As a parent or caregiver of a person with a disability, you probably face a variety of challenges when accessing health care services. Challenges can come in the form of architectural barriers or medical professionals unfamiliar with the specific needs and communication methods of your loved one.

Currently there are several recognized ways you can choose to support the person you are helping. A Power of Attorney allows you to make medical decisions on their behalf when they are unable to make their wishes known.

A conservatorship or a guardianship allows you full decision-making authority in certain areas. These legal options are often complex, costly, and hard to reverse. Typically, they do not give the person a say about the people who support them or how they receive this support.

Many families are investigating another option referred to as Supported Health Care Decision Making. This option is based on the philosophy that people with disabilities should be able to receive the help they need while still maintaining some control over their lives.

Supported Decision Making can be less expensive and easier to facilitate than the other alternatives.

When your loved one chooses to name you as a trusted supporter, you can access medical information on their behalf and provide many other types of support, including assistance communicating with medical staff and following a treatment plan.

Proposed model legislation hopes to take this a step further by developing Supported Decision-Making Agreements. These formal agreements would be easy to implement and fully acknowledged by the medical community. They would be completely optional. With your help, your loved one could choose to name multiple trusted supporters.

By encouraging him or her to broaden their circle of support, you will be:

- Sharing the responsibility of helping them make decisions and comply with treatment plans
- Establishing healthy boundaries between you and the person with the disability
- Empowering them to take a more active role in their own health care
- Helping them learn to make decisions with the support of others
- Ensuring they have the support they need even when you are unable to fulfill this role
These agreements will include many safeguards to protect the safety and well-being of the individual being supported. Health care professionals are not required to accept informed consent if they feel the patient was coerced or did not receive an adequate explanation of a procedure.

Filling out a Health Passport is one way a new supporter can learn about their medical history and personal preferences. It can be given to health care professionals during appointments or hospital visits. This document, along with a Supported Decision Making Agreement, can be included in a person’s plan of care.

For a video explaining Supported Health Care Decision-Making, please visit: SDM Video for Parents and Supporters


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