



Office of Developmental Primary Care

Improving outcomes for people with developmental disabilities

Video Script: Supported Health Care Decision-Making for Professionals and Policy Makers

People with disabilities face a variety of challenges when accessing the healthcare system. Common architectural barriers can lead to health disparities. Clinicians frequently have difficulty determining the capacity of patients with disabilities. The roles and legal authority of supporters are often difficult to ascertain when trying to obtain consent.

Currently, there are several legally sanctioned ways a person with a disability can receive support when making important medical decisions.

The person can choose a Power of Attorney. This power allows one person to make medical decisions on their behalf when they are unable to make their own wishes known.

A conservatorship or a guardianship transfers full medical decision-making power to another individual. It represents a heavy, long-term responsibility.

Conservatorship and guardianship are often complex, costly, and hard to reverse. Typically, they do not give the person with a disability a say in whom supports them or how they receive this support.

Samantha Crane: "When health providers don't recognize patients' capacity to make health care decisions with support, families may feel forced to seek guardianship. Under guardianship, there is no guarantee that he or she will continue to get health care support from someone they trust. If a trusted family member stops being able to serve as guardian, the court often appoints a "professional guardian" - often someone who does not have any personal knowledge of the individual."

An emerging philosophy known as Supported Health Care Decision-Making is based on the idea that people with disabilities should be able to receive the help they need while still maintaining control over their lives.

This philosophy acknowledges that people with disabilities have the right to receive support to make decisions about their health regardless of their diagnosis or functional abilities. Many people that are unable to make or communicate their decisions independently can do so with the proper support.

Proposed model legislation hopes to take this a step further by developing Supported Decision-Making (SDM) Agreements. In the future, these legally binding forms will allow a person with a

disability to name as many trusted supporters as they wish.

SDM Agreements will help clinicians clarify the roles and expectations of both patients and supporters. The agreements will provide formal protection for clinicians, supporters, and people with disabilities under HIPAA.

Supporters can help the person understand their medical options, but the individual still retains the right to make decisions about a treatment plan that works for them. Physicians can choose to work with patients and their supporters when obtaining informed consent. Supporters will also be able to access medical records and help patients follow treatment plans.

An individual supporter often plays a vital role in helping the physician overcome communication challenges, compile a detailed medical history, and improve health care coordination.

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

For more information on the [Model Legislation](#) and a [Questions and Answers Resource](#), visit: <http://autisticadvocacy.org/2014/07/asan-unveils-toolkit-for-advocates-on-health-care-and-the-transition-to-adulthood/>

Video Credits

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