

March 14, 2017

**The Honorable Dan Hawkins, Chair
House Health and Human Services Committee
RE: AARP Kansas Comments in Support of SB 68 As Amended by Senate Committee -
Kansas Lay Caregiver Act**

Good afternoon Chairman Hawkins and members of the Committee. My name is Dr. Maren Turner and I am the Director of AARP Kansas. AARP is a nonprofit, nonpartisan organization with a membership of nearly 37 million nationwide including 320,000 members here in Kansas. AARP fights for issues that matter most to families, such as healthcare, family caregiving and independent living. Along with my team, I fight for these issues in Kansas. I am grateful for the opportunity to appear before you today to share AARP's strong support for and explanation of the need for passage of Senate Bill 68.

Over the past several years, AARP has focused attention, resources and commitment in support of family caregivers – meaning those people who provide unpaid care for a loved one, be they spouses, partners, adult children, relatives, friends or neighbors. They are the unsung heroes who provide the majority of care for Kansas families. These efforts are particularly important in our state. AARP Public Policy Institute's 2014 Long-Term Services and Supports Scorecard showed that Kansas ranked 35th out of 50 states with respect to support that family caregivers receive.¹ We must better support the more than 345,000 individuals across the state who provide more than 4 million hours of care for their loved ones and contribute \$3.85 billion in unpaid care each year.²

A recent national survey conducted by AARP's Public Policy Institute and the United Hospital Fund found that nearly half of family caregivers (46 percent) reported performing medical and nursing tasks for care recipients with multiple chronic physical and cognitive conditions. These tasks include managing multiple medications, providing wound care, preparing food for special diets,

¹ 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/>

² Susan Reinhard, et.al., *Valuing the Invaluable: The Growing Contribution and Cost of Caregiving As* <http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf>

using monitors, and operating specialized medical equipment. These tasks were in addition to the assistance provided with bathing, dressing, eating, and household tasks.

Most caregivers reported they received little or no training for these complex medical and nursing tasks.

A 2016 AARP Kansas Statewide Caregiver Survey of Kansas registered voters, age 45 plus (n=800) revealed that:

- 94.7% of current caregivers believe it is important to provide care for a loved one so they can live at home or independently.
- 59.3% are responsible for other medical or nursing tasks on daily basis.
- 71.4% of current caregivers oversee medication management on a daily basis.
- 65% of Kansas caregivers would find assistance with understanding how to manage medications helpful.

From this and other data, it is clear that the role of family caregivers has expanded dramatically to include tasks of the kind and complexity once provided only by hospitals, nursing homes and home care providers.

SB 68, also known as the Lay Caregiver Act, recognizes the critical role family caregivers play in keeping their loved ones out of costly institutions. It puts in place some small but meaningful supports for caregivers during hospital transitions – a difficult and stressful time for both patients and caregivers. It provides for communication and instruction to caregivers when patients are discharged. The result will be smoother transitions home, better aftercare, improved health outcomes, and fewer costly readmissions to the hospital. In 2013, more than 2,000 hospitals – two-thirds of all U.S. hospitals – were penalized a total of about \$227 million for excessive readmissions by the Center for Medicare and Medicaid Services (CMS). Also in 2011, Theresa Shireman, PhD, RPh, of the University of Kansas Medical Center, in her report on Medicaid Costs and Key Facts, estimated that, while readmissions are not a key driver of increased Kansas Medicaid expenditures, there is a potential to reduce Medicaid costs (by about \$40 million/year).

Specifically, SB 68 takes three simple common-sense steps that ensure a designated caregiver is seen as a partner in a patient's care:

The first step is that upon admission, a hospital will provide the patient with the opportunity to designate a caregiver and have that caregiver's contact information entered into the patient's medical record. This designation will allow the family caregiver to receive timely information that can allow him or her to better provide post-discharge care. By including the designation of

a caregiver in the medical record, it shows that the caregiver is valued and it establishes an avenue by which the hospital can share important information.

