

Testimony to the Joint Committee on Children, Families and Persons with Disabilities in Support of An Act Relative to Supported Decision-Making Agreements for Certain Adults (H.261 / S.155)

Representatives Livingstone and Finn, and Senator Lovely September 9, 2025

Dear Chair Livingstone, Chair Kennedy and members of the Joint Committee on Children, Families and Persons with Disabilities,

My name is Jevon Okundaye. I am a Black autistic self-advocate. I am also a constituent of Senator Liz Miranda, the vice chair of the Joint Committee of Children, Families, and Persons with Disabilities. I work at Massachusetts Advocates for Children (MAC) as the Racial Equity and Access Program (REAP) Assistant. I am a member of the Massachusetts Supported Decision-Making Coalition that is co-chaired by Jonathan Gardner and Nora Bent from the Arc of Massachusetts. I was a member of the Center for Public Representation's Supported Decision-Making Advisory Project that was led by Mona Igram.

Today, I am submitting testimony on behalf of MAC in favor of <u>H.261</u> and <u>S.155</u>: An Act Relative to Supported Decision-Making Agreements for Certain Adults. More information is available in the bill factsheet: <u>SDM Fact Sheet (2025)</u>. <u>H.261</u> is sponsored by Representative Jay Livingstone, the chair of the Joint Committee of Children, Families, and Persons with Disabilities, and Representative Michael Finn. <u>S.155</u> is sponsored by Senator Joan Lovely. This bill is supported by a broad range of advocates including human services providers, self-advocacy groups, legal services, guardianship and elder attorneys, elder justice advocates and lawyers, families, and more. This includes organizations, such as MAC, the Massachusetts Developmental Disabilities Council (MDDC), and the Arc of Massachusetts.

I would like to share my personal experience. I think supported decision-making (SDM) should be made law in Massachusetts because it allows adults with disabilities, like me, and older adults to be independent while still getting help from others when they need it. When a person creates an SDM agreement, they are in charge of it and can make changes to it at any time. They choose support people to consult with before they make their final decisions.

Turning 18 and becoming an adult was hard for me because I was not prepared for legal responsibilities shifting from my mom to me. I was overwhelmed by the idea of having to attend important meetings by myself and sign legal documents for the first time. My mom and I explored guardianship, but it was not the right fit for me and my support needs. But just because I am autistic with lower support needs does not mean I do not need any support at all. For a while, I thought that guardianship was the only way for my mom to remain involved in my adult life, until we learned about supported decision-making.

Even though I was not under guardianship, my mom did not stop being involved in my life. I find it hard to attend meetings alone and to make big decisions by myself, so I give my mom

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permission to attend meetings with me and to speak to people on my behalf sometimes. I also talk to my mom when making financial and medical decisions and reading and signing legal documents. When I am confused, she helps explain things to me in a way that I understand. When I am overwhelmed, she helps calm me down. My mom and I work together to make the right choices for me. Essentially, my mom and I were using SDM even if we did not know about it.

If this bill is passed, it would not get rid of guardianship but rather require SDM to be discussed along with guardianship during a student's transition Individualized Education Program (IEP) meetings. If my mom and I had learned about SDM during my IEP meetings, my transition to adulthood would have been easier. Discussing SDM during IEP meetings can help transitionaged students determine what supports they will need when they become adults. It is important for families to know all their choices when planning for their loved one's future. It is not guardianship or nothing at all.

I am a <u>Charting the LifeCourse</u> (CtLC) ambassador. CtLC is a framework to help people organize their goals for the future using different vision tools. Some of the vision tools are the <u>Mapping Family Roles</u> worksheet and the <u>Integrated Supports Star</u>. There is even a specific <u>Integrated Supports Star for SDM</u>. I am bringing up CtLC because as a person with a disability gets older, their relationship with their family members may change, but they still may require a certain level of support. It is important for people with disabilities to know that they can still get assistance from their family members through SDM without having to give up control of their lives through guardianship.

Additionally, this bill would make SDM formally recognized in Massachusetts like it is in other states. Some people may be more reluctant to use SDM if it is not made into law. For example, my mom and I want to create an official SDM written agreement, but we do not want to sign an agreement that is not going to be recognized or accepted by other people if it is not official. We do not want our SDM agreement to be disregarded or invalidated.

Furthermore, people of color may prefer to use SDM over guardianship because they may not want to get involved in the court system. Immigrant families may have deportation concerns. People of color and people with disabilities have a history of not having their voices heard. SDM allows them to maintain their rights and still have a voice.

I hope you will support $\underline{\text{H.261}}$ and $\underline{\text{S.155}}$: An Act Relative to Supported Decision-Making Agreements for Certain Adults. Thank you.

Sincerely,
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