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November 1, 2023

The Honorable Michael Day Chair, Joint Committee on the Judiciary 24 Beacon Street, Room 136 Boston, MA 02133

By email to michael.musto@mahouse.gov

The Honorable James Eldridge Chair, Joint Committee on the Judiciary 24 Beacon Street, Room 511-C Boston, MA 02133

Dear Chair Day, Chair Eldridge, and Members of the Joint Committee on the Judiciary:

Re: Testimony in Support of H.1485, An Act Relative to Supported Decision-making Agreements for Certain Adults with Disabilities

The Massachusetts Association for Mental Health (MAMH) is pleased to submit to the Joint Committee on Children, Families and Persons with Disabilities this testimony in support of H.1485, *An Act Relative to Supported Decision-making Agreements for Certain Adults with Disabilities* and similar bills on the same subject, particularly S. 109 (Sen. Lovely). This bill would create a system for supported decision-making (SDM) in Massachusetts.

Since 1913, MAMH has worked to improve understanding of mental health conditions and combat disparities in health services access. Formed over a century ago, MAMH is dedicated to promoting mental health and well-being, while preventing behavioral health conditions and associated disability. We are committed to advancing prevention, early intervention, effective treatment, and research for people of all ages. We seek to eliminate stigma and discrimination and advance full inclusion in all aspects of community life. This includes discrimination affecting not only people with behavioral health conditions, but also people who face unequal burdens and barriers to the protections and benefits of citizenship due to their race, ethnicity, gender identity, or disability status. MAMH has a demonstrated track record of furthering its mission by convening stakeholders across the behavioral health and public health communities; disseminating emerging knowledge; and providing subject matter expertise to inform public policy, service delivery, and payment methodologies. We envision a day when all individuals and families across the Commonwealth have the resources and opportunities they need to promote resilience and protect overall health.

This bill would establish a legal framework for SDM agreements in Massachusetts, allowing the Commonwealth to join a growing number of states that provide statutory recognition of this important decision-making tool. SDM agreements allow people with disabilities to maintain autonomy in significant life decisions. Adults, including people with disabilities and elders, may choose one or more family member, friend, or other trusted individual to provide assistance in making life decisions. While decision-making authority remains with the individual, supporters can help clarify the problems at issue,

the options available, and, when needed, interpret and communicate the individual's preferences to others. This bill create the parameters for the use of such agreements in Massachusetts, including by setting out required elements of a written SDM agreement and providing protections and strong safeguards against abuse.

There are many reasons why SDM is particularly appropriate for some persons with mental health conditions who need support in decision-making.

For instance, research shows that SDM can benefit persons with mental health disabilities by reducing the need for and reliance on coercive interventions, including guardianships, detention in mental health facilities, and/or forced medication. Studying 107 outpatients with diagnoses of schizophrenia or bipolar disorder, researchers found that when patients participate in decision-making to a lesser extent than they would like to, they more frequently had compulsory admissions. This is significant as coercive interventions engender distrust, avoidance, and refusal of mental health services.

SDM can help people with mental health conditions enhance the patient – treater relationship. When their decision-making ability is enhanced through support, they are more able to participate fully in the respectful relationship with their providers that is crucial to a strong therapeutic alliance. A therapeutic alliance is tied to good outcomes. Meta-analyses have repeatedly found a linkage between a good therapeutic alliance and positive therapeutic outcomes.⁴

SDM can aid individuals with mental health disabilities in their recovery. Researchers have found that engaging mental health service users in decisions about their treatment promotes personal recovery. Such findings are consistent with growing emphasis, in the mental health field and the personal recovery movement, on the benefits of connectedness, hope, identity, meaning, and empowerment. This recognition has given rise to the use of other tools to promote participation including advance statements, joint crisis planning, and wellness recovery action plans (WRAPs). Healthcare professionals are increasingly incorporating means and protocols to ensure that people can express their own will and preferences regarding health care decisions. SDM offers individuals who can benefit from support

https://journals.sagepub.com/doi/full/10.1177/1049732318762371 (citing Kreyenbuhl, Nossel, & Dixon, 2009; Serobatse, Du Plessis, & Koen, 2014).

