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Honorable Adam Gomez, Chair Joint Committee on Children, Families and Persons with Disabilities State House Room 24 Beacon St. Boston, MA 02133

Honorable Michael J. Finn, Chair Joint Committee on Children, Families and Persons with Disabilities State House Room 24 Beacon St. Boston, MA 02133

Dear Chair Gomez, Chair Finn, and Honorable Committee Members:

Re: In Support of S.124/H.272: 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 this testimony in support of S.124/H. 272, An Act Relative to Supported Decision-making Agreements for Certain Adults with Disabilities. These bills 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.

These bills 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. These bills 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 against abuse.

SDM is particularly appropriate for people with mental health issues as it promotes a patient – treater relationship. Research indicates that people who are engaged by their treaters in decision-making are more likely to form a therapeutic alliance with those providers. A therapeutic alliance is tied to good outcomes. Meta-analyses have repeatedly found a linkage between a good therapeutic alliance and positive therapeutic outcomes.²

SDM is also constructive for people with mental health issues as SDM can aid such individuals in their recovery. Researchers have found that engaging mental health service users in treatment decision-making promotes personal recovery.³ 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.⁴ 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).⁵ Consistent with these developments, healthcare professionals have also incorporated, as part of the treatment process, means so that people can express their own will and preferences regarding health-related decisions.⁶

Research also suggests another reason SDM might benefit persons with mental health disabilities. By facilitating the pursuit of services that the individual selects, SDM will likely reduce the reliance on coercive interventions, including detention in mental health settings

https://www.tandfonline.com/doi/abs/10.1080/13651501.2019.1676452?journalCode=ijpc20 (citing Szmukler, 2017; Szmukler et al., 2014).

Massachusetts Association for Mental Health

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 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).

³ F. Knight et al., Supported Decision-Making: The Expectations Held by People With Experience of Mental Illness, Qualitative Health Research (Mar. 2018), https://journals.sagepub.com/doi/full/10.1177/1049732318762371 (citing Kreyenbuhl, Nossel, & Dixon, 2009; Serobatse, Du Plessis, & Koen, 2014).

⁴ Id. (citing Leamy, Bird, Le Boutillier, Williams, & Slade, 2011).

⁵ Id. (citing Henderson, Swanson, Szmukler, Thornicroft, & Zinkler, 2008).

⁶ 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),

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. ⁷ This is significant as coercive interventions engender distrust, avoidance, and refusal of mental health services.⁸

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 issues may participate actively in decision-making with additional supportive interventions.

SDM has been piloted in Massachusetts since 2014. Now is the time to provide people across the Commonwealth with the ability to enjoy the benefits of such agreements. We urge you and your committee to report S.124/H. 272 out favorably. Thank you.

Sincerely,

Danna Mauch, Ph.D. President and CEO

c: Senator Joan Lovely Representative Paul Tucker

⁷ 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

⁸ 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/

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 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 et al., 2007; Palmer & Jeste, 2006).