

Massachusetts Advocates Standing Strong

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June 25, 2019

Honorable Senator Chang-Díaz Honorable Representative Khan Co-chairs of the Joint Committee on Families, Children, and Disabilities 24 Beacon St. Boston, MA 02133

RE: Testimony in support Senate Bill 64

Dear Senator Chang-Díaz and Representative Khan:

My name is Anne Fracht, I'm from Allston, Massachusetts and I'm Chairperson of Mass Advocates Standing Strong. Mass Advocates Standing Strong has been working closely with the Center for Public Representation for over a year on the Supported Decision Making Bill. We support and accept the values in the Senate Bill, S. 64 filed by Senator Joan Lovely. For example, we believe many self-advocates have full potential to make their decisions without a guardian but to have instead their freely-chosen supporters as needed for each person. For example, if I'm going to a specialist and someone is telling me to have surgery — this can be scary and bring up questions about if I really need this, do I need help, how do I prepare, what are the steps — a team can help guide me through it so I can make a solid decision. The team can help me figure out how to make wise choices with my money and make it go further. This model can give people a better quality of life to know that you are in charge and this is your life and if you don't like the way things are going you can change it. You know for people who need somebody day to day it's a lot different than for someone who just needs

some support. We believe Supported Decision Making can give people the freedom that they want with the support needed to make good choices.

Though we endorse this bill we want to let you know the concerns we learned from our members. Mass has a Supported Decision Making Task Force that's been meeting since 2017 to explore the idea of Supported Decision Making. We held a Supported Decision Making Conference with our Members in 2018 to find out how they are making decisions now and what gets in the way. This past fall we held four Regional Forums where self-advocates learned more about Supported Decision Making and we got their thoughts and concerns about it. We've since done follow-up interviews with members who shared stories we wanted to know more about. Through this work we've learned that there are four major areas of concern for self- advocates:

- self-advocates often have difficulty getting others to respect their decisions, even if they don't have a guardian;
- "supporters" often try to make decisions for self-advocates, even though the "supporters" believe themselves only to be helping;
- especially for self-advocates that live in group homes, their representative payees can limit their opportunities to make financial decisions; and
- self-advocates with guardians want their guardians to act as "supporters" instead

We agree with the MASDM coalition that the Committee should delete the SDM Agreement form and instead allow groups to create their own agreements and forms. We will continue our work to make our own agreement and form with our members and educate others about Support Decision Making.

Thank you for listening and for everyone here supporting this bill.

Sincerely,

Anne Fracht

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Chairperson Massachusetts Advocates Standing Strong