



January 22, 2019

Chairman Barker and Committee Members of House Federal and State:

I am Mitzi McFatrach, executive director of Kansas Advocates for Better Care (KABC). I appreciate the opportunity to speak in favor of Supported Decision Making. Thank you for carving out time to understand the positive impact this legislation could have for older adults and their caregivers.

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. And while there are instances that this is a necessary if temporary step, the reality is that far too often the taking on of decision making extends into all areas of an older adult's life and 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 have an impact on 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 like the rest of us want to be in charge of their lives. Family caregivers usually want to be supportive. HB 2034 for Supported Decision Making provides the legal ground for an option that clearly supports the older adult's right to make decisions using input from trusted advisers and caregivers.

When my mother was 78 she fell down the basement stairs and sustained a serious head injury. 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 her finances. At her request I stepped in to help manage those functions, working with her, her financial service, and her bank to accomplish banking and bill paying, but with her direction. For the most part, she continued in the rest of her life without added assistance. Ten years later she suffered extreme sepsis, was hospitalized for three weeks and was physically very frail for the two years prior to her death. Her diminished physical health impacted her cognitive function and she needed significant physical and mental supports 24/7 which my sister and I provided. While my mother could make many decisions and provide direction for other decisions, it took her much longer to do so – both thinking through and communicating with us. My sister raised five children and was accustomed to doing what needs to be done to keep a household of seven running smoothly and quickly. And her approach was to make the decisions about many things – of course she took into account what she knew from my mother's history, preferences and past choices – but nonetheless she made decisions mom was able to make. Our primary goal as caregivers and daughters was to keep her safe and well cared for.

Supported Decision Making mapped out a different approach for us. To keep mom engaged, improving, and independent in all the ways she could be, we slowed down, asked what her goals were, and sought her direction for the daily and important decisions that needed to be made. In some instances it took longer, in other instances we needed to repeat the same information numerous times and in alternate ways. The results of this approach were visible, she was motivated and she motivated us – so we did 45 minutes of physical therapy every morning, mom asked about the sufficiency of her

financial resources, mom worked through the emotional distress of having her physical and cognitive abilities so changed, and of her feelings that she was burdening us. My parents had planned ahead and we did have Durable Power of Attorney documents. We used them in the instances in which we needed them.

I don't know that my mother's last two years of life would have been so positive for her or us had it not been for a supported decision making approach. Had it not been for my work at KABC, I like most families wouldn't know about this approach.

HB 2034 for Supported Decision Making is a positive for older adults and for caregivers. KABC supports passage of this legislation.

Thank you,  
Mitzi E. McFatrach, Executive Director, On behalf of Board of Directors, 650+ Members and Volunteers

KABC is a not-for-profit organization, beholden to no commercial interests and is supported almost entirely by donations from citizens who support our mission of improving the quality of elder care in all long-term settings. KABC was among a handful of non-profit consumer advocacy groups which worked to win passage of the Nursing Home Reform Act of 1987. Our interest is in quality care of older adults wherever they live - at home, and in licensed adult care facilities.

1. Supported Decision Making The Rights of People with Dementia

<https://www.ncbi.nlm.nih.gov/pubmed/27008152>

2. SUPPORTED DECISION-MAKING FOR OLDER PERSONS IN ISRAEL: THE 2015 PRECEDENT AND THE FOLLOWING 2016 REGULATION

<http://classic.austlii.edu.au/au/journals/ElderLawRw/2016/5.pdf>