Using Supported Decision Making (SDM) in Healthcare Settings

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California State Council on Developmental Disabilities

Learning goals

- Review concerns about SDM's use in healthcare settings
- Learn about Tools/Companion Documents for Health Care
- Become familiar with planning to use supported decision-making in healthcare settings.

We all need help sometimes…

Most of us get support when making decisions, especially medical decisions.

Some make decisions themselves (with or without support), some ask others to make decisions for them, and some are interdependent decision–makers, making decisions together with friends or family members.

What is Supported Decision Making for People with Disabilities?

A law called AB 1663 enables **people with disabilities (PWD)** to choose to use or formalize decision-making supports for themselves in **supported decision-making or SDM**.

In SDM, the PWD maintains their decision-making power, chooses supporters to help with decision-making, and makes the final decision.

PWD can choose to use SDM in all settings, including healthcare.

PWD can use supported decision making in healthcare settings

Attend	If you need to see a doctor or nurse, your supporter can go with you to the appointment.
Focus	Supporters can help the medical team understand that you are the decision-maker and the focus should be on you.
Remember	Supporters can help you remember your symptoms and what you want to talk to your medical team about.

PWD can use supported decision-making in healthcare settings

Communicate	Supporters can help you communicate with your medical team.
Understand	Supporters can assist you in understanding what a doctor or nurse tells you.
Assist	Supporters can assist you in making your medical care decisions.

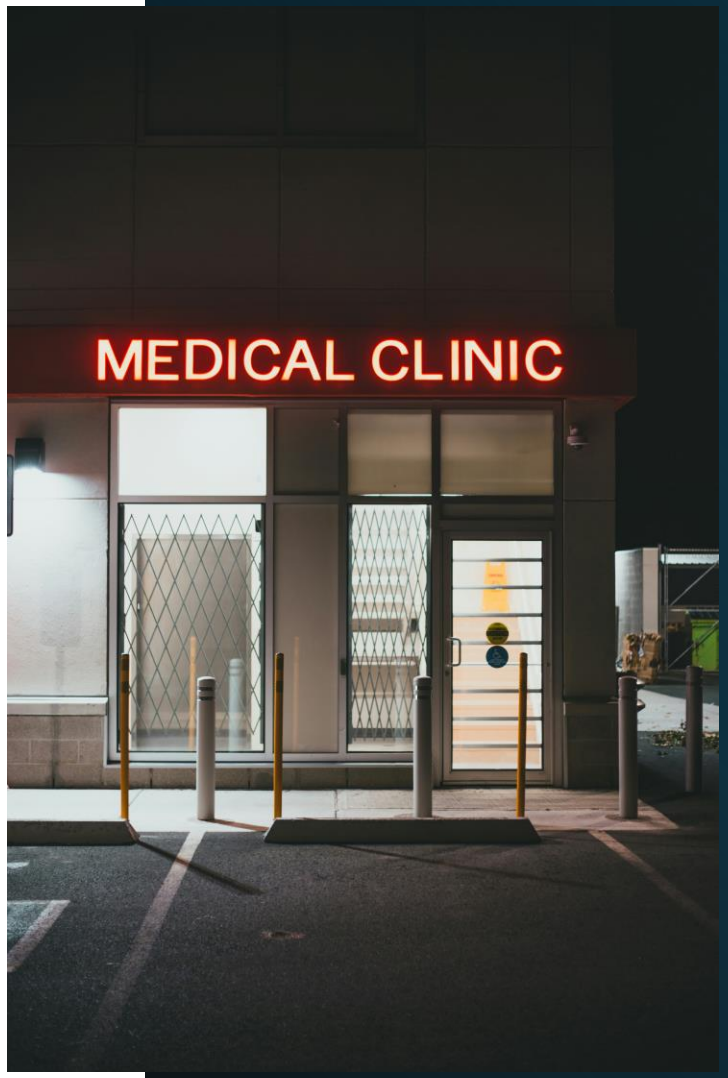
CONCERNS ABOUT SDM in HEALTHCARE SETTINGS

Concerns about Using SDM in Healthcare Settings

- PWD may need more time for the visit in order to be able to use SDM, and that may not be available in a short visit.
- The decisions that need to be made can be high-risk and may have short time lines.
- Medical practitioners may require documentation of the supporters' roles.
- PWD have reported that they can feel marginalized in healthcare settings when they bring in supporters, as the focus of the medical practitioners can shift to the supporter rather than the patient.

Concerns about Using SDM in Healthcare Settings

- Finally, there may be situations where people may not be able to easily communicate their needs/priorities and preferences (such as being unconscious or overcome with anxiety/panic) and worry that SDM cannot work in such circumstances.



Using SDM in healthcare settings can be easier (and some of the concerns eased) if the decision-maker and their supporters plan ahead. Specific documents or tools can assist, as well as planning with supporters on how and when to use SDM.

In addition, the decision-maker may want to specify situations where they ask someone else to make decisions for them, such as in emergency medical situations.

