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Senator Chang-Diaz  
Representatives Kay Khan  
Joint Committee on Children, Families and Persons with Disabilities  
Massachusetts State House  
Boston, MA 02133

Dear Chairman Chang-Diaz and Chairman Kay Khan;

I am writing to you in support of Senate bill #64 and House bill #172. I support the bill titled "An act relative to supported decision-making agreements for certain adults with disabilities. I am the proud parent of a 32 year old man who happens to have been born with Down Syndrome. I am also active with Massachusetts Families Organizing for Change, I have been a member of this organization for over 25 years and am currently the Co-Chairperson of the board. MFOFC is a statewide grassroots coalition of individuals with disabilities and/or chronic illnesses and their families. MFOFC 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.

Fourteen years ago, when he turned 18 Craig and his family made a decision to not pursue formal guardianship. Craig's life is and has always been "first presume competent, or the Least Restrictive." We are firm believers that Supported decision-making allows adults, including those with disabilities to maintain their rights, dignity, and independence by choosing one or more trusted supporters to provide assistance making decisions about their lives.

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. Where you chose to live, work, what you want to do, who you want to spend time with and most importantly such decisions as understanding and deciding on your own medical needs.

The traditional guardianship route for Craig and our family is not the way we have chosen to go. We believe that just because that is the typical way in history that anyone with an intellectual disability was presumed incompetent or incapacitated does not mean we agree with that statement. From Craig's early childhood to today, he is 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. As a teenager Craig endured and required life sustaining medical procedures and 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.

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 would establish roles for all involved, allow people with disabilities to have Supported Decision Making agreements with supporters they know and trust. 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.

Many respected national and federal agencies recommend SDM as an alternative to guardianship such as The American Bar Association, National Guardianship Association, The ARC of the United States, U.S. Department of Education, U.S. Department of Health and Human Services, and the National Council on Disability.

States across the United States are establishing these laws and it would be of great value for Massachusetts to do so as well. Thank you for your consideration on this matter.

Sincerely,

Sandra L. Heller