

**TESTIMONY OF ANNA KRIEGER, ON BEHALF OF MASSACHUSETTS
ADVOCATES FOR SUPPORTED DECISION-MAKING AND THE CENTER FOR
PUBLIC REPRESENTATION IN SUPPORT OF S. 64 AND H. 172**

Joint Committee on Children, Families and Persons with Disabilities

June 25, 2019

Dear Chair Chang-Diaz, Chair Kahn and Honorable Members of the Joint Committee on Children, Families and Persons with Disabilities:

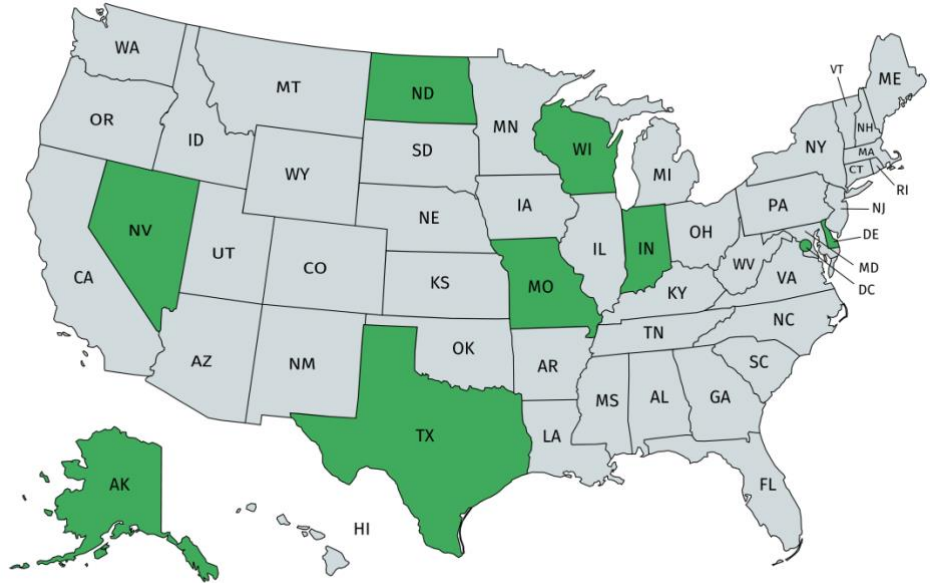
I appear on behalf of the Center for Public Representation and Massachusetts Advocates for Supported Decision-Making (MASDM) to express our strongest support of Senate Bill 64 and House Bill 172, legislation that would establish the legal framework for supported decision-making in the Commonwealth. The Center for Public Representation is a non-profit law firm that advocates for the rights of people with disabilities. We are based in Northampton and Newton. We have been an active member of the Massachusetts Advocates for Supported Decision-Making (MASDM), a large and diverse coalition of leading disability and elder organizations in Massachusetts that are advocating for the passage of supported decision-making legislation. Please see the end of this testimony for a list of members in the coalition.

Supported decision-making (SDM) allows adults with disabilities to exercise their autonomy, independence, and dignity by choosing a trusted group of people, called supporters, to help with decision-making. The arrangement is memorialized in a simple written agreement setting out the roles for the supporters and the individual with the need for assistance, the decision-maker. Too many people are unnecessarily placed under restrictive guardianships when they would be able to make their own decisions if they received individualized assistance from people they trust, allowing them to retain their legal rights and dignity. Supported decision-making creates this opportunity.

Passing this bill would **save time and money in probate courts** by reducing the number of guardianship petitions for people who do not need them. However, SDM does not replace guardianship for those who need it. It is an additional and less restrictive option.

This system of decision-making has been **gaining momentum across the country**, and Center for Public Representation has been **piloting SDM in Massachusetts** since 2014 with partners including, Advocates, Inc., Massachusetts Families Organizing for Change, Multicultural Community Services, Nonotuck Resource Associates, and the Northeast Arc. From our pilots, we know that the SDM model works, brings families together, and can transform lives. Many other states have also piloted SDM with great success. More stories of SDM are on our website: www.supporteddecisions.org

Other states that have already enacted supported decision-making statutes are: Texas (2015), Delaware (2015), Wisconsin (2018), District of Columbia (2018) Missouri (2018), Alaska (2018), North Dakota (2019), Indiana (2019), and Nevada (2019). We know from speaking and working with our



partners in these states that implementation of these statutes has resulted in improved decision-making capabilities for individuals with disabilities, increases in self-esteem, improved family relationships, and an apparent decrease in the need for guardianships.

Respected **national organizations** and **federal agencies** have recommended and endorse using supported decision-making as an alternative to guardianship, including: American Bar Association, National Guardianship Association, The Arc of the United States, the U.S. Department of Education, U.S. Department of Health and Human Services, American Association on Intellectual and Developmental Disabilities, United States Senate Special Committee on Aging, and the National Council on Disability. SDM is also recognized as a less restrictive alternative in the newly revised model guardianship law, the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Acts (2017).