Step 2 calls on the hospital to notify and alert the family caregiver if his/her loved one is being discharged home or transferred to another facility. By providing this timely information the caregiver can better coordinate and manage the transition from one care setting to another.

Step 3 creates a framework for hospitals to offer an opportunity, prior to the patient's discharge, to provide the family caregiver with instructions on how to perform the medical and nursing tasks that the patient will need upon return home. Rather than leaving it to the family caregiver to discover what tasks are necessary and how to perform them, we believe creating this framework will lead to the provision of better care and support for both patients and their caregivers.

These three common-sense provisions will help caregivers provide better care and, in the process, may help avoid a return trip to the hospital, or worse.

The 2016 AARP Kansas Caregiver survey also revealed that:

- 84.1% of caregivers support recording caregiver information in the patient's medical record upon admission.
- 92.8% support hospitals keeping the caregiver informed on pending transfer and discharge of the patient.
- 94.6% support requiring hospitals to explain and demonstrate medical and nursing tasks the caregiver will need to perform after the patient returns home.

Since it was first developed in 2014, the CARE Act has been enacted in 35 states. Even more significant is the political spectrum of states that have enacted the law, often unanimously. From red to blue and everything in between, it's clear that the CARE Act is resonating as a human issue that transcends politics. In the majority of states that passed the CARE Act, state hospital associations have either outright supported or have taken a neutral stance on the CARE Act. After passage of the Maryland CARE Act, that state's Hospital Association, for example, stated, "The Maryland Hospital Association will be working with AARP to encourage the designation of lay caregivers who can help patients follow their post-acute care plans." Caregivers are valuable partners in improved patient outcomes, can provide a smoother transition between care settings, and can help hospitals embrace the role of family and friends as trusted partners in caring for patients." AARP recognizes that hospitals will need to be a strong partner in this effort. We have been in discussions with the Kansas Hospital Association for well over a year now to discuss revisions in language. Those revisions are now before you as SB 68.

As caregivers are better informed, notified, and instructed in the after-care tasks they are being called upon to perform, they have a better chance to keep their loved ones safe at home with

better health outcomes. We ask that you support SB 68 As Amended by Senate Committee, pass it out of committee and send it to the full House for consideration.

Thank you for the opportunity to testify today. I am happy to take any questions you might have.

AARP Kansas

KANSAS LAY CAREGIVER ACT (SB 68 As Amended by Committee)
COMPARISON TO STATE AND FEDERAL REGULATIONS

CARE Act	KANSAS ADMINISTRATIVE REGULATIONS	THE CENTERS FOR MEDICARE AND MEDICAID SERVICES CONDITIONS OF PARTICIPATION (CoPs)	JOINT COMMISSION ON ACCREDITATION OF HEALTHCARE ORGANIZATIONS	PATIENT PROTECTION AND AFFORDABLE CARE ACT
<p>Provision in SB 68 As Amended by Committee.</p> <p>1. Provide an <u>opportunity</u> for patients upon admission to a hospital to designate a caregiver; record the name of the caregiver in the patient's medical record.</p>	<p>The KAR does not specifically require patients an opportunity to identify a caregiver, or the inclusion of the caregiver's name in the medical record.</p> <p><u>K.A.R. 28-34-9a</u> currently requires hospitals to maintain medical records for each patient admitted for care. <u>Subsection 9a(e)</u> specifies the content of the medical record, but does not require identification of a caregiver as part of the medical record.</p> <p><u>K.A.R. 28-34-57</u> requires ambulatory surgery centers to maintain medical records for each patient but does not require the identification of a family caregiver.</p>	<p>There are no CoPs that require hospitals to provide patients an opportunity to identify a caregiver, or include the name of the caregiver in the medical record.</p> <p><u>CoPs currently include requirements for:</u> (a) patient's rights; (b) discharge planning; and (c) notification of family/representative of the patient's admission to a hospital</p> <p>Federal regulations and the CMS State Operations Manual does not require an opportunity to identify and designate a caregiver, or include the name of the caregiver as part of the medical record.</p>	<p>The Joint Commission standards do not require hospitals to provide an opportunity for patients to designate a caregiver, or include the name of the caregiver in the medical record.</p> <p><u>The Joint Commission standards currently require</u> information in the medical record identifying the patient and "the name of any legally authorized representative." <u>The Commission's standards do not require an opportunity for the patient to identify and designate a caregiver, or include the name of the caregiver, who may/may not be the legally authorized representative, in the medical record.</u></p>	<p>The ACA does not require hospitals to provide an opportunity for patients to designate a caregiver, or include the name of the caregiver in the medical record.</p> <p><u>The ACA currently requires</u> in Section 3026, the establishment of Community-based Care Transitions Program to test models for improving care during transitions from hospitals or other settings, and reduce readmissions for high risk Medicare beneficiaries. Seventy-two community-based organizations (CBOs) are testing models across the nation, however, funding for expansion has ended. <u>The pilots are not associated with the CARE ACT.)</u></p> <p><u>Brewster Place</u> was the only CBO in Kansas—they support</p>

