



Speaking out for people with
intellectual & developmental disabilities

Issues to Consider Regarding Guardianship and Supported Decision-Making

By VOR's Committee on Guardianship Rights

Individuals with intellectual and developmental disabilities (I/DD) and their parents, family members and guardians may have heard about Supported Decision-Making (SDM), an initiative that could affect their decision-making rights. Some see SDM as an alternative to guardianship, while others view it as an attempt to remove the legal instrument that provides a safety net for vulnerable individuals.

VOR is a national organization that advocates for high quality care and human rights for individuals with I/DD. We understand the valuable role that guardians play in the emotional and physical well-being of their wards. As advocates who appreciate the diversity of the I/DD community and the need for a wide array of supports, we want to ensure that guardians and family members are aware of the issues connected to Supported Decision-Making so that they can make informed decisions about the care of their loved one with disabilities.

What is Guardianship?

Guardianship is the legal process whereby a state court appoints a person or organization to have the care and custody of an adult or child who has been determined to be legally incapacitated. Parents are the assumed legal guardians of their minor children, but a guardian may be appointed for a child if the parents are not able to fulfill that role. An incapacitated adult is one who has been determined by a court to lack capacity to make some or all personal and/or financial decisions and for whom a guardian has been appointed.

Guardianships are awarded to protect the "ward," the individual with a disability, from abuse, neglect, and exploitation. Guardians are expected to act in the best interests of the individual and to make decisions over medical, psychiatric, behavioral, and all other aspects of the person's care that are authorized by the court based on the degree to which the individual is incapacitated. Legal guardianship is both a responsibility and a privilege.

What is Supported Decision-Making?

The Supported Decision-Making movement is a new initiative that promotes the idea that, with almost no exceptions, all people with I/DD can make their own decisions with support from an informal network of advisors. Supporters of SDM claim that empowering individuals to make their own decisions would make most guardianships unnecessary. The advisors do not need to be court-appointed and do not bear any responsibility for ensuring the success of outcomes. Supported Decision-Making proponents view the "Right to Fail" as an important freedom, regardless of the individual's ability or vulnerability.

Issues to Consider

Supported Decision-Making might help those who need guardianship the least, if at all. In the process of attempting to change guardianship laws, it could weaken protections for those who are the most vulnerable. Those protected by guardianship include people with severe intellectual disabilities, people with I/DD who are susceptible to manipulation and coercion, and people with I/DD who lack awareness of the consequences of their actions and may cause harm to themselves or to others.

The primary goal of SDM is to move away from “substituted decision-making”, where the guardian makes decisions for the incapacitated ward. Proponents of SDM make the assumption that all people with disabilities are capable of making all decisions for themselves with help from a support team. This approach would then, in fact, be doing what SDM proponents criticize: substituting the judgment of the incapacitated ward with the judgment of a “support team”.

Guardians of people with I/DD usually have an existing network of informed persons to assist them in making decisions for their wards, including other family members, direct care providers, and medical personnel. This is what SDM promotes, but without the protection of court-ordered guardianship. The more individuals are able to express their wishes and play an informed, responsible role in their own decision-making, the more their participation should be included. But, it is irresponsible to remove an individual who lacks the capacity to make his or her own decisions from the protection of the court and ongoing evaluation. Most individuals with intellectual disabilities change over time, their needs change accordingly, and their ability to make their own decisions in a responsible manner should be examined at regular intervals.

VOR maintains that problems with guardianship can be avoided through strong enforcement and monitoring and better access to information on guardianship. To eliminate guardianship or make it more difficult for family members and friends to become guardians will leave people with I/DD more vulnerable to the abuse, exploitation, and neglect that guardianship is designed to prevent.

When people with I/DD and their families are presented with Supported Decision-Making, they should consider the following:

- The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) states: *“individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families.”*
- DD Act, 42 U.S.C. 15001(c)(3)(2000)
- Is the individual prepared to take on the responsibility of Supported Decision-Making?
- Is the individual's support group prepared to address the changing needs of the individual over the course of their lifetime? How will you maintain and ensure a consistent team of advisors?
- How do you reconcile the “Right to Fail” with the safety and comfort of the individual?
- How do you determine if SDM is not working and legal guardianship would be appropriate?
- You and your loved-ones with I/DD have the right to decide what is best for your unique situation, based on individual need. Take your time in making any major decisions regarding guardianship.

VOR does not oppose the use of SDM for all who voluntarily wish to use methods promoted by advocates of SDM. All decisions rest with the individual or the legal guardian as authorized by a state court and it must be understood that guardianship procedures are available to those who need them, regardless of their participation in SDM activities. As such, there is no reason to give up guardianship in order to use Supported Decision-Making.

Changes to guardianship laws in many states have already been proposed. Families should keep abreast of these changes and advocate for their loved-one with state officials if the changes could weaken the protections upon which he or she relies. VOR will do its best to keep you informed. Our vulnerable family members deserve nothing less than the protections that family guardians can provide.

VOR is a national organization that advocates for high quality care and human rights for people with intellectual and developmental disabilities. VOR advocates for a full range of options to address the full range of needs of people with intellectual and developmental disabilities and their families. <http://www.vor.net>