

Exploring the Fundamentals of Supported Decision-Making

Webinar Executive Summary

In August 2019, Applied Self-Direction hosted a member webinar, *Exploring the Fundamentals of Supported Decision-Making*, led by Michael Kendrick, Director of Supportive Decision-Making Initiatives at the Center for Public Representation.

What is Supported Decision-Making?



“Supported decision-making is a potential alternative to guardianship and related forms of substituted decision-making that allows the individual with a disability to consult with a mix of *personally selected* supporters to make his or her own choices about their life.”

Supported Decision-Making

VS

Substituted Decision-Making

Supported decision-making (SDM) allows the individual to be the one in charge of their support network for decision-making and **enable the person to make their own decisions** with assistance of trusted supporters.

This is a common practice among people, as we often informally use SDM by turning to friends, classmates, family, and others for advice and counsel.

It is important to note that individuals may turn to different people for support for different situations, which is accounted for in SDM by having a mix of supporters, unlike in substituted decision-making.

In substituted decision-making, or guardianship, another person is given the authority to decide for the individual with a disability, which can lead to choices being made about the individual without their consent or against their wishes.

The individual with a disability experiences “civil death”, or loss of rights and legal personhood. The day-to-day decisions others take for granted such as personal healthcare, finances, marriage, are no longer decisions they can make without permission and approval of the guardian.

Individuals under guardianship also lose the “dignity of risk,” or the ability to make mistakes and learn from them. They are also less likely to live in their own homes, have community jobs, or have friends than those not under guardianship. This shows the implications of not being able to have autonomy of choice have serious daily impacts on the lives of adults with intellectual and/or developmental disabilities (I/DD).

Increase in Supported Decision-Making



While SDM has been popular across the world, particularly in Canada and with the United Nations, the United States is just beginning to implement SDM initiatives. As of August 2019, nine states have passed SDM legislation, and SDM is endorsed by the American Bar Association.

Why Use Supported Decision-Making?

Many individuals with disabilities may need assistance making decisions about healthcare, finances, and other typical life concerns, but they do not necessarily need a guardian. They might instead need specific supporters that will **help them reach their own decisions**. This can also help build decision-making proficiency, as the individual will gain confidence and practice while knowing they have supports if needed.



Who Are Supporters?

Supporters can family, friends, coworkers, or anyone the individual trusts and is comfortable with. The most important aspect of the support network is that the **individual selects the supports**, as autonomy and respect of the individual's will and preferences is essential to the SDM model. While using natural or informal supports is part of the decision-making process, that does not preclude using formal supports, such as lawyers, doctors, or experts, or written materials such as manuals, handbooks and others.



The Role of a Supporter

It is crucial that supporters respect the will of the individual, even when it differs from the will of the support network, as the goal of SDM is to preserve dignity of risk. An individual's autonomy can be severely damaged if a supporter inserts their own agenda into the decision-making process, so supporters should be mindful of their role. Supporters often sign a Decision-Making Agreement, which identifies the areas of decision with which the individual will be consulting a specific supporter. The agreement is a shareable document that indicates the individual can make their own decisions and has the necessary support to do so.

It is often the case that not every supporter will be involved in each decision the focus person makes. Instead, there will often be certain people the individual consults depending on the decision, and they may not be working with a team. If an individual makes someone a supporter but does not feel that supporter is helping them with their goals, the individual is not obligated to continue utilizing that supporter.

SDM formalizes natural supports by explicitly emphasizing the set of decisions with which the focus individual (or decision-maker) seeks assistance—for example, helping an individual who may have a limited social circle, or who is isolated, craft a support network.

The Dignity of Risk and Supported-Decision Making Agreements

People make poor decisions every day, and their autonomy around making their own choices is not compromised because of it. The same should be true for individuals using SDM. Just because a choice is made with less-than-optimal results, the individual should be allowed to learn from their choices and use that information to gain new perspectives on future decisions. If someone makes choices that seem unwise, they should be given supports to help them in the future instead of having their ability to make choices removed.

SDM agreements are not legally binding, do not mean the decision maker can only consult those people listed in the agreement, and do not obligate the decision maker to their support network. The supporter is not obligated to agree with the individual, but they are obligated to respect their wishes. Finally, SDM agreements do not obligate third parties, and the agreement **does not authorize others to make decisions for the individual.**



Michael Kendrick, PhD is the Director of Center for Public Representation Supported Decision-Making Initiatives. These initiatives consist of five demonstration projects on supported decision-making in Massachusetts and one in Georgia in cooperation with the Georgia Advocacy Office, as well as a technical assistance center for Massachusetts. He has spent the last twenty years in international consulting and prior to that was the Assistant Commissioner for the Massachusetts Developmental Services Department, Director of the Institute for Leadership and Community Development and consultant to the International Initiative On Disability Leadership.