What follows is a section-by-section analysis of the Massachusetts legislation (references all to S. 64):

Section 5-508 (a). Definitions: This section describes the terms in the bill and is very similar to the statutes from Texas. The “decision-maker” is the person who uses supported decision-making and who executes the agreement. “Supporters” are the people decision-makers choose to assist them.

Section 5-508 (b). Voluntary arrangement: This section permits the decision-maker to enter into an SDM agreement and clarifies that this must be done voluntarily. It also establishes that the decision-maker is in control of the agreement and can amend or terminate the agreement at any time. These are important protections and safeguards.

Section 5-508 (c). Supporter’s assistance: This section describes the type of assistance a supporter can provide to a decision-maker, including assistance with understanding and communicating decisions.

Section 5-508 (d). Limit to supporter authority: This section clarifies that the supporter only has the authority granted to him or her in the SDM Agreement.

Section 5-508 (d)(1)-(2). Length of agreement: This section describes situations where an agreement would be terminated.

Section 5-508 (e) (1)-(2); (f). Accessing information: This section discusses access to confidential information and provides that a supporter can access confidential information about the decision maker *only* with the decision-makers permission and *only* to assist the decision-maker with a decision. The supporter must maintain the confidentiality of the protected confidential information.

Section 5-508 (g). Signing the Agreement: This section describes who must sign the SDM Agreement (the decision-maker, supporters, and, as a safeguard against any abuse, either two witnesses or a notary public).

Section 5-508 (h). Agreement: This section describes the SDM Agreement and clarifies that is a personalized document intended to be customized for the personal circumstances of the decision-maker.

Section 5-508 (i). Agreement Form: This section contains the model SDM form. This model form is based on the form used in Texas (the first state to enact an SDM law in 2015), modified with substantial input by a number of self-advocates. The MASDM coalition is in agreement that the Committee should consider deleting the form and substitute language that describes in broad terms what should be included in an agreement, similar to provisions in the Health Care Proxy Statute. Massachusetts General Laws, Chapter 201D.

Section 5-508 (j). Substantially similar agreement: This section clarifies that any agreement that is substantially similar to the Agreement in the bill is acceptable. This allows organizations or individuals to customize the form if they wish. This section would not be necessary if the model form is deleted.

Section 5-508 (k). Third parties and Agreements: This section provides that third parties must rely on an Agreement and recognize decisions made by decision-makers using an SDM Agreement. It also provides liability protection for third parties who rely on an Agreement in good faith. Similar provisions appear in most state laws.

Section 5-508 (l). Agreement cannot be condition of participation: This section provides that a program or service cannot make execution of an SDM agreement a requirement of participation. Though nationally we have not heard of any instances of this being a problem, this is preventative.

Section 5-508 (m). Safeguards: This section describes safeguards against abuse and neglect. Although there is no evidence of abuse or misuse here or in any of the states that have SDM pilots or SDM statutes, the bill includes a number of safeguards as an additional measure of protection.

Section 5-508 (n). Health Care Proxy and Power of Attorney: This section clarifies that individuals using SDM may also have a health care proxy or power of attorney.

Section 2. Guardianship Petitions: This section provides that petitions for guardianship must state that SDM was considered and was not a viable less restrictive alternative. This is consistent with recommendations of, among others, the American Bar Association. Similar language appears in the model Uniform Guardianship, Conservatorship and Other Protective Arrangements Act and in Maine's new guardianship law.

Section 3. Training: This section describes that relevant state agencies would establish an SDM training program and that individuals with disabilities will be involved in all stages of developing and presenting the training.

Section 4. Students and IEP Meetings: This section describes how SDM would be required to be raised at any Individual Educational Program team meeting where guardianship is being discussed. This section is important because many unnecessary guardianships are initiated when students approach adulthood and the vesting of rights under the special education laws. Many families want to continue to support their children, but do not want to become guardians. This section will provide important information to families and school personnel about decision-making alternatives.

Section 5. Transition Planning: This section requires that SDM be discussed as part of the transition planning process, when youth are transferring from special education to state agency services.

Our experience with supported decision-making has shown that it is a viable alternative to guardianship. Enactment of this bill would enable many more individuals and families in Massachusetts to take advantage of this innovative model. We urge the Committee to favorably report the bill.

Sincerely,

Anna Krieger

Attorney

Center for Public Representation

www.supporteddecisions.org

22 Green Street | Northampton, MA 01060 | 413-586-6024

246 Walnut Street | Newton, MA 02460 | 617-965-0776

**Members of Massachusetts Advocates for
Supported Decision-Making (MASDM)**

Advocates, Inc.

The Arc of Massachusetts

Boston Center for Independent Living

Center for Public Representation

Disability Law Center of Massachusetts

Greater Boston Legal Services

Massachusetts Advocates Standing Strong

Massachusetts Association for Mental Health

Massachusetts Developmental Disabilities Council

Massachusetts Families Organizing for Change

Massachusetts Guardianship Policy Institute

Mental Health Legal Advisors Committee

North Shore Elder Services

Northeast Justice Center