



AARP® Real Possibilities in
North Dakota

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Interim Human Services Committee

AARP North Dakota Comments on Study Priorities

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Chair Hogan and members of the Interim Human Services Committee, for the record my name is Josh Askvig and I am the Associate State Director for Advocacy for AARP North Dakota. Thank you for the opportunity to provide comments regarding our priorities in the *Family Caregiver Supports Study (hereafter Study)* for the 2017 Legislative Assembly.

Dr. Ethel Percy Andrus, a retired educator and AARP's founder, became an activist in the 1940s when she found a retired teacher living in a chicken coop because she could afford nothing else. Dr. Andrus couldn't ignore the need for health and financial security in America and set the wheels in motion for what would become AARP. We are a nonprofit, nonpartisan membership organization with more than 87,000 members in North Dakota and 38 million nationwide. We help people turn their goals and dreams into 'Real Possibilities' by changing the way America defines aging, including here in North Dakota.

AARP has been raising the profile of family caregivers in North Dakota and across the country. Through our research we know that there are approximately 62,100 individual caregivers in North Dakota that provide over 58 million hours of uncompensated care valued at over \$860 million. In recent years, the role of family caregivers has greatly expanded from coordinating and providing personal care and household chores to include medical or nursing tasks such as wound care and injections. For the individuals doing this work in North Dakota it is a labor of love, but it comes with stress, burnout and often times at a cost to their own health and financial stability. Providing support for these caregivers is critical toward ensuring that individuals can safely stay in their homes as they age. Our loved ones can remain independent at home with caregiver support.

As you know from our previous discussions, we have been collecting stories of caregivers here in North Dakota. This information was shared with Dr. Strommen's team and helped inform the

Study. Before we get into our suggested recommendations, we thought it important for you to see one of those stories. It highlights some of the struggles caregivers face, especially in rural communities across North Dakota. This story comes from [Mr. Larry Hinderer from Carson](#). Larry takes care of his wife with multiple sclerosis, every day, 24 hours a day. He does the cooking, bathing, and other necessary tasks that allow Larry and his wife to stay at home rather than move away from their homestead. It's a tough job, but for Larry and the other 62,100 North Dakota caregivers, it's a labor of love.

Larry's story is one of many in North Dakota. As you can see, these individuals want to assist their loved ones stay safe and stay at home. Now, our North Dakota caregivers need your support of the *Study* recommendations to get the tools they need to stay on the job, saving the State of North Dakota money in the short-term and over time. That is why we are excited about the recommendations made by Dr. Jane Strommen and her team of Dr. Gregory Sanders and Dr. Heather Fuller *Study*. They did a fantastic job and we support the proposals in the *Study*.

We would love to have all of the proposals completed today, but we are realistic in knowing that it will take some time for them to be fleshed out, considered and then put into action. In our view the proposals should be acted on and implemented over multiple legislative sessions. Having said that, we believe it is critical to move forward now with a subset of the study recommendations for consideration in the 2017 legislative session.

Lifespan Respite Care Program-

One of the top concerns raised by caregivers and stakeholders during the NDSU *Study* was the need for more respite for caregivers. North Dakota currently has the Family Caregiver Respite Program, but we can and should do more. The researchers found that North Dakota may be eligible for an additional federal grant from the Lifespan Respite Care Program. This grant program would allow the state to expand and enhance respite services in North Dakota. Additionally, it would allow us to streamline access and improve coordination of respite services. Last, it would assist in improving the quality of respite care services and filling in gaps where necessary. **The Legislature should direct the Department of Human Services to make an application for a Lifespan Respite Care Program grant should it become available in the 2017 calendar year.**

Aging and Disability Resource Link (ADRL)-

The NDSU *Study* highlighted the confusion and frustration caregivers face in finding and accessing services for their loved ones or themselves. In fact, just behind the financial cost of care, this was the biggest challenge identified by family caregivers in the research. Under the

recommendation “Improve resources to help family caregivers find, connect to, and navigate available services,” there are three proposed strategies. They include identifying marketing and communication strategies to promote the existing ADRL, creating a caregiver resource center within the ADRL to increase access to existing programs and services, and creating a comprehensive guide to caregiving for North Dakota caregivers. **The Legislature should include funding in its 2017-19 budget to implement and carry out these recommendations.** It is especially important that there are sufficient resources to ensure North Dakotans know about the ADRL and the assistance it can provide in aiding their loved ones. Promoting the regional ADRL toll-free numbers for aging and disability resources should be prioritized.