CARE Act	KANSAS ADMINISTRATIVE REGULATIONS	THE CENTERS FOR MEDICARE AND MEDICAID SERVICES CONDITIONS OF PARTICIPATION (CoPs)	JOINT COMMISSION ON ACCREDITATION OF HEALTHCARE ORGANIZATIONS	PATIENT PROTECTION AND AFFORDABLE CARE ACT
<p>Provision in SB 68 As Amended by Committee.</p> <p>2. Provide notification to the caregiver if the patient is being transferred or discharged</p>	<p>There are no regulations that require hospitals to notify caregivers if a patient is being transferred or discharged.</p> <p>KAR 28-34-139(c) currently requires abortion discharge instructions. KAR 28-34-141 requires follow-up care after abortions.</p> <p>There are no provisions that require notification to the caregiver of patient transfer or discharge.</p>	<p>There are no CoPs that require hospitals to notify caregivers if a patient is being transferred or discharged.</p> <p>CoPs currently require notification to a family member or legal representative of a patient's hospital admission. It cannot be assumed that the person identified as the family member/legal representative is (a) the caregiver, or (b) inclusive of individuals the patient may want to designate as a caregiver.</p>	<p>The Joint Commission standards do not require hospitals to notify caregivers if a patient is being transferred or discharged.</p> <p>The Joint Commission standards currently require that the patient's family should (a) participate in the patient's discharge or transfer and (b) when family is involved in decision making or in ongoing care they must be included in the discharge process. The Commission's standards do not recognize that the patient's primary caregiver may not be a family member.</p>	<p>The ACA does not address notification of caregivers regarding a patient's transfer or discharge.</p>

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<p>Provision in SB 68 As Amended by Committee.</p> <p>3. Provide discharge instruction of any after care tasks the caregiver will need to perform.</p>	<p>There are no regulations that require hospitals to provide discharge instructions to the person designated as the caregiver.</p>	<p>There are no CoPs that require hospitals to provide discharge instructions to the person designated as the caregiver.</p> <p><u>CoPs currently require</u> that patients and family members/interested persons must be counseled to prepare for post-hospital care, as needed. The “as needed” language allows for the hospital to determine when education/training will be provided to caregivers, which allows them to opt out from providing needed instructions to all caregivers.</p>	<p>The Joint Commission standards do not require aftercare instruction to the caregiver.</p> <p><u>The Joint Commission standards currently require that</u> (a) patients must be informed before discharge about the type of post-discharge care needed; and (b) patients and family members when they are involved in decision making/ongoing care must be informed of the kinds of continuing care, treatment, and services the patient will need.</p> <p>Informing, however, is (a) not the same as providing instruction and (b) may or may not include the individual designated as the patient’s caregiver.</p>	<p>The ACA does not address discharge instructions.</p>

