

Questions and Answers on the Model Supported Health Care Decision-Making Agreement Act

The Autistic Self-Advocacy Network developed this model legislation to help support supported health care decision-making arrangements. These arrangements allow people with disabilities to name a support person to help them make health care decisions, while ensuring that the person with a disability retains the ability to make all final decisions about his or her own health care.

We wrote this legislation in response to problems that many people with intellectual and developmental disabilities (ID/DD) face when trying to manage their own health care. Some doctors will not respect decisions that people with ID/DD make for themselves, based on the assumption that people with ID/DD cannot provide “informed consent” to medical treatments ranging from medication to surgery. Other doctors will not discuss health care with, or provide information, to the people who support individuals with ID/DD. Although some people with disabilities are able to sign forms, known as health care proxies or health care powers of attorney, which allow a trusted person to make medical decisions on their behalf, some doctors and judges will not respect these forms if the person who signed them had ID/DD.

Supported Health Care Decision-Making Agreements allow people with disabilities to name trusted supporters to help them manage their health care and make decisions. Supporters are allowed to talk to doctors and receive information about individuals’ health status and treatment. Doctors are allowed to act on decisions made with the help of a supporter, even if the person with a disability would not have been able to give informed consent without support.

Who could be a supporter?

Under this legislation, a person with a disability could name any trusted individual as a supporter, as long as the individual is willing to act as a supporter and does not have a conflict of interest. Supporters could be parents, siblings, friends, spouses, romantic partners, or even people who provide home and community-based services to people with disabilities living in their own homes.

Individuals could name only one person as a supporter, or they could name many people as supporters.

What is a conflict of interest?

Some situations that might influence a supporter’s judgment would be considered “conflicts of interest.” Someone with a conflict of interest cannot act as a supporter. A person who is involved in a lawsuit against a person with a disability (including a contested petition for guardianship), staff at an institution where the person with a disability lives, and the doctor or other health care provider of a person with a disability (other than providers of home and community-based services), all would be considered to have conflicts of interest. People who have committed abuse or neglect of the person with a disability also could not act as supporters.



Who could sign a supported health care decision-making agreement?

Any person with a disability who wants a supporter could sign a supported health care decision-making agreement – even someone who needs significant assistance to do so. The legislation would allow people to enter into a supported health care decision-making agreement even if a court would have considered them unable to make their own health care decisions or to sign valid contracts without support.

What could a supporter do?

Supporters could help people with disabilities with a variety of health care-related activities. They would be allowed to help gather health and treatment information, make appointments, and help people with disabilities speak to their doctors or health providers. They could make recommendations about which health care decisions to make. They would also be allowed to help people with disabilities process information, make health care decisions, and follow a treatment plan.

What couldn't a supporter do?

Supporters could not make final health care decisions in place of a person with a disability. They could only help a person with a disability understand his or her options and make recommendations. Other documents, such as health care proxies or medical powers of attorney, could be used to name someone to make health care decisions in situations when the individual could not make them him- or herself (such as medical emergencies in which the individual is unconscious).

Supporters also could not force or coerce people with disabilities into making certain health care decisions. Coercion may include, for example, threatening to petition for guardianship or threats of interference with the person's housing situation, livelihood, or access to benefits. It would not include minor incentives aimed at encouraging healthy decisions, such as reassuring a person who is afraid of a shot by offering to buy him or her ice cream afterwards.

What if I don't like my health care supporter?

You would be able to cancel your health care decision-making agreement at any time.

Would doctors have to respect decisions that they do not think are informed?

Health care providers usually must obtain a patient's informed consent before providing medical treatment. This law would allow doctors to provide treatment to people with disabilities who might need support in order to provide informed consent. A doctor would not, however, have to provide treatment if he or she believes that the patient and supporter have not been given all the necessary information to make a truly informed decision, if he or she believes that the supporter is withholding information from the patient, or if he or she believes that the supporter has coerced the patient into making a particular decision.

Health care providers should not refuse treatment solely on the basis of the fact that the person has a disability, or refuse to treat individuals with disabilities who do not have legal guardians. Such policies may amount to discrimination under the Americans with Disabilities Act.

Would doctors still be required to provide auxiliary aids and services, such as communication assistance or sign language interpretation?

Yes. Although supporters could help people with disabilities communicate with their doctors, the Americans with Disabilities Act would still require doctors to provide certain kinds of communication services as well. These may include sign language interpretation or communication in alternative formats such as writing or pictures. Doctors would have to provide these services when requested, even if the patient also has a supporter.

Would doctors have to allow supporters to accompany people with disabilities in medical settings, such as emergency rooms?

Health care providers sometimes decide not to allow family members and supporters to accompany a person into an emergency room, operating room, or other similar setting. For example, a doctor may not allow a supporter into a controlled, sterile setting if the supporter appears to be sick. A doctor may also need to ask a person questions about suspected domestic abuse outside the presence of anyone who may have committed the abuse. This law would not prevent doctors from making this sort of medical judgment. However, the Americans with Disabilities Act requires health care professionals to make reasonable modifications to their usual policies in order to allow people to be accompanied by their supporters.

How would the legislation prevent abuse or neglect by supporters?

This legislation would include a variety of safeguards. Supported health care decision-making agreements would have to be signed by the individual and co-signed by two witnesses in the presence of a notary. The presence of a notary helps protect against agreements that are coerced or fraudulent. Additionally, health care providers who suspected abuse or neglect would not be required to honor the support agreement and would instead be encouraged (or, in some states, required) to report their suspicions to the department of adult protective services.

Most importantly, people with disabilities would keep the authority to make their own final decisions on health care and would be able to cancel the supported decision-making agreement at any time. In contrast, when a court appoints a guardian for a person with a disability for the purposes of making health care decisions, the person with a disability loses the authority to make his or her own health care decisions and cannot cancel the guardianship relationship without approval by a court.

Who would be allowed to act as a witness to the supported health care decision-making agreement?

A witness must know the person with a disability and must be able to communicate using that person's preferred form of communication, which may include speech, sign language, typing, or other alternative forms of communication. The same conflict of interest restrictions that apply to supporters also apply to witnesses.

Would supported health care decision-making agreements require court approval?

In general, no. Some states may require court approval for these agreements in special situations (such as when the person with a disability is under guardianship, and the guardian is not willing to co-sign the agreement).