



Office of Developmental Primary Care

Improving outcomes for people with developmental disabilities

Supported Health Care Decision-Making for Professionals and Policy Makers

- **Supported Health Care Decision-Making allows adults with disabilities to name trusted supporters to help them manage their health care and understand choices.**
- **The person with the disability retains the ability to make all final health care decisions.**

Like everyone, people with disabilities may need support to access medical care. They may need help making appointments; communicating, making informed consent decisions, and following through on their plan of care. Some people receive this support informally from family members or friends. Others may receive support from service providers or care coordinators.

What is Supported Health Care Decision-Making?

Supported Health Care Decision-Making is an emerging practice that empowers people with disabilities to name one or more trusted supporters to help them manage their health care. This acknowledges that people with disabilities should have the same right to make health care choices as everyone else. They should also have the right to receive the help they want and need from the supporter of their choice.

Supported Health Care Decision-Making recognizes that people can manage their own care with proper support even if they cannot do so independently. People with disabilities should have the same right to make decisions about their body and their healthcare as anyone else.

Supporters can be family members, friends, professionals, or people who assist them in the community who can be paid or unpaid. 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.

Clinicians already have experience working with other types of supporters such as translators and cultural brokers. Supporters play the same role for people with disabilities. They help them understand their situations and choices, so they can make their own well-informed decisions.

Drawbacks of Guardianship/Conservatorship and other Structures

Sometimes health care providers have concerns about medical-legal liability when obtaining informed consent from patients with disabilities. Providers may not have a sufficient amount of time or the practical experience to engage in the communication methods or learning styles that work best for the patient. When these situations occur, the obstacles to care are often managed by finding alternate decision-makers such as guardians, conservators, or Powers of Attorney. Guardianship and conservatorship can be complex, costly, and hard to reverse. Worse, they can take away the person's right to make life choices. Too often, the person has no say in who will make their decisions. Although Powers of Attorney are cheaper and easier to reverse, they also result in transferring the right to make decisions from the person with a disability to a friend or family member.

Supported Health Care Decision-Making Agreements

Proponents of Supported Decision-Making have developed model agreements to formalize the support relationship in the health care setting. These agreements enable patients, supporters, and health care providers to work together, to share confidential information, develop plans of care, help the patient understand his or her situation and choices, and act on decisions the patient makes with support. Agreements are inexpensive for patients to implement. They are flexible, efficient, and clarify roles and responsibilities.

Benefits for Clinicians and Patients

A supporter makes a commitment to help the patient understand information and treatment options using communication methods and styles that work best for them. Supporters can also provide other types of personalized support including physical assistance during an appointment and help following treatment plans. Supporters serve as valuable assets to clinicians as well. Supporters can help physicians overcome communication challenges, compile a detailed medical history, and improve health care coordination. However, clinicians should continue to communicate primarily with their patients. Supporters can assist both parties as needed or requested by a patient. This teamwork ensures that the patient is respected and receives the highest level of culturally competent medical care. Under these agreements, the person with the disability retains the right to make ultimate decisions regarding their body and health.

Safeguards and Protections

This model legislation would provide legal recognition to supporters. It includes protections for clinicians who share confidential information with supporters. It also protects clinicians who act on informed decisions made or communicated with support. Medical 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. In addition, the patient has the power to change or cancel each agreement at any time, for any reason.

For a video explaining Supported Health Care Decision-Making Agreements, please visit: [SDM Video for Professionals and Policy Makers](#). 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/>