



*For people with intellectual  
and developmental disabilities*

December 3, 2021

The Honorable Adam Gomez, Senate Chair  
Joint Committee on Children, Families and  
Persons with Disabilities  
Room 413B  
Boston, MA 02133

The Honorable Michael Flinn, House Chair  
Joint Committee on Children, Families and  
Persons with Disabilities  
Room 146  
Boston, MA 02133

Re: Testimony in Support of H.272/S.124: An Act relative to supported decision-making agreements for certain adults with disabilities

Dear Chairs Gomez and Flinn, and Members of the Committee:

My name is Ellen Taverna, I am the Director of Public Policy at The Arc of Massachusetts (The Arc). Thank you for the opportunity to present testimony, on behalf of the Arc, to support H.272/S.124: an act relative to supported decision-making agreements for certain adults with disabilities, sponsored by Representative Paul Tucker and Senator Joan Lovely. This bill remains a high priority for The Arc and we have been working for over three years with the coalition that is supporting this bill led by Anna Krieger at the Massachusetts Developmental Disabilities Council.

We believe the time has come for Supported Decision Making (SDM) to be formally recognized in Massachusetts, as it has proven to be an important alternative to guardianship for certain individuals with intellectual and developmental disabilities (IDD) and other disabilities as well as elderly individuals who need assistance in decisions about finances, health, and other issues. At The Arc we advocate to promote community supports, services and tools for individuals with IDD and autism that foster social inclusion, self-determination, and equity across all aspects of society and SDM fits well in our mission. The Arc strongly promotes person-centered planning, which is an approach to future planning that focuses on the preferences of a person with a disability and his or her family. The person-centered planning process can assist individuals in developing a vision to pursue full lives engaged in community life. Person-centered planning is an excellent example of a type of supported decision-making. It is a tool that allows individuals to retain their legal rights and the freedom to make decisions for themselves with the support of people they trust.

The Arc of Massachusetts

217 South Street  
Waltham, MA 02453-2710

T: 781.891.6270  
F: 781-891.6271  
arcmass@arcmass.org  
www.arcmass.org

*Achieve with us.*

Scott Borchardt  
President

Leo V. Sarkissian  
Executive Director

---

The Arc in Massachusetts Includes the Following Chapters:

Berkshire County • Bristol County • Brockton Area • Cape Cod • Center of Hope Foundation  
Charles River Center • Communitas • Greater Haverhill-Newburyport • Greater Lawrence • LifeLinks • Greater Plymouth • Greater  
Waltham • Minute Man AHS • Northeast • The Arc of Opportunity (North Central) • Opportunities for Inclusion  
South Norfolk County • South Shore • The United Arc

First and foremost, this is about promoting choice for individuals. At The Arc's conferences and trainings, we often hear from family caregivers of individuals with IDD and autism who are turning 18 and looking for how best to support their loved ones. Unfortunately, guardianship is often the only option presented to them by their school. While guardianship may be the appropriate option for some individuals, we want to ensure people with disabilities and their families have all the information about the different alternatives available to best assess their needs.

Because SDM is often the unknown choice, people may be concerned about what types of protections exist for it. In the SDM process, there are several safeguards put in place that protects the decision-maker against abuse, neglect or exploitation. In most cases, the decision-maker chooses more than one supporter, which creates a natural safeguard against abuse. Unlike guardianship where there is typically only one person appointed guardian, with supported decision-making there are almost always multiple supporters. The more people involved in supportive decision-making provides a broader perspective on issues. But passing these bills would create additional protections against abuse of the model, such as directing where reports of concerns about abuse or neglect could be directed.

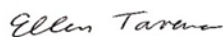
Most importantly, supporting independence and self-determination can help decrease the likelihood of experiencing abuse. Studies have shown people are less likely to experience abuse, neglect or exploitation when they are provided the opportunity and education to speak up for themselves. The consequences of not being allowed to make decisions, or of having one's decisions ignored, has been associated with increased likelihood of depression, anxiety, loneliness, and may worsen psychological symptoms. It is better to teach someone how to identify toxic, abusive, or exploitive behavior than to rely on someone always being available to do that for them. There is no guarantee of safety under any arrangement, including guardianship. But that is not a reason to limit the options available for people to live their best lives. Protection from future uncertain harm must be carefully balanced so as not to unnecessarily infringe on someone's civil rights.

Further, formally recognizing SDM would help doctors, bankers, lawyers, and other third parties to feel confident in accepting the decision of the person with a disability without fearing lawsuits or malpractice claims. Often when an individual obtains a guardian it's difficult to change that status unless the guardian agrees. This ultimately clogs up the courts and there are often high costs to the legal proceedings for guardianship.

In addition to my work at The Arc, I'm also a mother of a 10-year-old with autism and an intellectual disability. My husband and I chose to raise our children in Massachusetts because this state has always been on the forefront of setting high standards for educating students with disabilities. We teach our son to be independent and to advocate for himself and his local public school offers opportunities for him to make his own decisions. Yet, despite all this progress when it comes time for him to turn 18 – unless we make changes in the law now – his school will continue to present guardianship as the default choice. We hope that Massachusetts will take this opportunity to change the landscape for individuals with disabilities and others seeking a different path.

The Arc supports these two bills, H.272/S.124, and urge that they receive the endorsement of your joint committee.

Sincerely,



Ellen Taverna  
Director of Public Policy  
The Arc of Massachusetts