



Office of Developmental Primary Care

Improving outcomes for people with developmental disabilities

Supported Health Care Decision-Making for Parents and Supporters

- **Making decisions with support helps people with disabilities control their lives.**
- **The opportunity to make decisions improves skills, safety, and independence.**
- **People with disabilities are responsible for the outcomes of their decisions.**
- **Supported Health Care Decision-Making Agreements help define support roles and responsibilities.**

What is Supported Health Care Decision-Making?

If you are a parent or supporter for a person with a disability, you may be worried about who will help if you are no longer able to provide the same level of dedicated support. Supported Health Care Decision-Making empowers adults with disabilities to name supporters to help them make medical decisions so they can be directly involved in their own care. It is based on the understanding that people with disabilities have the same right as everyone else to direct their own lives. Research shows that people with disabilities who have more control over their lives have better life outcomes, including improved health, welfare, and independence.

In Supported Decision-Making, individuals choose supporters to help them understand the situations they face, and choices they can make. Supporters then provide the type and amount of help the person chooses. The person remains the final decision-maker.

With the person's consent, a supporter can assist them with a variety of tasks such as, communicating with doctors, following treatment plans, understanding procedures, or maintaining a healthy lifestyle. The amount and type of support provided will vary from person to person. For example, some people with disabilities may want support communicating with a specialist, but feel confident talking to their primary care provider. Others may need more intensive support. Many families already practice Supported Health Care Decision-Making principles when assisting a loved one, even if they do not call it by that name.

Who Can and Cannot Serve as a Supporter

When people with disabilities choose to receive this type of support, they can identify one or more trusted supporters. Supporters can be family members, friends, professionals, or people who assist

them in the community. Supporters can be paid or unpaid. They must be willing and able to help. They must also accept the individual's final decision-making authority and responsibility. Thus, while supporters may share their personal opinions, they do not make decisions.

Certain conflicts of interest may interfere with this role. A person's health care provider, anyone involved in a legal action against the individual, or an employee of a person's residential home should not serve as a supporter.

Supported Healthcare Decision-Making Agreements

Advocates of Supported Health Care Decision-Making have drafted model legislation that describes Supported Health Care Decision-Making Agreements. These agreements define individual levels of support, and identify who can help meet these needs. They are voluntary and optional. Agreements are for people with disabilities who have the capacity to make at least some of their own decisions. This capacity is often overlooked because of how people learn or communicate. Sometimes, the more decisions people make for themselves, the more experience and skills they develop, and the less support they need.

This legislation would give supporters a legal status. In many cases, this would reduce the need for Power of Attorney, conservatorship, and guardianship. These take away a person's right to make decisions. Supported Health Care Decision-Making Agreements would be simple to implement with a notary, and easy to modify as needed.

How will Supported Health Care Decision-Making Agreements Help Families?

Supported Health Care Decision-Making agreements help people manage their care and broaden their circle of support. By encouraging the use of Supported Decision-Making, you:

- Empower people with disabilities to take an active role in their own health care
- Help the person with a disability learn to make decisions with the support of others
- Ensure your loved one has the support they need, even if you are unable to fulfill this role
- Establish healthy boundaries between you and the person you support

Safeguards Included in the Agreements

Supported Health Care Decision-Making Agreements include many safeguards. Making an informed decision means understanding the risks and benefits of each option; weighing them against each other; and communicating a choice. Many people who do not have the capacity to make informed decisions independently can do so with support. Medical professionals are not required to accept informed consent if they feel it was not explained adequately or coerced. They are protected if they accept a valid decision which was made with support. Most importantly, the person with the disability has the power to change or cancel an agreement at any time, for any reason.

For a video explaining Supported Health Care Decision-Making, please visit [SDM Video for Parents and Supporters](#). For more information on the [Model Legislation](#) and a [Questions and Answers Resource](#), please visit: <http://autisticadvocacy.org/2014/07/asan-unveils-toolkit-for-advocates-on-health-care-and-the-transition-to-adulthood/>