



Commonwealth of Massachusetts
Massachusetts Developmental Disabilities Council

108 Myrtle Street, Suite 202
Quincy, Massachusetts, 02171

CHARLES D. BAKER
GOVERNOR

KARYN E. POLITO
LIEUTENANT GOVERNOR

HOLLY E. SIMIONE
CHAIRPERSON

DANIEL M. SHANNON
EXECUTIVE DIRECTOR

Testimony of Anna Krieger
Joint Committee on Children, Families and Persons with Disabilities
Monday, November 22, 2021

**S. 124/H. 272: An Act Relative to Supported Decision-Making Agreements
For Certain Adults with Disabilities**

Dear Chair Gomez, Chair Finn and Honorable Members of the Joint Committee on Children, Families and Persons with Disabilities:

I appear on behalf of the Massachusetts Developmental Disabilities Council and as a member of the Massachusetts Advocates for Supported Decision-Making (MASDM) on Senate Bill 124 and House Bill 272, legislation that would establish the legal framework for supported decision-making in the Commonwealth.

The Council an independent state agency that is federally mandated by the Developmental Disabilities Assistance and Bill of Rights Act to empower developmentally disabled people and their families to help shape policies that impact them. Our work includes advocacy, systems change, and capacity building efforts that promote self-determination, integration, and inclusion. A central aspect of this work is educating policymakers about issues that impact the disability community and supported decision-making is a priority area for the Council.

The Council is an active member of the Massachusetts Advocates for Supported Decision-Making (MASDM), a large and diverse coalition of leading disability and elder organizations, including the state-wide self-advocacy organization Massachusetts Advocates Standing Strong. Please see the end of this testimony for a list of Coalition members.

In this testimony we will provide:

- 1) An overview of supported decision-making as a guardianship alternative**
- 2) A section-by-section analysis of the proposed legislation**



(617) 770-7676 (Voice)
(617) 770-1987 (Facsimile)
www.mass.gov/mddc

SUPPORTED DECISION-MAKING: A GUARDIANSHIP ALTERNATIVE

MORE OPTIONS, MORE VOICE, MORE AUTONOMY

Media coverage of Britney Spears’ experience under conservatorship has brought an unprecedented national spotlight on guardianship. In recent months, many people in Massachusetts are wondering for the first time what guardianship looks like in our state and asking whether there is a need for change. The answer is yes. Our coalition members have been working toward reforms for some time. We welcome the spotlight on the guardianship system and invite you to listen to the voices of those impacted by guardianship.

The bills before you today present an opportunity to make substantial progress and embrace a widely respected alternative to guardianship called supported decision-making. Supported decision-making has been piloted with success here in Massachusetts by Coalition member the Center for Public Representation, as well as across the U.S.¹ Pilots have demonstrated the model works² and people are eager to use the practice in their own lives, but passing Senate Bill 124 and House Bill 272 would have a transformative impact across the state and give many more people who want it access to this alternative. Passing this measure would mean Massachusetts would join the thirteen jurisdictions that have already codified supported decision-making in state law. This proposal presents chance to make our system better for all.

Too many people in Massachusetts 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. Like every other state, data in Massachusetts on guardianship is limited and incomplete,³ but we do know that typically 11,000

¹ Stories of supported decision-making from Coalition member Center for Public Representation’s Massachusetts pilots with partners including Coalition members Nonotuck Resource Associates, Mass Families, and Advocates, Inc. <https://supporteddecisions.org/stories-of-supported-decision-making/>. See also Cathy Costanzo, Hon. Kris Glen, & Anna Krieger, *Supported Decision-Making: Lessons from Pilot Projects* (April 2021), <http://law.syr.edu/uploads/docs/academics/constanzo-glen-krieger.pdf> (background paper prepared for the Fourth National Guardianship Summit describing in detail pilots in Massachusetts).

² Evaluations of Center for Public Representation’s initial pilot with Coalition member Nonotuck Resource Center available here: <https://supporteddecisions.org/resources/hsri/> and <https://supporteddecisions.org/resources/hsri-evaluation-year-2-of-cpr-nonotuck-sdm-pilot/>.

