



Topeka Independent Living Resource Center

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Testimony in Support of House Bill 2034, The Supported Decision-Making Agreements Act

Presented to the House Committee on Federal and State Affairs

Representative John Barker, Chair

By

Mike Oxford, Executive Director for Policy and Advocacy

The Topeka Independent Living Resource Center (TILRC) is a civil and human rights organization. Our mission is to advocate for justice, equality and essential services for a fully integrated and accessible society for all people with disabilities. TILRC has been providing cross-age, cross-disability advocacy and services for 39 years to people with disabilities here in Shawnee County and across the state of Kansas. Our agency has been particularly interested in and committed to assuring that people who require long term services and supports have access to information, services and supports that offer choices; choices that promote freedom, independent lifestyles and dignity, including the dignity of risk.

Supported decision-making is needed in Kansas. The disability community has experienced a lot of social, legal and health-related progress over the past generation since passage of the Americans with Disabilities Act in 1990. There are many, many more people with all kinds of disabilities and health conditions and of all ages living in their own homes and communities these days compared to 30 years ago. Folks with disabilities are increasingly working, volunteering, being educated and otherwise participating in community life. However, the legal and human right to communicate in one's own fashion, and to be heard, and have the expressed wishes of the speaker honored, has not kept pace with these other advances. This leaves individuals with disabilities and their support networks in legal limbo, or else requires more restrictive measures, such as court-ordered guardianship, and/or conservatorship, than are necessary or desired. Further, many find this framework overly legalistic, confusing and difficult to navigate without the expense of an attorney.

The right to communicate what, and how, we want is a fundamental civil and human right. For almost all of us, this right is critical to feelings of agency and self-esteem. For many people with disabilities, however, there has been little progress in gaining an actual right over this critical area of communication. People with communication disabilities and their support networks are too often just ignored. Further, misunderstandings that conflate communication difficulty with lack of capacity to make decisions and exert control over one's life are far too common. People with physical disabilities such as MS or cancer, people with developmental or intellectual disabilities such as CP or Down's Syndrome, people with brain injuries, older people with cognitive disabilities or dementia, and people with mental health disabilities can experience communication disabilities and all could benefit if supported decision-making were available.

In keeping with the mission of Topeka Independent Living Resource Center, House Bill 2034 advances the communication rights of people with disabilities. As with other social and legal gains, advancing communication rights will allow increasing numbers of people with more significant disabilities to integrate into their communities and live more independently. HB 2034 provides for supported decision-making on a cross-age, cross-disability basis.

Please report HB 2034 favorable for passage.