



HOUSE Judicial Proceedings Committee

March 9, 2022

HB 529: Estates and Trusts – Supported Decision Making
Position: FAVORABLE

Good afternoon, Delegate Pena-Melnyk and members of the Committee. My name is Gail Godwin, I live in Baltimore City, and I am the Founder of Shared Support Maryland, Inc. (SSMD). SSMD stands in strong support of House Bill 529 which, if passed, would authorize the use of supported decision-making contracts to assist people to make, communicate or effectuate decisions without the need for a court appointed substitute decision maker. Thank you for this important session to hear from Marylanders on this civil right. Support to make decisions is already an established freedom and passing this bill will allow recognition to the formal processes of SDM agreements.

SSMD is a non-profit providing Support Brokerage to over 135 people in Maryland who use Self Directed Services, Individual Support Services, Department of Rehabilitation Services and privately pay. SSMD is a proud member of the Maryland's Cross Disability Rights Coalition who has entered testimony in favor. Our objective is not to run the lives of people with disabilities but to support people to run their own. We work in collaboration with people and other organizations to move the resources and information closest to the person so that what defines people as vulnerable has less of a chance of doing so. People live in their own homes, alone, or with people whom they choose. People hire, are the employer of record and are in charge of their own support staff and contractors, hold jobs that pay a living wage, and spend their time in activities of their choosing. We are one of fewer than 75 agencies in the country that provides this kind of person-directed, customized support and services to people with any level or multiplicity of disability, without exception. In everything SSMD does, the intent is to support people to make decisions for themselves. Supported Decision Making, the fact that everyone communicates and presuming capacity are 3 of SSMD's basic operating principles. SSMD does not hire anyone to work here without them, if we make a mistake, we move them along ~ that keeps our customers off of that learning curve.

Shared Support Maryland, Inc.

For 16 years SSMD has worked for hundreds of people who have chosen to leave nursing facilities and institutions, who use up to 24 hours a day of support, people with co-occurring mental illness, co-occurring addictions, acquired injuries, children, people who are aging.. With people's own determination and/or support, **these are the same people** with disabilities who who have made major life decisions about:

- What, if and how to receive their services, sometimes decisions not to use a service when others disagree
- Leaving an institute, nursing facility or family home and all of the key decisions that go along with that, like deciding where to live, with whom and how
- Having children and how many,
- Changing gender identity,
- Finding and landing jobs that pay a living wage,
- Saving and spending money,
- Learning to read or going back to school for an advanced degree
- Recruiting, employing, managing/retaining, terminating employees and all of the Human Resources decision making that goes along with that, like approving their time for payroll, providing feedback and giving raises,
- Making determinations to press criminal charges for medicaid fraud, which goes beyond the initial report to our system which, while important, is ineffective in putting an end to it,
- Receiving serious mental health treatment, even when highly recommended or potentially dangerous.
- Futures planning so that when their support system is no longer available or available in the way that it is now, that the person does not acquire a guardian, undecidedly go to a group home for living or segregated services otherwise.

Supported Decision Making is a tool that uncomplicates information and the general public uses it. Routinely, people obtain free and paid advice in order to make decisions. They use accountants to break the numbers down, engineers/builders and architects to show them why their version of a dream home won't be possible, fertility clinics to help weigh options about how to start a family, doctor's second, and third opinions, a therapist to help a couple choose divorce, expert witnesses support lawyers through difficult cases, friends help you decide on the paint for

Shared Support Maryland, Inc.

your room or how to wear your hair. No one is necessarily asked to demonstrate the support that they receive and the support people use is rarely up for debate.

The tools of SDM are endless. Assuming people do understand or that they can understand is first and then making it clear that supporters do not have the authority to make a decision for a person, rather the person remains the decision maker. Then, relying on the capacity of direct supporters to help someone learn; adapting material and information into plain language, graphics, pictures, use of color and pie charts; reading something out loud when a person does not read; calling someone with information from electronic communication every time an email is sent about them when they don't use email; understanding someone who uses a facial expression to state their dissatisfaction about something; bringing in others who know more about a topic; uses coaching and mentoring tools; supporting people through their communication; waiting minutes, hours, days or years for someone to weigh risks and benefits of making certain decisions; using the time that Medicaid pays us for in order to support decision making (Medicaid pays for people to spend time with people); and educating and expecting the same from other supporters including families who are helping their children with decision making for the first time even as adults.

Person directed planning is another SDM tool. SSMD holds a major grant through the Maryland Developmental Disabilities Council that pays people with disabilities and family members to decide on and develop curriculum about Person Centered Planning since they are subject matter experts because of their experience. Trainers, who have disabilities and family members train and mentor others with disabilities and family members on person centered planning. A main takeaway of the training is to stay in charge, expect accountability from teams to do what they say and *for people to take the time that they need to make decisions* (not 1 hour, once a year). Planning time is an ideal place for decision making and determining structure on how decisions are made.

Guardianship and guardians are not the only people that make decisions for people. Currently, our system allows others, who are not appointed guardians, like providers, family members and others to make major decisions for people on a regular basis about service provision, where to live and with whom, what services they will get, and who provides them. In the general public, families can make

Shared Support Maryland, Inc.

decisions about their family members' living situation and care who experience a decline in health and/or ability that is easily acted on by service providers (including institutions and nursing facilities) as if the person were asking for the service themselves. Many of these decisions result in more segregation and isolation, creating an opportunity for abuse that can go unnoticed.

People with disabilities who use a system of support, may inherently see authority in that system and not a place where they can make decisions and be in charge of their lives. The system is designed on the premise that people need something because they have a disability. We are well aware of what can happen when someone has a sphere of influence in someone's life significantly impacting their decision making, rather than supporting it. *This is not Supported Decision Making.* People may be well meaning, they may not consider or are aware of options and information available to support people in their decisions. Some common examples are 1) decisions made by others for someone about behavior services and interventions when people are expressing their need for change and to have control over their lives, 2) a person making a decision to work less because they have been told not to work more than 20 hours a week or they will lose their benefits and services (misinformation), and 3) guiding a person to make a decision to move to a group home because they may be facing difficulty making ends meet or homelessness. When people are in vulnerable positions, they may be more influenced to make decisions they otherwise would not. *This is the danger*, common and essentially acceptable practice. *This is not Supported Decision Making.* Supported decision-making is about ensuring that the person remains the decision-maker, and that they get the support they need to do that.

SDM legislation is not intended to replace power of attorney agreements and guardianship, it is an additional tool. As an additional tool, SDM legislation may give way to reconsideration of current appointments, agreements and other similar contracts if this tool is also and ultimately change a system that is built on people making decisions for other people about what's best because of their diagnosis.

Shared Support Maryland, Inc. and I urge you to vote in favor of House Bill 529/Senate Bill 559 and join the increasing number of states in the US who have passed SDM legislation and the United Nations who mandates SDM.

Shared Support Maryland, Inc.

Thank you for believing in the capacity of all Marylanders and allowing us to join our colleagues and partners in this movement and testimony.