

February 3, 2016

The Honorable Dan Hawkins
Chair, House Health and Human Services Committee

Reference: **Support of HB 2058 as amended by KHA and AARP.**

Good afternoon Chairman Hawkins and members of the House Health and Human Services Committee. My name is Dr. Maren Turner. I am the Director of AARP Kansas. AARP Kansas represents more than 321,000 members in Kansas. I am grateful for the opportunity to appear before you today and share AARP's strong support and explanation of need of passage of HB 2058 with amended language.

Since the introduction of HB 2058 during the 2015 legislative session, AARP Kansas and representatives from the Kansas Hospital Association have worked on new bill language that is agreeable to both parties. We therefore offer a balloon amendment that will strike the original language in HB 2058 and insert new language crafted by AARP and KHA.

Also, since the introduction of HB 2058 as amended, AARP volunteers and staff have crisscrossed the state and attended events, talking to Kansans of all ages about the need for caregiver support. At these events we collected and listened to stories of problems with hospital discharge events, readmissions, loss of life and trials and tribulations of families and caregivers across the state. We also collected thousands of petitions from Kansans supporting the need for a law such as this which would support Kansas caregivers. We have brought a sampling of petitions from your constituents. Some of you have more and some less depending on parts of the state where we were able to spend time. We also have thousands more to process.

To date, a total of 35 states have either passed or are working on passage of caregiver support acts. Twenty-three (23) states have had the support of their hospital associations or those associations have remained neutral. Twelve states are in discussions at state legislatures, including our Missouri friends, where the hospital association is working with AARP Missouri toward passage of a Missouri CARE Act. Eighteen (18) states and the territory of Puerto Rico have passed such acts.

While it's true that, during conversations in these states, some have raised the question of how much this will cost hospitals. There has not been one of the states where this became a major concern, overriding passage of law or the health outcomes of patients. Small changes to existing forms would be necessary one time only, to allow for the family caregiver to be identified in the hospital admission record or wherever the hospital chooses and to add information to the discharge plan regarding what is expected of the caregiver in performing after care medical tasks. We believe this is because the hospitals eventually realized that the cost to hospitals, if any, would be very minimal compared to the reduction in readmissions and quality health outcomes of their patients and all Kansans.

It is said that almost everyone is currently, has been, or will be a caregiver. The average family caregiver is an unpaid relative, partner, friend or neighbor who has a significant relationship with, and who provides a range of assistance for, an older adult or an adult with chronic or disabling condition(s).

Over the past few years, AARP has raised its attention on family caregivers — spouses, partners, relatives, friends, or neighbors who provides unpaid care for a loved one. We have watched the situation facing caregivers evolve. That evolution includes longer life spans and an increase in the number of persons with complex medical conditions that have stressed current support systems. Too, the growth in the number of Baby Boomers who find themselves squarely in the sandwich generation, caring for both children and parents, has created

demand for new models of care and greater access to information. Finally, the increase in complex conditions requiring coordination 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 Kansas, these efforts are particularly important. AARP Public Policy Institute's 2014 Long Term Scorecard showed that Kansas ranked 35th out of 50 states with respect to support that family caregivers receive.² While this is average, we can better support the more than 345,000 individuals across the state who provide more than 4 million hours of care for their loved ones during the year and contribute \$3.85 billion in unpaid care.³

The goal of this bill is to achieve a transition to home that is as seamless as possible, where communication about home care is understood according to appropriate cultural standards, language and literacy levels for both the patient and the caregiver. House Bill 2058 as amended recognizes that Kansas caregivers play critical roles in keeping their loved ones out of costly institutions, enhancing the quality of care and reducing the possibility of costly hospital readmissions for their loved ones. Specifically, the bill takes several common sense steps to ensure a designated caregiver is seen as a partner in a patient's care.

As medical care has evolved, more patients are leaving the hospital soon after surgery and other medical procedures. Many times these patients need continued medical care such as injections, infusions, medications, or wound care

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: The Growing Contribution and Cost of Caregiving As* <http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf>

when they return home. The responsibility for ensuring that they receive this care often falls on the patient's family, friends or neighbors.

The prevention of medical complications and unnecessary hospital readmission may often depend upon the quality of care provided to a patient after being discharged from a health care facility. Without a designated caregiver of record, people may easily be sent home to uncertain circumstances, often with a break in communication between them and their health care team, sometimes resulting in the worst possible outcome. In many situations, family members and/or friends are unexpectedly thrust into the caregiver role because they are given only momentary notice of the patient's impending discharge from a facility, learning too late that insurance will not cover the costs of home health care and the out-of-pocket cost for private duty caregivers is not affordable. This leaves family and/or friends in a situation where they must perform complex assessments and procedures that are typically performed by nurses in the hospital, and they are expected to perform these tasks at home with little or no instruction on how to manage them. We need to address these issues in the interest of the health and safety of each person.