¹ P. Blanck & J.G. Martinis, The National Resource Center for Supported Decision-making, The Right to Make Choices, Inclusion (2015), http://supportmydecision.org/assets/tools/Supported-Decision-Making-Overview.pdf

² I. Morán-Sánchez *et al.*, Compulsory admissions and preferences in decision-making in patients with psychotic and bipolar disorders, Soc. Psychiatry Epidemiol. (May 2020), https://sci-hub.se/10.1007/s00127-019-01809-4

³ M. Zinkler, Supported Decision Making in the Prevention of Compulsory Interventions in Mental Health Care, Frontiers in Psychiatry (Mar. 2019), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6449721/

⁴ R. B. Ardito & D. Rabellino, Therapeutic Alliance and Outcome of Psychotherapy: Historical Excursus, Measurements, and Prospects for Research, Frontiers in Psychology (Oct. 2018), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3198542/ (citing studies).

⁵ F. Knight *et al.*, Supported Decision-Making: The Expectations Held by People With Experience of Mental Illness, Qualitative Health Research (Mar. 2018), https://iournals.sagepub.com/doi/full/10.1177/1049732318762371 (citing Krevenbuhl, Nossel, & Div

⁶ Id. (citing Leamy, Bird, Le Boutillier, Williams, & Slade, 2011).

⁷ *Id.* (citing Henderson, Swanson, Szmukler, Thornicroft, & Zinkler, 2008).

⁸ L. Penzenstadler *et al.*, Supported decision making for people with mental health disorders in clinical practice: a systematic review, International Journal of Psychiatry in Clinical Practice (Oct. 2019), https://www.tandfonline.com/doi/abs/10.1080/13651501.2019.1676452?journalCode=ijpc20 (citing Szmukler, 2017; Szmukler et al., 2014).

when making decisions to fully participate in and guide the course of their treatment.

SDM is an effective tool to involve people in their own mental health care. Researchers note that while some individuals with mental health disabilities "may require greater support in the decision-making process, the use of support to make decisions is rather similar to the typical decision-making process among most adults, in which consultation with trusted partners on major life decisions is common." 9

Other research regarding strategies that might enhance decision-making capacity for people with mental health disabilities also suggests that having someone who can reiterate and explain information is useful. Studying the informed consent process, where patients are routinely called upon to make important personal decisions, researchers found that the repeated presentation of information and multimedia presentation of information can improve decision making in adults, resulting in greater capacity to consent. ¹⁰ The findings of this research are encouraging for the implementation of SDM; individuals with mental health conditions may participate actively in decision-making with additional supportive interventions.

The use of SDM for people with disabilities, and particularly for people with mental health conditions, is gaining traction nationally. The U.S. Department of Health and Human Services (USDHHS) has recently proposed revisions to its Section 504 regulations that identify SDM as a possible reasonable modification owed to service recipients by entities receiving federal funds who provide medical or human services. ¹¹ Thus, these service entities may in certain cases need to serve individuals who use SDM as a means of engaging in a service that would otherwise be inaccessible; to fail to do so could constitute disability discrimination. The proposed USDHHS regulation explicitly discusses how SDM might be used by people with cognitive, neurological, and psychiatric disabilities, including a statement that people with psychiatric disabilities may be entitled to a reasonable modification "to allow a third-party support person to join the conversation and allow that person to assist the patient in understanding their options and coming to an independent decision on how to proceed." ¹²

SDM has been piloted in Massachusetts since 2014, including with people with mental health diagnoses. Now is the time to provide people across the Commonwealth with the ability to enjoy the benefits of such agreements. We urge the Committee to report a supported decision-making bill favorably. Thank you.

Sincerely,

Jennifer Honig, JD

Co-Director of Public Policy and Government Relations

c: Representative Michael Finn Senator Joan Lovely

⁹ D. V. Jeste *et al.*, Supported Decision Making in Serious Mental Illness, Psychiatry (2018), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6093283/#R8 (citing Palmer, Dunn, Appelbaum, & Jeste, 2004; Palmer et al., 2007; Blanck & Martinis, 2015).

10 Id.

¹¹ U.S. Department of Health and Human Services, Proposed Rule: Discrimination on the Basis of Disability in Health and Human Service Programs or Activities (Sept. 14, 2023), https://www.federalregister.gov/documents/2023/09/14/2023-19149/discrimination-on-the-basis-of-disability-in-health-and-human-service-programs-or-activities, at 63474-63475.

¹² *Id.* at 63489.