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**Testimony of Sandra L. Heller**  
**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 Chairperson Gomez, Chairperson Finn, and Honorable Committee Members.

I am here today as an appointed member of the Massachusetts Developmental Disability Council regarding the Supported Decision-Making bills, Senate Bill 124 and House Bill 272. The Council is an independent state agency that is mandated by the Developmental Disabilities Assistance and Bill of Rights Act to empower intellectually and developmentally disabled people and their families to help shape policies that impact them. The bill before you, “An act relative to supported decision-making agreements for certain adults with disabilities” would make an immense difference for the Commonwealth and for the families and people I work with.

I am also active with Massachusetts Families Organizing for Change. I have been a member of Mass Families for over 25 years and am currently the Chairperson of the board. Mass Families is a statewide grassroots coalition of individuals with disabilities and/or chronic illnesses and their families. Mass Families provides sustained advocacy and leadership training in pursuit of high quality, individualized community support and service options, including family support, for people with disabilities and their families.

I am the proud parent of a 34-year-old man, Craig, who happens to have been born with Down Syndrome. Sixteen years ago, when he turned eighteen, Craig and his family members made a decision to not pursue guardianship. As he approached eighteen, our family was told many times, by our school district staff and others, that we should get a guardianship for Craig. However, this was not right for Craig. Our approach to Craig’s life has always been: first, presume competent, and then take the least restrictive approach. Instead of getting a guardianship, Craig began practicing supported decision-making. At the time, there wasn’t even a name for what we were doing but we were naturally using the approach that has now been termed supported decision-making. Craig got help from people he trusts with making decisions



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and communicating them. Later, when we learned about supported decision-making, we created a formal supported decision-making agreement that defines who Craig's supporters are and what type of support he will get from them. And Craig has always had a health care proxy in case of emergency and a power of attorney for financial matters.

Today, I am happy to say that Craig's supported decision-making agreement works!! He has chosen four people in his life that are family and caregivers to be his "supporters" on things that every person should be given the opportunity to decide.

From Craig's early childhood to today, he has been given every opportunity to be a decision-maker. He is proud and respected for being a registered voter, deciding where he lives and with who, how he spends his own earned money from working, who he wants to spend time with and most importantly, he is given the information and respect to understand his own medical needs. Because of the support he gets from his supporters, he can make decisions for himself.

As a teenager Craig had complex medical needs and endured and required life sustaining medical procedures. During that time, not one day went by that everyone around him--from the doctors to his family--did not inform, explain, and help him through these difficult years. Supported decision-making worked for him even during this extremely challenging time for his health.

The traditional guardianship route for Craig and our family is not the way we have chosen to go. Historically our society has presumed people with an intellectual disability are incompetent or incapacitated – we do not agree with that. We have seen how supported decision-making allows adults like Craig to make his own decisions, with support and maintain his rights, dignity, and independence.

We all learn through our own life experiences and we all rely on others in our lives to help us with decision making, my son is no different.

This bill is so important because it would make families more willing and able to use supported decision-making. Craig and I train families all across the state (and even internationally) about supported decision-making. Many times, family members believe supported decision-making could work for their loved one, but they are hesitant to use the approach because they are worried doctors or others they have to interact with will not understand what it is and the supporters will not be able to assist the individual. They know that guardianship is familiar to society.

This bill would make a huge difference for these families, because supported decision-making would be in Massachusetts law and third parties would be required to respect it. I believe that passing this bill would make many more families willing to try supported decision-making in situations where guardianship is not needed.

Most importantly, the bill will require the courts to consider supported decision-making **first** before establishing a guardianship and ensure all youths turning 18 are offered information on supported decision-making as an option at their Individualized Educational Programs (IEP) meetings and during their transition. In my advocacy work, I hear over and over from families that schools and other systems are telling them they must get guardianship and no other options are presented. Essentially, one of the biggest issues is that families simply don't know about

alternatives and think guardianship is the only choice. For that reason, this bill could make a huge difference.

Thank you for your consideration on this matter.

Sincerely,

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