



AARP® Real Possibilities in
North Dakota

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Interim Human Services Committee
Testimony on Hospital to Home Transitions
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Chair Hogan, members of the Interim Human Services Committee, I am Josh Askvig, Associate State Director of Advocacy for AARP North Dakota. Thank you for the opportunity to appear before you today to share AARP's thoughts on improving hospital to home transitions.

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 85,000 members in North Dakota and 37 million nationwide. We understand the priorities and dreams of people 50-plus and are committed to helping them live life to the fullest, including here in North Dakota.

Over the past few years, AARP has raised its attention on family caregivers — spouses, partners, relatives, friends, or neighbors who provide unpaid care for a loved one. We have watched the situation facing caregivers evolve — longer lifespans and an increase in the number of persons with complex medical conditions that have stressed current support systems; the growth in the number of Baby Boomers who find themselves squarely in the sandwich generation, caring for both children and parents, that has created demand for new models of care and greater access to information; and the increase in complex conditions requiring coordination that has left "caregivers trying to tie together the fragmented pieces of their family

member's care with several different clinicians, hospital stays, and transitions between settings."¹ As such, we have intensified our efforts to ensure that family caregivers have the support they need to care for their loved ones.

In North Dakota, these efforts are particularly important. AARP Public Policy Institute's 2014 Long Term Scorecard showed that North Dakota ranked 33rd out of 50 states with respect to support that family caregivers receive.² AARP believes we can do more for the 62,100 individuals across the state who provide care for a loved one during the year and contribute \$860 million in unpaid care.³

To get a better picture of why hospital transitions are so important, AARP North Dakota has undertaken a couple of steps to further define the need for caregiver recognition and involvement in the transition process in North Dakota. First, in November 2014, we commissioned a telephone survey of 800 North Dakota voters age 45 and over. We discovered that North Dakota caregivers are helping or have helped their loved ones with complex care like managing medications (66%) and other nursing and medical tasks (56%).⁴

Second, AARP launched an online survey asking North Dakota family caregivers to provide some input of the work they do to care for their loved ones. Attached to your testimony is a copy of the questions we asked in the online survey.

Finally, we held a series of "listening lunches" in October 2015, where we asked attendees the same questions we ask on the online survey. As you can see, one of the questions we asked the attendees was "...what do you think the North Dakota Legislature should know as they look to improve supports for family caregivers like

¹ Susan Reinhard, *Home Alone: Family Caregivers providing Complex Chronic Care*, AARP http://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf

² Susan Reinhard, *Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers* <http://www.longtermscorecard.org/>

³ Susan Reinhard, et.al., *Valuing the Invaluable 2015 Update: Undeniable Progress, but Big Gaps Remain* <http://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf>

⁴ 2014 AARP Caregiving Survey of North Dakota Voters Age 45 and Older: Support for Family Caregivers When Loved Ones Are Hospitalized

you?" Here is a sample of what we heard about bringing home a loved one from the hospital:

"Caregivers need specific information and directions for taking care of a loved one when they are released from the hospital."

- Marilyn from Mayville

"They (hospitals) seem to be very uninterested in the level of care their patient receives after they are discharged"

- James from Grand Forks

"More info before sending patient home!"

- Lillian from Bismarck

"That we don't know who to call or ask for help...Support is necessary!"

- Carolyn from Fargo

Doesn't it make sense that hospitals should ensure those helping loved ones remain independent at home get the information and support they need to care for their loved ones? We at AARP think so and that is why we have drafted model legislation to support family caregivers who provide assistance with transitions from hospitals to home. The Caregiver, Advise, Record, Enable (CARE) Act puts in place some small, but meaningful supports for caregivers during transitions from a hospital, which can be a difficult and stressful time for both patients and caregivers.

Specifically, the bill takes several common sense steps that ensure a designated caregiver is seen as a partner in a patient's care.