³ See, e.g., National Council on Disability, *Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities* (June 10, 2019), at 41 https://ncd.gov/sites/default/files/NCD_Turning-Rights-into-Reality_508_0.pdf [hereinafter: Nat’l Council on Disability, *Rights into Reality*]. See also Letter from Sen. Elizabeth Warren & Sen. Robert P. Casey, Jr. to Hon. Xavier Becerra, Sec’y, Dep’t of Health & Hum. Serv. & Hon. Merrick Garland, Att’y Gen., Dept. of Just. (July 1,

guardianships and 3,000 conservatorships are filed every year, for a total of over 43,000 over four years.⁴ Moreover, our advocacy, outreach, and education work has shown us that, consistent with national trends, guardianship is often presented as the default choice,⁵ resulting in unnecessary guardianship. The consequences are significant and there is a need for change.

Supported decision-making is part of the solution. An essential aspect of guardianship reform includes promoting alternatives to guardianship like supported decision-making. Without viable alternatives, people will continue to resort to guardianship when it is not necessary. Not only does this mean that people unnecessarily lose their rights under guardianship, but it burdens our state’s Probate and Family Courts and ties up limited resources that could be used for monitoring against abuse by guardians.

However, supported decision-making does not replace guardianship. It is an *additional* and less restrictive option that is entirely voluntary. If these proposals are enacted, guardianship in Massachusetts will remain available in its current form for anyone who wants it.

Supported decision-making allows adults with disabilities or cognitive impairments to exercise their autonomy, independence, and dignity by choosing a trusted group of people, their supporters, to help with making and communicating decisions.

While supported decision-making may be a new term for many, the concept is familiar to everyone. **Supported decision-making allows adults with disabilities or cognitive impairments to exercise their autonomy, independence, and dignity by choosing a trusted group of people, their supporters, to help with making and communicating decisions.** From work on the pilots here in Massachusetts and elsewhere, we know that the model works, brings families together, and can transform lives.

With supported decision-making the disabled person or older adult, called the “decision-maker,” chooses a group of trusted **supporters** to assist with helping making decisions about issues like their health care, finances, services, or other matters that are important to the decision-maker. Supporters are typically family, friends, neighbors, or other people the decision-maker trusts and who understand how the decision-maker communicates. In most cases, the decision-maker chooses more than one supporter, which creates a **natural safeguard** against abuse.

2021) <https://www.warren.senate.gov/imo/media/doc/2021.07.01%20Letter%20to%20DOJ%20and%20HHS%20re%20Conservatorship.pdf> (requesting detailed agency data on guardianships to inform policy work).

⁴ In Massachusetts Probate and Family courts, 9,317 guardianship petitions were filed in fiscal year 2020. In previous fiscal years there were about 11,000 a year. See *Probate and Family Court Department, Filings By Fiscal Year and Case Type*, <https://www.mass.gov/doc/probate-family-court-summary-of-cases-by-fiscal-year/download>.

Under Massachusetts law, a conservatorship is when someone is appointed by a court to make financial decisions about a person’s property and financial matters. Mass. Gen. Laws ch. 190B, § 5-419.

⁵ Nat’l Council on Disability, *Rights into Reality*, at 29.

The arrangement can then be memorialized in a simple written agreement. The agreement sets out the roles for the supporters and decision-maker, making clear what kind of support is expected and desired. Supported decision-making is typically coupled with other guardianship alternatives such as a **health care proxy** or **power of attorney**. It is through this combination of supports that the decision-maker can exercise their will and preferences and communicate their decisions.

In practice, decision-makers get **support** in a range of ways from their supporters. For example, a supporter might help a decision-maker understand the pros and cons of whether to get an MRI or another kind of test so they can choose which one to get. What the support looks like depends on the person's needs: support could be explaining concepts in a different way, repeating ideas,



A supporter might help a decision-maker understand the pros and cons of whether to get an MRI or another test so they can choose which one to get. The support depends on the person's needs: support could be explaining concepts in a different way, repeating ideas, or using visual tools to reinforce aids.

or using visual aids to reinforce choices. Support can also involve helping the decision-maker **communicate** the decision to someone else, like a doctor, after the decision has been made.

Supported decision-making is widely recognized as a practice. Respected **national organizations** and **federal agencies** have recommended and endorse using supported decision-making as an alternative to guardianship.⁶ Supported decision-making is also

recognized as a less restrictive alternative in the newly revised **model guardianship law**.⁷

Further, at the recent **Fourth National Guardianship Summit** leaders in the field of guardianship law and reform recommended states adopt practices and laws that promote supported decision-making, including adopting the model law and creating diversion programs and training that include supported decision-making.⁸

⁶ See *Organizations endorsing Supported Decision-Making*, <https://supporteddecisions.org/about-supported-decision-making/organizations-advocating-for-supported-decision-making/> (describing endorsement of supported decision-making by 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).

