



March 11, 2021

Chairman Patton and Members of House Judiciary Committee:

I am Margaret Farley, executive director of Kansas Advocates for Better Care (KABC). KABC is a not-for-profit organization whose mission is to improve the quality of long-term care for older adults in nursing and assisted facilities and in-home. Thank you for the opportunity to add our voice in support to HB 2122/Supported Decision-Making Agreements Act.

There are a number of diseases and brain injuries which may impact an older adult's decision-making ability, including Alzheimer's, Parkinson's, Stroke, Vascular Dementia, and Traumatic Brain Injuries resulting from accidents. Often times the result of such illness or accident is that family/caregivers or others feel the need to "take over" life decisions for an older loved one. While there are instances where this is a necessary, even if temporary step, the reality is that far too often taking on decision-making will extend into all areas of an older adult's life. Others will make daily choices, many of which the older adult is very capable to make on her/his own. Frequently this occurs in conjunction with a Durable Power of Attorney, Legal Guardianship and/or other legal documents created to provide a legal means to assure that a person's choices are honored when he/she loses capacity or is at the end of life.

KABC regularly receives calls from older adults who are experiencing the loss of a right to decide because the assigned Durable Power of Attorney or Guardian has appropriated that right. The loss of right may be about who may visit her/him in a care facility, or it may be access to her/his money and the ability to spend money on something desired, or it may be that property is being sold or given away without her/his consent. Each of these decisions will impact the person's quality of life. And well-meaning or not, it deprives the person of her/his right to make choices, and of her/his positive view of self, sense of safety and autonomy.

Older adults, just like the rest of us, want to be in charge of their lives and involved with making decisions that effect them. Family caregivers are usually well-intentioned and want to be supportive. HB 2122 provides the legal ground for an option which clearly supports the older adult's right to make decisions using input from trusted advisers and caregivers.

I would like to share an example which demonstrates the benefits of supported decision-making: A friend's 78-year-old mother sustained a serious head injury when she fell down the basement stairs. Amazingly and in spite of a dire prognosis, she recovered many of her pre-injury cognitive functions. Her greatest challenge was numbers and math equations – obviously an important cognitive function for someone living on her own, needing to pay bills and manage finances. She asked one of her daughters to help manage her financial affairs

913 Tennessee Suite 2 Lawrence, Kansas 66044-6904  
phone: 785.842.3088 fax: 785.749.0029 toll-free: 800.525.1782 e-mail: [info@kabc.org](mailto:info@kabc.org) website: [www.kabc.org](http://www.kabc.org)

but at her direction. Ten years later she suffered extreme sepsis, was hospitalized for three weeks and remained physically very frail until she died two years later. Her diminished physical health impacted her cognitive function and she needed significant 24/7 physical and mental supports which her daughters provided. Their mother could make many decisions and provide direction for other decisions, but it took her much longer to do so – both thinking through and communicating her thoughts. They continued to respect their mother’s history, preferences and past choices, but nonetheless they had to make some decisions for her. Their primary goal as caregivers and daughters was to keep her safe and well cared for.

Supported decision-making mapped out a different approach for this family allowing them to keep their mother engaged, improving and independent in all the ways she could be. Using this model, they slowed down, asked their mother what her goals were, and sought her direction for the daily and important decisions that needed to be made. The results of this approach were visible, she was motivated, and she motivated her family who did 45 minutes of physical therapy with her every morning. During that time, their mom asked about the sufficiency of her financial resources, she worked through the emotional distress of having her physical and cognitive abilities so changed, and of her feelings that she was burdening her family.

KABC supports HB 2122 because it provides the legal ground for an option which clearly supports the older adult’s right to make decisions using input from trusted advisers and caregivers. It provides support and direction for caregivers as they help older adults make decisions.

Thank you for the opportunity to offer testimony and ask that you join KABC in supporting HB 2122.

Margaret Farley, Executive Director - On behalf of Board of Directors and Members

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