1. Designation of the Caregiver in the Medical Record — The bill provides a patient or his/her legal guardian an opportunity to designate a caregiver upon admission into the hospital and if the patient does designate a caregiver, it requires that the hospital simply include this designation in the medical record with other patient information. This designation allows the family caregiver to receive timely information that can allow him/her to better provide post-discharge care. Including the designation in the medical record shows that the caregiver is valued and establishes another avenue by which the hospital can share important information.

2. Notification to the Caregiver of Discharge — This legislation calls on the hospital to alert the family caregiver, in a timely fashion, if his/her loved one is being discharged home or transferred to another facility. By providing the caregiver with information well before discharge, the caregiver can better manage the transition from one care setting to another.

3. Instruction of After-care Tasks — Most importantly, the legislation creates a framework through which a caregiver can receive instruction in the tasks that they will be asked to perform upon discharge. Remember, a high number of North Dakota caregivers are responsible for overseeing medication management (66 percent) and medical or nursing tasks (56 percent) such as administering injections, operating specialized medical equipment, doing wound care and performing other complex health maintenance tasks.

The November 2014 telephone survey showed strong support for provisions in the legislation. Specifically, 92 percent of the survey respondents support requiring hospitals and health care facilities to explain and demonstrate medical and nursing tasks that family caregivers will need to perform after the patient returns home; 91 percent support keeping a family member informed of major decisions, like transferring or discharging the patient; and 82 percent support recording the name of a patient's family caregiver in the medical record upon admission. Again, the strong support for these proposals is even more relevant because of the high number of North Dakota caregivers who are responsible for overseeing increasingly complex medical tasks.

AARP has had and welcomes continued conversations with providers about the CARE Act. We do understand that providers already take some steps to involve family members in the discharge process and we commend them for the steps they have taken. However, we still believe the CARE Act is warranted. To better explain, we thought it might be useful to compare the CARE Act with current regulations to better understand what changes would occur with the CARE Act. Attached to your

testimony is a handout entitled “North Dakota CARE Act Comparison to State and Federal Regulations.” Let me walk you through that handout.

As caregivers are better informed, notified, and instructed in after-care tasks, they have a better chance to keep their loved ones safely at home. AARP asks you to continue the discussions about how to implement the CARE Act in North Dakota. Thank you for the opportunity to testify today and I am happy to take any questions you might have.

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>



Thank you for joining us! As a family caregiver, could you use a little help?

If you are caring for an aging parent or loved one, you're probably feeling the weight of time, money and stress involved in this labor of love. Join AARP and other family caregivers by answering a few questions below that can help highlight the challenges you face.

AARP will share the feedback with lawmakers to urge them to support legislation that could help family caregivers.

1. Your Information:

Name: _____

Email: _____ Phone Number: _____

Address: _____

City/State/ZIP: _____

2. Are you or were you employed while providing care for a loved one? (circle one)

- A) Yes- Full Time B) Yes- Part Time C) Yes- Part Time, due to caregiver duties
D) No E) No- My caregiving role prevents me from working F) I am not a caregiver

3. As a caregiver, do you get enough breaks or respite from your caregiving duties? (circle one)

- A) Yes B) No C) No- It is too difficult to find someone to help so I can take a break
D) I am not a caregiver

4. When providing care, do you perform any medical or nursing tasks? (circle up to 6 selections from the choices below)

- A) I use meters , administer test kits or use telehealth equipment B) I prepare special food diets
C) I do wound care and/or ostomy care D) I help with mobility devices like canes or walkers
E) I manage medications F) I do not provide any medical/nursing tasks

(MORE ON BACK)

5. Did you receive any instruction or training before helping your loved one with medical or nursing tasks? (circle one)

A) Yes B) No C) I do not perform medical or nursing tasks

6. What non-medical tasks do you perform as a caregiver? (Please make up to 6 selections from the choices below)

A) Shopping B) Transportation C) Household chores D) Meal preparation

E) Financial/Insurance or other paperwork assistance F) Other G) I am not a caregiver

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

8. Thinking about your caregiving experience and journey, what do you think the North Dakota 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.

Please leave completed surveys in the boxes provided or send back to

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