⁷ Uniform Law Commission's Guardianship, Conservatorship, and Other Protective Arrangements Act Sec. 301(a)(1)(A) (requiring that "court order appointing a guardian for an adult must include a specific finding that clear-and-convincing evidence established that the identified needs of the respondent cannot be met by a protective arrangement instead of guardianship or other less restrictive alternative, including use of appropriate supportive services, technological assistance, or supported decision making"). The Uniform Act has been adopted in Maine and Washington state.

⁸ The Summit hosted by the National Guardianship Network was a gathering of 125 leading advocates, family guardians, judges, lawyers, scholars, and other stakeholders. The summit produced a set of recommendations that embraced supported decision-making and recommended states adopt practices and laws to promote the practice. See Fourth National Guardianship Summit, *Recommendations Adopted by Summit Delegates*, (May 2021) Adopted,

Passage of S. 124 and H. 272 would have the effect of expanding supported decision-making dramatically in the Commonwealth for those who want it, while creating important protections for the practice. These proposed bills provide a clear legal framework for supported decision-making, establish safeguards, and require courts explicitly consider whether supported decision-making is a less restrictive alternative for a person before ordering a guardianship. In summary, the proposals would:

- define supported decision-making and establish roles for those involved
- allow people with disabilities and elders to enter into a supported decision-making agreement with people they trust, or “supporters”
- establish required elements of a supported decision-making agreement form
- create protections against abuse of the model
- require that courts first consider supported decision-making before establishing a guardianship
- establish training for people using the model (supporters and decision-makers)
- ensure all youth turning 18 are made aware of the supported decision-making option at Individualized Educational Plan (IEP) meetings

While supported decision-making is already being practiced in Massachusetts, codifying these provisions would make supported decision-making more accessible to more people who want it. **In our experience providing training and education on supported decision-making, some families would like to use the model but do not want to do so until it is legally recognized in Massachusetts.** These families rightfully worry about whether their supported decision-making agreements will be respected in a crisis or emergency and fear they will be prevented from providing support at a critical moment in their loved one’s life. As described in detail in excellent testimony from Coalition members from the Suffolk Law School Health Law Clinic, these concerns are compounded for low-income, Black, Indigenous, People of Color (BIPOC), and immigrant families. These hesitations have been echoed by some families with children with complex medical needs because they interface so regularly with different health care providers, specialists, and systems. **These are all families that believe supported decision-making could work for their loved one, but until a supported decision-making law is passed, they are left only with guardianship.** We must not leave behind these families and these communities.

In addition, provision in S. 124 and H. 272 would help avoid unnecessary guardianship at key moments for diversion: in court and in schools. First, provisions in the bill would require that the Probate Court consider whether supported decision-making would be a less restrictive

Recommendations 2.1, 2.2., 2.3, 2.4, 3.1, 3.3, 3.4, http://law.syr.edu/uploads/docs/academics/Fourth_National_Guardianship_Summit_-_Adopted_Recommendations_%28May_2021%29.pdf.

alternative before ordering a guardianship. S. 124 Sec. 2, at 7, line 117-122. In addition, the proposed bills would ensure that transition age students learn about supported decision-making, not just guardianship. S. 124, Sec. 4 & 5, at 8 Line 134-149. We hear repeatedly from families that they were not aware of any other option beside guardianship, and even felt pressured to obtain guardianship by systems they interacted with. These provisions would help make sure families and loved ones have an opportunity to learn about and consider supported decision-making, not just guardianship.

Twelve states and the District of Columbia have already enacted supported decision-making statutes similar to the one proposed in Massachusetts, starting with Texas in 2015.⁹ We know from 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.¹⁰

SECTION-BY-SECTION ANALYSIS OF PROPOSED LEGISLATION

What follows is a section-by-section analysis of the Massachusetts legislation (references all to S. 124):

Section 5-508 (a). Definitions: This section describes the terms in the bill and is very similar to the 2015 statute from Texas, which was the first such law enacted. The “decision-maker” is the person who uses supported decision-making and who executes the agreement. “Supporters” are the people decision-makers enter into the agreement with and choose to assist them.

Section 5-508 (b). Voluntary arrangement: This section permits the decision-maker to enter into a supported decision-making agreement and clarifies that this must be done voluntarily and without undue influence or coercion. 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.

