

National Multiple Sclerosis Society

Testimony in Support of HB 529 – Supported Decision Making

March 9, 2022

The National Multiple Sclerosis Society strongly supports HB 529 regarding supported decision-making for people with disabilities in Maryland. We thank Delegate Pena-Melnyk for bringing forward this important legislation.

Multiple sclerosis (MS) is an unpredictable, often disabling disease of the central nervous system that disrupts the flow of information with the brain, and between the brain and the body. Symptoms vary from person to person and range from numbness and tingling to walking difficulties, fatigue, dizziness, pain, depression, blindness, and paralysis. The progress, severity, and specific symptoms of MS in any one person cannot yet be predicted. The cause is unknown and there is no cure. Most people with MS are diagnosed between the ages of 20 and 50 and it is the leading cause of disability in young adults. While it is much rarer, MS is sometimes diagnosed in children. There are an estimated 1 million Americans living with MS.

As you consider our support of this bill, please reflect on the mission of the National MS Society, which is “We will cure MS while empowering people affected by MS to live their best lives.” Our mission is congruent with HB 529.

Recognition of supported decision-making is a foundational civil rights issue for people with disabilities. Too often, people with disabilities have been placed in overbroad and unnecessary guardianships based on stereotypes about their capabilities. Under guardianship, a person living with MS loses their ability to make decisions for themselves, which is placed in the hands of their guardian. A person can lose their right to vote, their ability to marry or partner with the person they love, their ability to control what medical care they receive or who can visit them, and other decisions.

Once placed under guardianship, it is very difficult for a person to receive a termination of guardianship. We have seen people with disabilities remain under unnecessary guardianships and even experience abuse and neglect, because they cannot access the medical evaluations or legal resources needed to terminate it. Studies have shown that people in overbroad guardianships experience “a significant negative impact on...physical and mental health, longevity, ability to function.” While guardianship still may be the appropriate tool in some cases, it must not be the default for people with disabilities. Guardianship should be a tool of last resort.

Supported Decision-Making (SDM) allows individuals with disabilities to make choices about their own lives with support from a team of people they choose resulting in a structured agreement. Legal recognition of supported decision-making in Maryland will reduce the need for guardianship rulings. Supported decision-making provides an alternative that courts must consider before placing someone under guardianship and allows a person to continue to make their own decisions—just recognizing that they use support to do so. It preserves a person’s right to make their own choices—fundamentally it is their right to have rights.

Supported decision-making is not a new concept. It has been recognized as a reasonable accommodation under the Americans with Disabilities Act and over 20 states have passed similar laws recognizing supported decision-making agreements. Several national organizations, including the National Guardianship Association, the National Council on Disabilities, the US Administration on Community Living, the American Civil Liberties Union, and others, have endorsed supported decision-making as an alternative to guardianship. It is time that Maryland joins the ranks of those that more broadly recognize supported decision-making and an alternative to guardianship.

This bill that builds on and incorporates best practices from others who passed and implemented supported decision-making in other states, including by:

- Helping to prevent abuse and neglect of people with disabilities by bolstering their self-determination and control of their own lives
- Creating a framework for how to make a supported decision-making agreement so that third parties are more likely to recognize them
- Ensuring that the manner of an individual's communication is not grounds for determining that a person is incapable of making a supported decision-making agreement
- Allowing courts to terminate or limit guardianship due to the existence of a supported decision-making agreement
- Making it clear that a supporter does not have the authority to decide for a person, rather the person remains the decision-maker
- Limiting liability for those who in good faith rely on the use of supported decision-making agreement

Thank you for the opportunity to provide comment on this legislation. The Society strongly urges Committee members to support this bill. If you have any questions regarding the Society's position, please contact Shannon Wood, Director of Advocacy and Policy, at [shannon.wood@nmss.org](mailto:shannon.wood@nmss.org).