



Topeka Independent Living Resource Center

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Testimony in Support of House Bill 2345, The Supported Decision-Making Agreements Act

Presented to the House Judiciary Committee

The Honorable Representative Susan Humphries, Chair

By

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Thank you to Chair Humphries and members of the House Judiciary Committee for the opportunity to provide these written comments in support of HB 2345 and its proposed enactment of supported decision-making for disabled people.

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 43 years to people with disabilities here in Shawnee County and across the state of Kansas. Our support of HB 2345 evolves out of the work we do as and with disabled people.

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 40 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 ignored. Further, misunderstandings that

Advocacy and services provided by and for people with disabilities.

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 multiple sclerosis (MS) or cancer, people with developmental or intellectual disabilities such as cerebral palsy 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.

Failing other, less intrusive options, it is the experience of our agency that many families turn to Guardianship as an option to provide support to a member with a disability. As my grandfather would have said, this is like driving in a toothpick with a sledgehammer. Even though Guardianships can be narrowly written, our experience in working with people under Guardianship is that template forms are how most are ordered, so even people who may be able to make decisions for themselves in many areas of their lives lose their agency as the orders and protections put in place are all-encompassing. Guardianship limits disabled people's ability to make choices as fundamental as where they will live, who they will have as friends or romantic involvements, whether they will go to school, participate in day service programs, or get a job. This can place families in an unnecessarily antagonistic relationship when the disabled member/ward wants to have greater autonomy but a family member feels they are under court-order to handle all aspects of the person's life. Further, Guardianship limits families' ability to provide formal and informal supports under Kansas' Home and Community Based Services waiver programs. Supported decision-making offers an alternative that allows disabled people to get the help they need making and expressing their life choices and preferences without creating unnecessary legal restrictions for the people involved.

In keeping with the mission of Topeka Independent Living Resource Center, House Bill 2345 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 2345 provides for supported decision-making on a cross-age, cross-disability basis.

Please report HB 2345 favorable for passage.