⁹ States and jurisdictions passing comprehensive supported decision-making statutes similar to the Massachusetts proposal include: Tex. Est. Code Ann. §§ 1357.001 - 1357.102 (West 2019); Wis. Stat. Ann. §§ 52.01-52.32 (West 2018); Alaska Stat. Ann. §§ 13.56.010-13.56.195 (West 2018); Del. Code Ann. tit. 16, §§ 9401A-9410A (West 2016); D.C. Code Ann. §§ 7-2131 – 7-2134 (West 2018); Ind. Code Ann. §§ 29-3-14-1 - 29-3-14-13 (West 2019); N.D. Cent. Code Ann. §§ 30.1-36-01 - 30.1-36-08 (West 2019); 42 R.I. Gen. Laws Ann. §§ 42-66.13-1 - 42-66.13-10 (West 2020); Nev. Rev. Stat. Ann. §§ 162C.010 - 162C.330 (West 2020); Wash. Rev. Code Ann. §§ 11.130.700 et. seq. (West 2020) (effective Jan. 1 2022), 2020 Wash. Legis. Serv. Ch. 312 (S.S.B. 6287) Part VI § 601-612 (West 2020); La. Stat. Ann. § 13:4261.101- 13:4261.302 (West 2020); Sen. Bill No. 75, 73rd Gen. Assembly, 1st Reg. Sess. (Col. 2021); and N.H. Rev. Stat. § 464-D:1 (NH 2021).

¹⁰ *Guardianship requests decline as knowledge of alternative legal option grows*, WASW (Aug. 9, 2021) <https://www.wsaw.com/2021/08/10/guardianship-requests-decline-knowledge-alternative-legal-option-grows/> (Describing decrease in guardianships from 5,147 in 2017 to 4,146 by 2020).

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 them in the supported decision-making agreement.

Section 5-508 (e)(1)-(3). Length of agreement: This section describes situations where a supported decision-making agreement would be terminated. An agreement could be terminated if there is an expiration date included, if the decision-maker revokes the agreement, or if supporters withdraw.

Section 5-508 (e)(4). Termination of agreement due to abuse, neglect, or exploitation: This section describes the process for handling allegations of abuse, neglect, or exploitation by a supporter and a process for court oversight of such allegations. The Court may, after a hearing, revoke, terminate, terminate, or suspend the supported decision-making agreement if there is evidence of abuse, neglect, or exploitation.

Section 5-508 (f) (1)-(2); (g). 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. Decision-makers can still access their personal information without a supporter, even if they have given the supporter access to their information.

Section 5-508 (g). Signing the Agreement: This section describes who must sign the supported decision-making 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 elements that need to be included in a supported decision-making agreement. This approach is similar to that taken in the Health Care Proxy Statute (Massachusetts General Laws, Chapter 201D), which also describes required elements of a form rather than including a model form itself in statute. This section also clarifies that a supported decision-making agreement is a personalized document intended to be customized for the personal circumstances of the decision-maker.

Section 5-508 (j). Third parties and Agreements: This section provides that third parties must rely on a supported decision-making agreement and recognize decisions made by decision-makers using such an agreement. It also provides liability protection for third parties who rely

on an agreement in good faith. Similar provisions appear in most state supported decision-making laws.

Section 5-508 (k). Agreement cannot be condition of participation: This section provides that a program or service cannot make execution of a supported decision-making 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 (l). Safeguards: This section describes safeguards against abuse and neglect. Although we believe supported decision-making by design prevents abuse because of the presence of multiple supporters, the bill includes a number of safeguards as an additional measure of protection.

Section 5-508 (m). Health Care Proxy and Power of Attorney: This section clarifies that individuals using supported decision-making 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 supported decision-making was considered and was not a feasible 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, in Texas' supported decision-making statute, and in Maine's new guardianship law.

Section 3. Training: This section describes that relevant state agencies would establish a supported decision-making 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 supported decision-making 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 or are unaware of other options. This section will provide important information to families and school personnel about decision-making alternatives.

Section 5. Transition Planning: This section requires that supported decision-making 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.

Sincerely,

/s/

Anna Krieger
Director of Public Policy

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

Advocates, Inc.

The Arc of Massachusetts

Boston Center for Independent Living

Center for Public Representation

Dignity Alliance Massachusetts

Disability Law Center of Massachusetts

Disability Policy Center

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

Nonotuck Resource Associates

Northeast Justice Center

Suffolk Law School Health Law Clinic

** This testimony is submitted only on behalf of the Massachusetts Developmental Disabilities Council. Other coalition members are listed for reference.*