billings County Council on Aging	Billings, Golden Valley
Beach Senior Center	Hettinger
Hettinger County Social Services	Hettinger
Volunteer Services	
RSVP+	Stark
Dakota Prairie Helping Hands	Slope, Bowman, Adams
Regent Senior Citizens	Hettinger

References



AARP (2016). *Caregivers & technology: What they want and need.* Retrieved from http://www.aarp.org/content/dam/aarp/home-and-family/personal-technology/2016/04/Caregivers-and-Technology-AARP.pdf?intcmp=RDRCT-ESI-INNOV50-CAREGVRTECH-20160427

AARP of North Dakota. (2015). *Family Caregiver Survey.* Unpublished Report.

Adler, R. & Mehta, R. (2014) *Catalyzing technology to support family caregiving. National Alliance for Caregiving.* Retrieved from http://www.caregiving.org/wp-content/uploads/2010/01/Catalyzing-Technology-to-Support-Family-Caregiving_FINAL.pdf

ARCH National Respite Network and Resource Center (2011) National Respite Guidelines: Guiding Principles for Respite Models and Services. http://archrespite.org/productspublications

Bauer, M., Fitzgerald, L., Haesler, E., and Manfrin, M. (2008). Hospital discharge planning for frail older people and their family. Are we delivering best practice? A review of the evidence. *Journal of Clinical Nursing, 18,* 2539-2546.

Coleman, B. (2000). *Helping the helpers: State supported services for family caregivers. AARP Public Policy Institute.* Retrieved from http://assets.aarp.org/rgcenter/health/2000_07_help.pdf

Connor, K.I., Siebens, H.C., & Chodosh, J. (2015). Person-centered approaches to caregiving. In J. E. Gaugler & R. L. Kane (Eds.), *Family caregiving in the new normal* (pp. 251-268). London, UK: Elsevier Inc.

Davis, L.L., Burgio L., Buckwalter K.C., & Weaver, M. (2004). A comparison of in-home and telephone-based skill training interventions with caregivers of persons with dementia. *Journal of Mental Health and Aging, 10,* 31-44.

Delaware Division of Services for Aging and Adults with Physical Disabilies. (2015). *Caregiver support blueprint for Delaware: A report to the Delaware general assembly.* Retrieved from http://dhss.delaware.gov/dhss/dsaapd/files/caregiver_support_blueprint.pdf

Demiris, G. (2015). Information technology to support aging: Implications for caregiving. In J. E. Gaugler & R. L. Kane (Eds.), *Family caregiving in the new normal* (pp. 211-224). London, UK: Elsevier Inc.

Doody, R.S., Stevens, J.C., Beck, C., Dubinsky, R.M., Kay, J.A., et al., (2001). Practice parameter: Management of dementia (an evidence-based review). *Neurology, 56,* 1154-1166.

Dunnion, M.E.B. & Kelly, B. (2005). From the emergency department to home. *Journal of Clinical Nursing, 6(4),* 776-785.

Eisdorfer, C.,Czaja, S.J., Loewenstein, D.A., Rubert, M.P., Arguelles, S., Mitrani, V.B., & Szapocznik, J. (2003). The effect of a family therapy and technology-based intervention on caregiver depression. *The Gerontologist, 43,* 521-531.

Family Caregiver Alliance *National Center on Caregiving.* (2016). Retrieved from: https://www.caregiver.org/support-groups.

Feinberg, L.F. & Newman, S.L. (2005). Consumer direction and family caregiving: Results from a national survey. Rutgers Center for State Health Policy.

Grabowski, D.C. & O' Malley, A. J. (2014). Use of telemedicine can reduce hospitalizations of nursing home residents and generate savings for medicare. *Health Affairs, 33,* 244-250. doi:10.1377/hlthaff.2013.0922

Griffiths,F., Johnson, M., & Piper, M. (2004). A nursing intervention for the quality use of medicines by elderly community clients. *International Journal of Nursing Practice, 10,* 166.

Growing ND by the numbers. (2014, November). North Dakota Census Office. Retrieved from http://www.commerce.nd.gov/uploads/8/CensusNewsletterNov2014.pdf

Hall, S.S., Kandiah, J., Saiki, D., Nam, J., Harden, A., & Park, S. (2014). Implications of Smart Wear technology for family caregiving relationships: Focus group perceptions. *Social Work in Health Care, 53,* 994-1014, doi: 10.1080/00981389.2014.925997.

Kachouie, R., Sedighadeli, S., Khosla, R., & Chu, M-T. (2014). Socially assistive robots in elderly care: A mixed-method systematic literature review. *International Journal of Human-Computer Interaction, 30,* 369-393.