SPED sliding fee schedule-

Specifically, the sliding fee schedule for state-funded Service Payments for the Elderly and Disabled (SPED) has not been adjusted since 2009. Having these fee schedules “frozen” for over eight years means many individuals who have had small cost-of-living adjustments in their Social Security benefits are actually falling behind. They are now being charged above what their actual income can support for needed services due to these schedules not keeping up with inflation. Individuals are not utilizing these services because of the fee schedule, which means the full workload falls on caregivers contributing to their burnout and stress. **The fee schedule should be updated and then the schedule should be indexed with an automatic inflator so it does not fall behind again.** Adjusting the schedule will ensure individuals needing SPED supports can remain independent at home and assist caregivers in knowing their loved ones are getting needed services at an affordable rate.

Homemaker Services reimbursement-

During the current biennium, the department was directed to make some very drastic budget cuts due to the decline in revenue collections by the State. The cut to homemaker services rates has and will continue to have a detrimental impact on caregivers and their loved ones. This service is often the first step in getting the other necessary services related to activities of daily living that keep individuals independent and at home. Because of the cuts, AARP has heard from a wide array of providers that they will either be capping or - in many instances - no longer offering this service. This will undoubtedly lead to fewer other personal care services being provided in the future. **The nearly 50% cut in rates should be rescinded and funding provided in the 2017-19 DHS budget to reimburse homemaker services at the regular rate.** Again, if providers cap or quit providing this service, this is another burden that will likely fall on caregivers contributing to their already heavy assignment.

Caregiver Advise Record and Enable (CARE) Act-

While this specific bill was not a recommendation of the *Study*, there is plenty in the study results that support its implementation in North Dakota. As the *Study* points out, almost half of family caregivers report they did not receive any instruction or training on providing medical care (see attachment slide from NDSU May Presentation). Additionally, even providers noted in the study that the No. 1 challenge facing caregivers from the North Dakota Family Caregiver Support Program (FCSP) survey of users was assisting with activities of daily living and instrumental activities of daily living. This finding further highlights the need for the CARE Act. The *Study* highlights as one of its recommendations the need for more training and instruction for caregivers. The CARE Act is a step toward meeting this recommendation. We fully understand that the CARE Act is not a “silver bullet,” but it does provide a necessary safeguard for patients and their caregivers.

Additionally, we would note, we have made a good faith effort to meet the concerns of the hospitals on this legislation, including using their choice of a model bill. Additionally, the CARE Act has the potential to save the state money by preventing avoidable hospital readmissions that are paid for by Medicaid and other state funds. As we pointed out in January (attached as an addendum is the January chart), there are still gaps that exist in the state, CMS, and Joint Commission standards that should be closed to assure that family caregivers get the support they need every time. The CARE Act closes these loopholes and gives family caregivers the support they deserve. **We urge you to move the CARE Act forward to the 2017 Legislative Session.**

Medicaid Expansion-

We fully understand that Medicaid Expansion is not under the purview of this committee nor a part of the *Study*. However, we wanted to take a moment to highlight the importance of Medicaid Expansion for North Dakotans, including potentially caregivers. Since the 2013 implementation of Medicaid Expansion, almost 20,000 North Dakotans have insurance and access to preventative care that can save lives, reduced the need for expensive emergency room care, and eased emergency room overcrowding that threatens us all. This is especially important to the 33% of recipients who are between the ages of 45-64. Medicaid Expansion may ensure they have coverage until they reach Medicare age. Remember, twelve percent (12%) of caregivers said they were not employed due caregiving duties and another six percent (6%) of the caregivers stated that they had switched to working part-time as a result of their caregiving duties (see the attached slide from NDSU May presentation), placing them at risk of losing their health insurance. Medicaid Expansion ensures those that might lose health

coverage due to taking on caregiving duties will still be able to obtain health insurance for themselves.