Most Kansas registered voters age 45 and older (75%) believe that being cared for at home with caregiver assistance is the ideal situation when the basic tasks of life become more difficult due to aging or illness. In fact, over half of Kansas registered voters age 45 and older (51%) say they are providing or have provided care on an unpaid basis for an adult loved one who is ill, frail, elderly or who has a disability.

Most Kansas caregivers are helping or have helped their loved ones with more complex care like managing medications (70%) and other nursing and medical tasks (70%). Two-thirds of these caregivers (67%) say it is extremely, very, or somewhat likely that they will need to provide this type of care in the future. As such, these caregivers believe it is important to be able to provide care so that their loved ones can keep living independently in their own homes and to have more caregiver resources and training to allow family caregivers to continue to provide in-home care.

AARP Kansas commissioned a telephone survey of 800 Kansas registered voters age 45 and older to learn about their experiences with family caregiving. The 2014 AARP Caregiving Survey of Kansas Registered Voters Age 45 and Older found that a very high percentage support proposals to require hospitals to engage with family caregivers. 80% support recording caregivers in patient records and 95 % support informing caregivers of major decisions involving patients and providing instructions to caregivers on medical tasks.

HB 2058 as amended language addresses voids in current Kansas statutes concerning caregivers as part of discharge planning. Below is a comparison of HB 2058 requirements and current Kansas law:

1. *Designation of the Caregiver in the Medical Record* —This section of HB 2058 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.

In Attachment 1, Page 8, a comparison of Kansas Caregiver and Discharge Regulations, are three main provisions of the CARE Act, comparing those provisions to Kansas hospital discharge laws/regulations.

**Regulations are found in Kansas Administrative Regulations (K.A.R.). They are part of Agency 28, Kansas Department of Health and environment Title 10, Article 34 – Hospitals.*

*** Summary of Findings: 1. Identification of family caregiver/including in Patient record - None found in Kansas Regulation Citations.**

2. Notification to the Caregiver of Discharge —This section of HB 2058 as amended 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.

In Attachment 1, Page 9, a comparison of Kansas Caregiver and Discharge Regulations, are three main provisions of the CARE Act comparing those provisions to Kansas hospital discharge laws/regulations*.

**Regulations are found in Kansas Administrative Regulations (K.A.R.). They are part of Agency 28, Kansas Department of Health and environment Title 10, Article 34 – Hospitals.*

Summary of Findings: 2. Notification of Caregiver if patient is being discharged or transferred – None in Kansas Regulation Citations except regulations pertaining to abortion discharge.

3. Instruction of After-care Tasks —This section of HB 2058 as amended creates a framework through which a caregiver can receive instruction in the tasks that they will be asked to provide upon discharge. In a survey of caregivers, 78% of caregivers reported managing multiple medications, administering injections, operating specialized medical equipment, doing wound care and performing other complex health maintenance tasks.⁴ Many caregivers also reported that they often learned how to perform after-care tasks on their own. AARP supports modifications to the bill that give hospitals flexibility to coordinate live demonstrations.

In attachment 1, Page 11, a comparison of Kansas Caregiver and Discharge Regulations, are three main provisions of the CARE Act comparing it to Kansas hospital discharge laws/regulations*.

⁴ Reinhard, Home Alone.

**Regulations are found in Kansas Administrative Regulations (K.A.R.). They are part of Agency 28, Kansas Department of Health and environment Title 10, Article 34 – Hospitals.*

Summary of Findings: 3. Provision of training in any after care tasks caregiver will need to perform – None found in Kansas Regulation Citations.

HB 2058 as amended will improve the position of family caregivers in the hospital setting and establishes a strong foundation for hospitals to build on, or continue to build on, to ensure quality transitions for hospital to home and help prevent unnecessary readmissions. Readmissions are costly. One in every eight Medicare beneficiaries who leaves the hospital is readmitted within 30 days. For hospitals with 30 day readmissions for heart attack, heart failure and pneumonia, Centers for Medicare and Medicaid Services (CMS) began reducing Medicare payments by up to 1% (increasing to 3% in FY 2015) in 2015, expanding to 7 conditions. The Kaiser Family Foundation Health News, August 2013, reported that 53 percent or 29 out of 55 Kansas hospitals had penalties. HB 2058 as amended supports caregivers by providing them training and support, enabling more seniors to stay at home where they want to be and preventing unnecessary hospitalizations. HB 2058 as amended can help Kansans live independently longer at home with more resources for them and the family caregivers who assist them.

