

Testimony to the Joint Committee on Children Families and Persons with Disabilities

September 9, 2025

S.155, H261: An Act relative to supported decision-making agreements for certain adults with disabilities

Senator Robyn Kennedy
Senate Chair
State House, Room 312-D
Boston, MA 02133

Representative Jay Livingstone
House Chair
State House, Room 146
Boston, MA 02133

Dear Chairperson Kennedy, Chairperson Livingstone and Committee Members:

I am a constituent of Senator Patrick O'Connor and Representative James Murphy, and am writing in support of S155, H261, **An Act relative to supported decision-making agreements for certain adults with disabilities**. Supported Decision Making ("SDM") is an alternative to guardianship that recognizes that individuals may need help in making decisions. Through SDM a person establishes a system of supports to help them make decisions. This means the person does not have their rights taken away in favor of an authoritative figure, the guardian, who has power and control over every facet of their life.

As a caring family member of a disabled person **under a detrimental guardianship** and recipient of the 2014 Crocker Fellowship, awarded by the Massachusetts Network of Developmental Disabilities (the Massachusetts Developmental Disabilities Council ("MDDC"), the Disability Law Center, the Shriver Center and the Institute for Community Inclusion), I conducted research on the status of guardianship in the Commonwealth for individuals with Developmental and/or Intellectual Disabilities. My findings showed that there are many areas of improvement needed in the guardianship system in Massachusetts and sparked the creation of a cross-disciplinary Guardianship Working Group sponsored by the MDDC. Finding a way to reduce the number of guardianships (often needlessly created) is a way to keep more individuals from being placed into a system that by and large, is antiquated, paternalistic, lacking in oversight, and devoid of standards. **Pretty much anyone can be a guardian as there is no vetting process other than a limited background check and no requirements other than age - there is no training required and self-reporting is the only oversight. The system allows and supports guardians who are themselves limited in capacity.** This bill would codify an essential guardianship alternative, SDM, and would be an important and critical step toward moving away from over-reliance on the guardianship system in Massachusetts.

The drawbacks of guardianship: Guardianship takes away the rights of the individual who typically have no representation in the process. Even well-intended guardians who act in the best interest of the person under guardianship may make decisions that are not necessarily aligned with what the individual would choose if they were not under guardianship, as every individual – be they elderly, developmentally and/or intellectually disabled, nonverbal, physically handicapped, or experiencing symptoms from mental illness or are labeled as such, has preferences.

Guardianship may intentionally or inadvertently compromise the network of supports that an individual with a disability has, often through excluding involvement of family members and other

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caring individuals thus creating barriers to self-determination, self-advocacy, and the realization of a good quality of life. By definition guardianship prohibits advocacy for an individual by anyone other than the guardian, i.e. if the guardian is overreaching in their authority, negligent, abusive, or exploitative there is no complaint mechanism and by law the guardian has power over the individual. (My own sister was not able to return to her group home following the COVID pandemic due to the intentionally hostile decision making of her guardian and there was no recourse for my sister to seek assistance in this matter.) Further, while individuals undergoing guardianship proceedings are entitled to legal representation, this is a right that is often overlooked, as many do not have the awareness of this right, nor the access to resources that would enable them to execute it and the court does not require that they have representation. Guardianship proceedings often take place without the prospective respondent present, despite the right to an alternative more appropriate venue. Such rights - legal representation and more appropriate venue are thus, inexecutable.

How Supported Decision Making helps: Supported Decision Making overcomes many of the aforementioned drawbacks to guardianship. The individual may choose his/her supporters, and may change them at any time. There is no court process involved, thus no chance of the court appointing a guardian without ever having met the ‘incapacitated’ individual and ascertaining their abilities or compatibility with the proposed guardian. With SDM there is typically more than one supporter, the potential for exploitation is minimized because the presence of multiple supporters acts as a natural check on any potential bad actors. The dependency created when a guardian is appointed is absent in an SDM arrangement and, as a result, individuals’ decision making abilities are likely to improve over time because they are getting a chance to practice making their own choices with support. An additional benefit to reduced dependency/increased independence is the ability of an individual to recognize if and when they may be being abused, and the ability to seek help. While full autonomy may not be realized in all cases, self-determination is advanced. Caring individuals are involved.

Many folks with ID/DD are placed under guardianship at the age of 18, long before their full potential is realized at the age of 26 when full neurological development is achieved regardless of the disability. This becomes a lifelong sentence, as terminating a guardianship is very difficult and expensive. SDM may be implemented and revisited if at some point in the future it is determined that some form of guardianship is more appropriate. Note that at least one state places a limit on the number of years an initial guardianship may be in place. Additionally, there are hundreds if not thousands of individuals in the Commonwealth who are appointed attorneys as guardians who are strangers and have caseloads that do not allow proper or sufficient engagement with the individuals.

Further, as noted in 115 CMR 5.07, the fact that an individual is served by the Department of Developmental Services (“DDS”) does not imply that they have been deemed incapacitated and therefore must have a guardian. Some opposition to SDM takes the view that all individuals receiving services through DDS are vulnerable and need protection, and that SDM seeks to replace guardianship. One size does not fit all – just as not all individuals served by DDS need guardians, only those who are able to successfully engage in Supported Decision Making will use it. Without this alternative the already overburdened system of guardianship remains bloated and in many cases ineffective.

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SDM was brought to the forefront as a result of the 2006 United Nations Convention on the Rights of Persons with Disabilities that highlighted the violation of human rights under guardianship. In 2017 the Uniform Law Commission included provisions that courts should consider SDM as a less restrictive alternative to guardianship in the Uniform Guardianship Conservatorship and Other Protective Arrangements Act (“UGCOPAA”). The American Bar Association supports SDM: in 2017 the American Bar Association passed a resolution encouraging state legislatures to require that SDM be considered before guardianship is imposed and as a grounds for termination of guardianship. Twenty three states and the District of Colombia have passed SDM legislation similar to the bill before you and many, many more have proposals, in addition to Massachusetts. Several countries throughout the world have also adopted SDM as a less restrictive alternative to guardianship that does not infringe on the rights of the individual.

Disability can happen at any time, to any of us and we can take measures so that we are not placed under guardianship Please take a moment to think about how you would want an alternative to guardianship for yourself or a loved one if a complete removal of rights is not necessary. Your support of this bill would give recognition to the fact that individuals with disabilities are individuals first – they have hopes and dreams and, no matter their level of disability, they have abilities. Thank you for your consideration.

Sincerely,



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