Home- and Community-Based Service Funding-

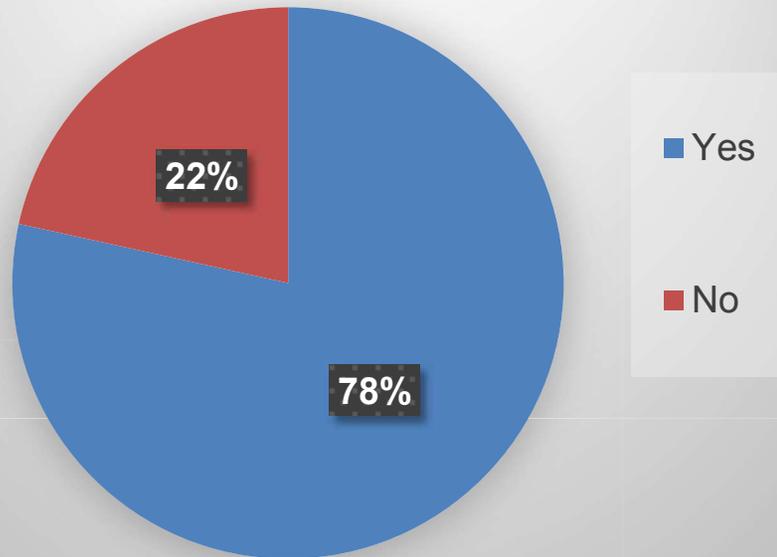
Last, we wanted to take a moment to note that North Dakota continues to have a significant imbalance in the funding it provides for individuals to get services and supports in a home setting versus an institutional setting. While we commend the department for the steps they have made toward balancing that effort, we believe there is more that could and should be done. According to the *Raising Expectations 2014: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers*, North Dakota ranks last out of the 50 states and District of Columbia when it comes to the “Percent of Medicaid and state-funded LTSS spending going to HCBS for older people and adults with physical disabilities.” This study indicator shows how a state’s Medicaid spending is used to provide supports for older individuals. Being in last place is never a positive rating. According to the report, North Dakota only spends 14.5% of its budget on HCBS for long term care supports. This finding is a root cause of many of the issues highlighted in the NDSU Study. Consumer confusion and frustration about ADRL services, high costs of care, an underfunded respite care program - all of these are direct results of the state prioritizing its dollars for institutional care instead of home- and community-based services. It’s imperative that **the 2017-19 Legislature look at moving toward a more balanced approach in how we fund and support individuals living independently**. This may include funding to conduct a study on how to best restructure our funding model regarding long term services and supports. The state should also take advantage of technical assistance offered with the Money Follows the Person Demonstration and look to lessons learned or best practices from other states to help with the state’s rebalancing plan.

Chair Hogan and Members of the Committee, thank you for the work you have done on this important issue. The *Study* is a great roadmap of how North Dakota can build upon its foundation of caregiver support. As we have said - and as Larry says in his story - North Dakotans want to stay at home as they age. Again, we appreciate the opportunity to provide comments and input as you prepare legislation for the 2017 Legislative Assembly. I’d be happy to answer any questions.

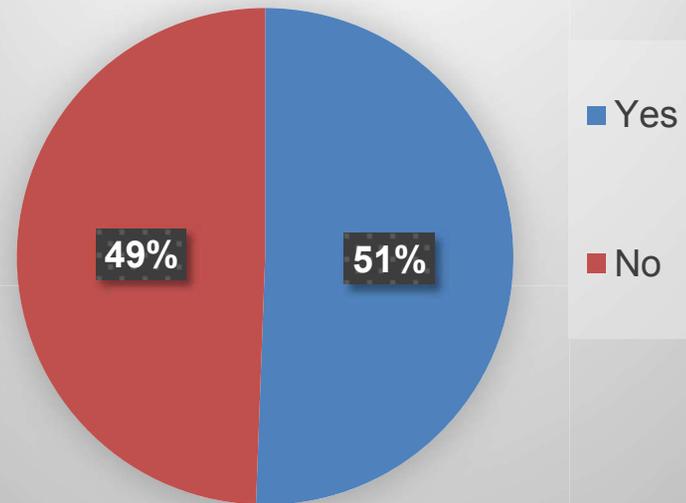
Aim 2: Caregiver's Perspective

AARP Caregiver Survey (2015)

Do you provide medical or nursing cares?



Did you receive any instruction or training on providing medical cares?



NORTH DAKOTA CARE ACT COMPARISON TO STATE AND FEDERAL REGULATIONS

All of these regulations are found in North Dakota Century Code and Administrative Rules. They are all part of Chapter 33-07-01.1 North Dakota Licensing Rules for Hospitals. Access to Regulations is through North Dakota Department of Health; Health Facilities:

http://www.ndhealth.gov/hf/North_Dakota_Hospitals_Critical_access.htm. Upon entering the website navigate to the appropriate regulation through the menu links.

CARE Act	NORTH DAKOTA ADMINISTRATIVE REGULATIONS	CONDITIONS OF PARTICIPATION (CoPs)	JOINT COMMISSION ON ACCREDITATION OF HEALTHCARE ORGANIZATIONS
<p>Identification of Family Caregiver and Including him/her in Patient Record</p>	<p>No requirement for identification of the family caregiver or including the information in the patient record</p> <p>33-07-01.1-20. Medical records services.</p>	<p>Hospitals and state hospital associations may claim that they currently perform the tasks outlined in the CARE Act (i.e., identification of the caregiver in the medical record, notifying the caregiver of a transfer or discharge, and providing instructions for the caregiver to perform post-discharge medical tasks).</p> <p>While the CoPs include requirements for patient’s rights and discharge planning, the federal regulations and State Operations Manual that provides interpretive guidelines of the regulations do not include the specific provisions of the CARE Act.</p> <p>While the CoPs require the hospital to notify a family member or representative of the patient’s admission into a hospital, the CoPs do not require the hospital to provide the patient an opportunity to designate a caregiver or for the information to be added to the patient’s medical record.</p>	<p>The Joint Commission’s standards for medical record keeping require information identifying the patient and “the name of any legally authorized representative.” There is no mention of nor any requirement of the need to elicit and document the identification of the patient’s caregiver.</p>

