

January 10, 2018

Senate Committee on Workforce Development, Military Affairs, and Senior Issues Senator Testin, Chair State Capitol, Room 131 South Madison, WI 53707

Dear Senator Testin and members of the committee:

Thank you for the opportunity to provide public comment in support of SB 552, which formally recognizes supported decision-making (SDM) as a legal option that people with disabilities and older adults can use to retain their rights to make their own decisions, select who they want to help them (a Supporter) and the types of decisions they want help with, and define what assistance a Supporter can give (information gathering, access to records, helping the Person understand options, and communicating the Person's decisions to others). SDM can be used for any decisions the Person feels they need additional support—such as housing, health care, financial affairs, employment, or other areas the Person identifies.

The Wisconsin Board for People with Disabilities (BPDD) strongly supports SB 552, and believes that the addition of SDM as a legal alternative to guardianship will benefit many people with developmental disabilities, their families, and ultimately the state. Our board considers SDM to be so important to furthering people's independence and ability to make choices about their lives that it is one of two public policy issues emphasized in our federally required five-year state plan.

SDM is a fundamental part of Self-determination. People with greater self-determination are: healthier, more independent, more well-adjusted, and better able to recognize and resist abuse (safer)¹.

Nationally, disability organizations, attorneys, courts, and state legislatures are recognizing the value of SDM as an alternative to guardianship. SDM has been endorsed by the U.S. Department of Health and Human Services' Administration for Community Living, which funds the National Resource Center for Supported Decision-Making, and has gained international recognition, notably in the United Nations Convention on Rights of Persons with Disabilities (CRPD).

The <u>American Bar Association adopted a Resolution</u> August 14, 2017 encouraging the use of Supported Decision Making as an alternative to guardianship, and specifically urged states to revise their statutes to include supported decision-making as a legally recognized option. Texas and Delaware have already enacted supported decision-making legislation, with legislation pending in Tennessee. Indiana, Maine, and North Carolina are also exploring Supported Decision-Making legislation.

¹Wehmeyer, Palmer, Rifenbark, & Little 2014; Powers et al., 2012; Khemka, Hickson & Reynolds 2005; Wehmeyer & Palmer, 2003; Shogren, Wehmeyer & Shwartz, 1997 & 1998; Wehmeyer, Kelchner, & Reynolds 1996

Under Wisconsin law, all adults are considered to have the capacity for decision-making. But too often, families of people with Intellectual or Developmental Disabilities (I/DD) are advised—often when a child is just 17—to obtain guardianships, which takes away some or more commonly all of the person's civil rights to make decisions about their lives. No one makes perfect decisions, certainly not at age 17-18. But that is exactly the age where many youths with disabilities' decision-making capacity is evaluated, and once a guardianship is granted it is rarely changed.

People with disabilities can acquire new skills and decision-making capacity throughout their lives. Everyone, no matter their limitations, needs opportunity, experience, and support in order to learn how to make well-informed decisions. SDM can provide support as the person practices making decisions, and SDM agreements can be updated easily as the Person's ability and capacity to make decisions changes over time.

Unfortunately, guardianship is used first and almost exclusively for people with I/DD when it should be used last and rarely. Parents routinely tell us that guardianship is presented as the only option, and is portrayed as administrative process rather than a decision that has permanent legal ramifications for both the individual and families.

BPDD focus groups on SDM found that many parents were unaware of the role and responsibilities of a guardian, did not feel their children were legally incompetent, but also felt that guardianship was expected and were unaware of alternatives. Our focus groups also found that if SDM was an option many families would have tried it first, and that it would have helped them evaluate whether a guardianship was needed.

Formally establishing SDM agreements as a legal expression of an individual's wishes gives Professionals a document they can rely on and establishes a legal framework for Supporters to document their role in helping the Person to others (bankers, state agencies, other professionals, etc.). Even though under the law people are presumed to be competent to make their own decisions, often the first question a person with a disability is asked by service providers and others is "who is your guardian?" They see the disability, not the person, and automatically assume that someone else—a guardian—makes decisions for them.

Formalizing SDM within Wisconsin's statutes provides a needed continuum between no support and full guardianship. SB 552 will result in greater independence, self-determination, and community inclusion for people with I/DD, and we urge the committee to advance this bill to the full Senate.

BPDD is charged under the federal Developmental Disabilities Assistance and Bill of Rights Act with advocacy, capacity building, and systems change to improve self-determination, independence, productivity, and integration and inclusion in all facets of community life for people with developmental disabilities.

Our role is to seek continuous improvement across all systems—education, transportation, health care, employment, etc.—that touch the lives of people with disabilities. Our work requires us to have a long-term vision of public policy that not only sees current systems as they are, but how these systems could be made better for current and future generations of people with disabilities.

Thank you for your consideration,

Both Sweden

Beth Swedeen, Executive Director, Wisconsin Board for People with Developmental Disabilities