Kelly, K., Reinhard, S.C., and Brooks-Danso, A. (2008). Executive summary: Professional partners supporting family caregivers. *AJN, 108,* 6-12.

Levine, C. Halper, D., Peist, A., and Gould, D. (2010). Bridging troubled waters: Family caregivers, transitions, and long-term care. *Health Affairs, 29,* 116-124.

Lykens, K., Moayad, N., Biswas, S., Reyes-Ortiz, C., & Singh, K.P. (2014). Impact of a community based implementation of REACH II program for caregivers of Alzheimer's patients. *PLoS One, 9(2),* 1-8.

Mailey, S.K. (2002). Disaster planning education for home care nurses, patients, and caregivers. *Home Health Care Management & Practice, 15(1),* 39-46.

MetLife National Study of Adult Day Services: Providing Support to Individuals and their family caregivers (2010). Retrieved from https://www.metlife.com/assets/cao/mmi/publications/studies/2010/mmi-adult-day-services.pdf

Miller, R. H. & Sim, I. (2004). Physicians' use of electronic medical records: Barriers and solutions. *Health Affairs, 23,* 116-126. doi:10.1377/hlthaff.23.2.116

National Alliance for Caregiving for ReACT. (2012). *Best practices in workplace eldercare.* Bethesda, MD: Donna L. Wagner, Andrea Lindemer, Kelly Niles Yokum, & Mary DeFreest.

Naylor, M.D., Brooten, D., Campbell, R., Jacobsen, B.S., Mezey, M.D., Pauly, M.V., & Schwartz, J.S. (1999). Comprehensive discharge planning and home follow-up of hospitalized elders: A randomized clinical trial. *The Journal of the American Medical Association, 281(7),* 613-620.

New Mexico Aging & Long-Term Care Services Department. (2015). *New Mexico state plan for family caregivers.* Retrieved from http://www.nmaging.state.nm.us/uploads/FileLinks/93d89f60b10b4732be44e6c31f403060/New_Mexico_State_Plan_for_Family_Caregivers_final.pdf

New York State Caregiving & Respite Coalition. (2013): *Report: Caregivers in crisis.* Retrieved from http://states.aarp.org/wp-content/uploads/2013/11/Caregivers-in-Crisis-FINAL.pdf

Nikzad-Terhune, K., Anderson, K.A., & La Bey, L. (2015). The impact of the internet and social media on caregiving. In J. E. Gaugler & R. L. Kane (Eds.), *Family caregiving in the new normal* (pp. 269-290). London, UK: Elsevier Inc.

North Dakota Compass. (2016). Percent of Population Age 65+, 2014 U.S. Census [Demographic map]. Retrieved from http://www.ndcompass.org/demographics/key-measures.php?km=age#0-6944-g

North Dakota Department of Human Services, Division of Aging Services. (2014). *North Dakota Family Caregiver Support Program Survey Report.* Unpublished Report.

North Dakota Department of Human Services, Division of Aging Services. (2015). *North Dakota Family Caregiver Support Program Survey Report.* Unpublished Report.

North Dakota Senior Service Providers. (2015). *Feeding grandpa: A 2015 legislative document.* Retrieved from http://www.ndseniorservices.org/Feeding%20Grandpa.pdf

Reinhard, S., Feinberg, L.F. Choula, R., & Houser, A. (2015). *Valuing the invaluable: 2015 update. AARP Public Policy Institute.* Retrieved from http://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf

Rose, M.S., Noelker, L.S., & Kagan, J. (2015). Improving policies for caregiver respite services. *The Gerontologist, 55,* 302-308. doi:10.1093/geront/gnu120

Schulz, R. & Martire, L.M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *American Journal of Geriatric Psychiatry, 12,* 240-249.

Sterling, M. (2014). What family caregivers need from health IT and the healthcare system to be effective health managers. Connected Health Resources. Retrieved from www.connectedhealthresources.com

Silberberg, M. and Caruso, D. (2001). New Jersey's Statewide Respite Care Program: A study of program design, implementation, clients and Services. The Center for State Health Policy. Rutgers, The State University of New Jersey.

Toseland, R.W., McCallion, P., Smith, T., & Banks, S. (2004). Supporting caregivers of frail older adults in an HMO setting. *American Journal of Orthopsychiatry, 74,* 349-364.

Williamson, S.S., Gorman, P.N., & Jimison, H.B. (2014). A mobile/web app for long distance caregivers of older adults: Functional requirements and design implications from a user centered design process. AMIA Annual Symposium Proceedings Archive, 1960-1969. Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4419890/