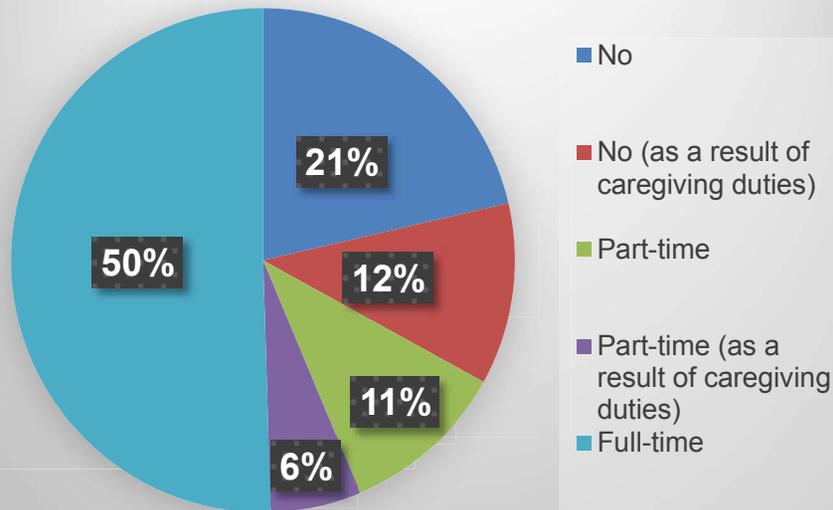
CARE Act	NORTH DAKOTA ADMINISTRATIVE REGULATIONS	CONDITIONS OF PARTICIPATION (CoPs)	JOINT COMMISSION ON ACCREDITATION OF HEALTHCARE ORGANIZATIONS
<p>Notification of Caregiver if Patient is Being Discharged or Transferred</p>	<p>Although a specific requirement to notify the caregiver is not included, discharge planning must be consistent with patient and family needs, inferring family involvement. In addition, the family receives instruction upon discharge (see below). This would imply some sort of notification of the patient’s pending discharge or transfer.</p> <p>33-07-01.1-09. Governing body</p>	<p>It cannot be assumed that the person identified as a family member or legal representative for the purpose of admission notification is the patient’s caregiver. Further, the reference to a family member or legal representative is not inclusive of all individuals the patient may want to identify as a caregiver. The CARE Act simply requires the hospital to ask the patient or the patient’s representative if s/he would like to designate a caregiver.</p>	<p>While the Joint Commission’s standards state that the patient’s family should participate in the patient’s discharge or transfer, the standards do not specify the role of the patient’s caregiver.</p> <p>The Joint Commission’s standards state that when the family is involved in decision making or in ongoing care, they must be included in the discharge process. However, the Joint Commission’s standards do not recognize that the patient’s primary caregiver may not be a family member.</p>
<p>Provide Training of Any After Care Tasks Caregiver Will Need to Perform</p>	<p>Instructions to family members upon discharge are required. Training on after care tasks may be implied but not specified.</p>	<p>The CoPs requires that “as needed, the patient and family members or interested persons must be counseled to prepare them for post-hospital care.</p> <p>While the CoPs include language for hospitals to provide education and training to caregivers as part of the discharge planning process, the regulation includes a loophole with the language “as needed”.</p> <p>This language allows for the hospital to determine when education and training will be provided to caregivers, which allows them the option to opt out from providing education and training to caregivers.</p>	<p>The Joint Commission’s standards do not require actual instruction of the caregiver in the continuing care needed.</p> <p>Before the hospital discharges or transfers a patient, it must inform and educate the patient about the type of post-discharge care a patient is going to need.</p> <p>Before the patient is discharged, the hospital informs the patient, and also the patient's family when it is involved in decision making or ongoing care, of the kinds of continuing care, treatment, and services the patient will need.</p> <p>However, this is clearly not the same as providing instruction or training to the patient’s family. And furthermore, the patient’s family may or may not include the</p>

CARE Act	NORTH DAKOTA ADMINISTRATIVE REGULATIONS	CONDITIONS OF PARTICIPATION (CoPs)	JOINT COMMISSION ON ACCREDITATION OF HEALTHCARE ORGANIZATIONS
		<p>The CARE Act simply closes the loophole and requires that all caregivers be trained to perform the post-discharge tasks necessary to keep the patient safe.</p>	<p>individual designated as the patient's caregiver. There is no specific mention of providing training to caregivers.</p>

Aim 2: Caregiver's Perspective

Data from AARP Caregiver Survey analyzed (2015) – 110 Caregivers across ND

Current Employment



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