What do patient readmissions cost the state? At a Medicaid Reform Public Input and Stakeholder Consultation process meeting held on August 17, 2011, in Overland Park, Kansas, Theresa Shireman, PhD, RPh University of Kansas Medical Center, discussing a fiscally sustainable Medicaid program, reported key findings were that 30-day readmission rates for Kansas Medicaid =9.9% and for Medicare =18%. The average cost of a readmission is approximately 50% higher than the average cost of all admissions. While readmissions are not a key driver of increased Medicaid expenditures, there is potential to reduce Medicaid costs (~\$40 million/year).

General Medicine, The Post-Hospitalist Company, reported that the cost of hospital readmissions varies by demographic. Medicaid or low-income and disabled patients accounts for the second largest share of all hospital readmissions at 20.6%. Medicaid readmissions account for 12.5% of all Medicaid hospitalizations and cost each state \$77 million per year.

Hospitals nationwide have gone to great lengths in an effort to reduce readmissions and improve patient quality. However, despite these concerted efforts, hospitals continue to incur fines from Medicare for excessive rates of patient readmissions. Roughly one of every five Medicare patients sent to the hospital ends up returning within a month. The Medicare Readmission Penalties by State, Year 4, evaluated the readmission rates of the nation's hospitals in determining the fourth year of penalties in the Hospital Readmissions Reduction Program. Medicare reported that 32 Kansas hospitals, or 24 percent of Kansas hospitals, would be penalized for frequent readmissions. Improving care transitions by providing support to caregivers could help reduce these readmissions, saving state and federal dollars and improving health outcomes.

In Less follow-up care, more hospital readmissions for rural Medicare beneficiaries making caregivers even more important, Wolters Kluwer, Law and Business, August 20, 2015 by Mary Damitio reported that Medicare beneficiaries in rural areas are less likely to seek follow-up care after hospital visits, which may put them at an increased risk for visits to the emergency departments (EDs) and hospital readmissions. In the study, published in Medical Care, researchers compared rural and urban hospitals based on follow-up care visits, emergency department visits, and unplanned hospital readmissions. Compared to urban areas, they found that patients who lived in small rural areas had a 44 percent higher chance of an emergency room visit 30 days after discharge and a 52 percent higher risk in large rural areas.

Sadly, the real cost of hospital readmission has nothing to do with currency – it has to do with the patients. Leaving one hospital stay just to be readmitted within 30 days is discouraging to both patients and their families. Not only is the patient battling illness

for longer than they should, but his or her trust of health care providers and their abilities can drop significantly.

Indeed, this effort is the hospital's best interest to ensure that the patients are discharged to an environment that will provide care necessary to prevent readmission to the hospital. The Affordable Care Act allows for penalties to be imposed if patients are readmitted too soon after discharge. Hospitals will have a financial incentive to involve any and all who provide care to avoid the patient's readmission to the hospital.

Though many hospitals already say they follow these processes as part of discharge planning, the Kansas Lay Caregiver Act ensures that caregiver education is required by state law. It recognizes in state statute the important role that a caregiver plays in caring for a patient when they leave the hospital. There is nothing clearly defined in Kansas law that recognizes the importance of caregiving and the patient's well-being.

This law is in no way meant to train family or friends to replace home health workers but rather to ensure that a patient's loved one understands how to follow through with discharge instructions. If a patient's doctor orders professional home care, that would still be a necessary part of their post-hospital treatment plan. Home health brings the skilled nurse or skilled therapist that comes intermittently and makes sure that the care being provided is reaching the goals intended. They are an important part of the continuum of care, but they are rarely with a patient around the clock. Patient caregivers need to know how to provide the basic care necessary to prevent readmissions and to ensure that discharge instructions are followed for better health outcomes.

Finally, The Honorable Sam Brownback, Governor of the great state of Kansas proclaimed March 2015 as Kansas Caregiver Month. In that proclamation, he urged "all citizens to learn more about the struggles faced by adult caregivers and the benefits that adult caregivers will provide to the loved ones in our great state. Whereas, despite

the vast importance of family caregivers in the individual's day-to-day care, many family caregivers find that they are often left out of discussions involving a patient's care while in the hospital and, upon the patient's discharge, receive little to no instruction on the medical and nursing tasks they are expected to perform...."

Therefore, AARP asks you to support those 345,000 Kansas caregivers and their efforts to provide \$3.85 billion in unpaid hours of care each year by supporting House Bill 2058 as amended and passing it out of committee to the House for a vote.

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

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