

Chairman Hawkins and members of the House Health and Human Services Committee,

My name is Judy Davis-Cole. I am a retired nurse with 42 years of nursing experience, 14 of which were in home care. I am also a volunteer with AARP, a non-partisan organization that advocates for citizens aged 50 and above. Thank you for the opportunity to ask for your support of SB 68 – The Kansas Lay Caregiver Act (also referred as “The CARE Act”).

The main tenets of this legislation:

- The hospital will be required on admission, or as soon after admission as possible, to ask the patient or legal guardian if there is a specifically designated home caregiver for the patient. This may differ from ‘next-of-kin’ and/or emergency contact.
- The named caregiver is recorded in the patient record along with contact information
- When the patient is to be transferred or discharged, the hospital must attempt to contact the recorded home caregiver and offer the opportunity for face-to-face instruction and hands-on demonstration if relevant.

Why we need this legislation:

- The Kansas 2014 State Long-Term Services and Supports Scorecard indicates that Kansas ranks 35 out of 50 states in the area of “support for family caregivers”
- There are approximately 345,000 lay caregivers at any time in Kansas. According to AARP surveys, nearly 1/3 of these providers report receiving less than adequate discharge training/instruction; this indicates great *lack of consistency* in discharge training from hospital to hospital, and sometimes within the same hospital.
- These caregivers save Kansas approximately \$3.8 billion dollars annually in unpaid care.
- Lay caregivers must be recognized and supported in their efforts to relieve anxiety associated with care, provide a safe care environment, and decrease the chances of costly re-hospitalization
- Existing state and federal regulations fall short of the requirements listed in SB 68. The CMS regulations do not mandate identification of specific caregiver; do not require that the caregiver be a part of the medical record; and they do not require an attempt to notify the named caregiver of patient transfer or discharge.
- Personal interviews by AARP volunteers and staff at the Kansas State Fair and other public venues indicate that people responsible for discharge planning and training (nurses, social workers, therapists) recognize the need for this legislation, and signed petitions to that effect.
- The issue of inadequate discharge planning and training has now been recognized as a national issue. To that point there have been articles printed in CNN, AARP magazine and AARP Bulletin, The Journal of Science, Engineering, and Medicine (see below quote), addressing this issue.

“Caregivers are, on the one hand, heavily relied upon but on the other hand overlooked,” said Richard Schulz, chair of the 19-member expert panel that crafted the report and a professor of psychiatry at the University of Pittsburgh.

Your identity needs to be documented in your loved one’s medical records.

“We need to start by having a clear sense of who the caregiver is so that individual can be recognized as part of a team looking after an older adult, Schulz said. Currently, this doesn’t happen routinely.”

- Furthermore, 35 states recognizing the problem with inadequate discharge training, have now passed legislation like the Kansas Lay Caregiver Act.

Answers to Opposition to SB 68

- A legislative act is not required; it can be handled with a resolution followed by education of hospital admissions and discharge planners
 1. A resolution does not have the impact of legislation that mandates compliance.
 2. Education is not the issue. All nurses, therapists, and social workers receive training in discharge planning and training in their respective schools. Nearly all discharge planners and clinicians will say that discharge planning and training are important.

3. The issue is that this training does not *consistently* happen. If 1/3 of the 345,000 lay caregivers in Kansas say that they do not receive adequate training, we are missing about 100,000 caregivers
- CMS already has regulations around discharge planning and training. This was addressed above. A statement from the 2016 issue of the Journal of Hospital Medicine recognizes the benefits of combining CMS regulations with The Lay Caregiver Act (or CARE Act):

“... although it might be reflexive to view the CARE Act in isolation as yet one more initiative requiring new effort and resources to address, widening the lens may confirm that the contributions of family caregivers are integral and aligned across nearly all efforts aimed at promoting greater value, and in this light could be viewed as complementary rather than competitive.” (with CMS)

- Hospitals do not need more regulation and government mandates.
 1. This act is not about unnecessary regulation. It is about providing the patients and the caregivers the planning and information and practice that they need to insure safe and efficient care once the patient is out of the institution. This is patient and caregiver-oriented legislation.
- There are no penalties in the law should the hospital not comply with the CARE Act
 1. The “penalties” would come into play should the CMS, JCAHO, and state surveys determine that there is a trend that the hospital is not in compliance. Standard survey remediation procedures for non-compliance would apply.
- There will be additional cost to the hospitals if this legislation is passed.
 1. There should be no, or little cost to the hospital. Discharge planning and training should already be practiced – this legislation raises the bar of compliance with which hospitals and most clinicians want to achieve
 2. Most admissions departments are automated. There should be no cost tied to the software vendor or I.T. department adding a line on the admission form for lay caregiver information. If the admissions department is still on paper, hospital forms are reviewed and updated routinely. The required changes to their forms would be made permanent at that time.
 3. Additional staff training dollars will not be necessary to carry out the requirements of the CARE Act. Instructions on what the legislation is, and how to comply can easily be accomplished in existing required staff meetings, and/or in hospital newsletters.
 4. Hospitals are penalized by CMS with decreased reimbursement for hospital readmissions within 30 days of discharge. Better and more consistent discharge planning and training will be achieved via the Lay Caregiver Act, leading to a potential decreased number of readmissions.

In conclusion:

- Discharge planning and training is not occurring consistently in our state.
- Nearly 1/3 of the lay caregivers in our state report receiving less than adequate discharge training necessary to feel safe and competent in the care of their loved one once they are back home.
- Passage of The Kansas Lay Caregiver Act will mandate improvements to the discharge planning and training of patients and caregivers before the patient is discharged.
- Penalties for non-compliance will be via state and national survey findings and subsequent remediation.
- There is no fiscal note for the state, and very minimal, if any, cost to hospitals.
- Passage of this legislation may decrease the rate of hospital readmissions and decrease CMS reimbursement penalties.

I respectfully ask for your support in working and passing The Kansas Lay Caregiver Act (The CARE Act).

Thank you for your time and attention,

Judy Davis-Cole, R.N., M.N. (retired)

AARP Volunteer