TOOLS/COMPANION DOCUMENTS

Permission to Exchange Information (PEI) or Release of Information (ROI)

https://supporteddecisions.org/getting-started-with-supported-decision-making/sdm-and-health-care-decisions/

Having access to information about a health care decision may be essential for a supporter to assist a person with making a decision.

The Health Insurance Portability and Accountability Act (HIPAA) is a federal law that prevents your health care providers from sharing information about someone without consent.

The individual with the disability using SDM may need to sign a release of information if he or she wants a supporter to access protected health information.

Some health care providers/systems can require a particular form be executed. It may also be possible to use a standard HIPAA compliant release.

Authorized Representative/Personal Representative

An authorized or personal representative is someone you choose to act on your behalf. This person will have access to all of your personal health information. You may also allow them to make health care decisions for you.

Managed Care Plans often have forms that can be completed for authorized representative often just with a signature or signature stamp. Some organizations may require witnesses or notarization.

Durable Power of Attorney for Health Care

A Durable Power of Attorney for Health Care is a legal document that allows you to assign someone else to make decisions about your health care if you become unable to do so yourself. It provides that person (called your agent) with instructions regarding the types of medical treatment you prefer.

This document should be honored across medical settings.

Supported Decision Making Agreement (SDMA)

- An SDMA can be signed by the decision maker, but is not necessary for SDM.
- An SDMA specifies the roles of the supporters and their access to information.
- It can also be signed by supporters confirming that they understand their role.
- It can include backup plans if the supporters are unavailable or if the decision-maker is unable to communicate their needs or choices.

PLANNING FOR SDM

Whether or not a person chooses to use companion agreements or an SDMA, planning for the use of SDM in healthcare settings can improve the decision-making process for people with disabilities (PWD).

Initial questions to consider when planning

- Who are the PWD's long-term medical team members (e.g., Primary Care Provider (PCP), nurse practitioner, counselors/therapists, etc.)? Which supporter(s) will assist in specific situations? What information do they need to have to be effective?
- How much support does the individual want for health care decisions? For example, do they need supporters to attend appointments, have independent conversations with providers, or access medical records?

Continued: Questions to consider

- Is there any information or handouts that the PWD wants to share with the medical team about SDM or the importance of focusing on the patient and not the supporters?

- Do supporters need copies of the patient's insurance or ID card and any other relevant information?

Planning for Individual Medical Visits

1.Discuss the purpose of the appointment:

- Is it a routine checkup or is there a specific issue to be discussed?
- What does the decision-maker want out of the appointment.
- It is important that expectations are clear, particularly given that a health care provider might have limited time.

2. Determine who will attend the appointment and what everyone is responsible for during the appointment.

Adapted from https://supporteddecisions.org/getting-started-with-supported-decision-making/sdm-and-health-care-decisions/

Planning for Individual Medical Visits

3. Determine what role the individual and the supporter will play at the appointment.

Questions to consider:

- If a supporter is attending the meeting, will that supporter communicate with other supporters after the meeting? Can that supporter contact the health care provider after the meeting with follow-up questions, and are releases in place to allow this communication?
- Who will speak to the health care provider? Who will ask questions of the provider?
- Who will record what occurs in the appointment? Who will record what items need follow-up and what questions are unresolved?
- If the individual needs accommodations (e.g. more time to respond to a question, information presented in a particular format), who will communicate that need in the appointment (or in advance)?

Planning for Individual Medical Visits

4. Understand that you may need to provide information and education around SDM

Many medical personnel may be unfamiliar with the concept of SDM. The process will be individualized, and the following questions can guide the discussion:

- When will you explain SDM to the provider? Before the appointment? Is it possible to have a phone call or mail or email written materials?
- Who will explain the concept of SDM? How will you explain the role of the supporter? How will you communicate the values of SDM?
- If you choose to provide written materials, what will you provide?

5. Make sure you have all the needed documents (i.e. , permission to exchange information, information on SDM or SDMA).

Planning for Emergencies

- In an emergency, what information should supporters have? What is their role then? How would they be contacted?
- Is there an emergency plan? Do they know what hospital to go to and when? Do they understand what the preferences the person has for their health care?
- Should one or more supporters be an authorized representative or hold durable medical power of attorney? How will copies of any documentation be available in an emergency?

ANOTHER OPTION: AB 2338 Next of Kin Law

Under AB 2338 “a health care provider or a designee of the health care facility caring for the patient may choose a surrogate to make health care decisions on the patient’s behalf, as appropriate in the given situation.”

The exact language in PC §4712 is as follows: “The patient’s surrogate shall be an adult who has demonstrated special care and concern for the patient, is familiar with the patient’s personal values and beliefs to the extent known, and is reasonably available and willing to serve.

The idea behind the next-of-kin law, proponents say, is to empower representatives to advocate for patients rather than allow a hospital to make medical decisions, which can be influenced by cost, bed space, or insurance pressures.

AB 2338 Next of Kin Law

The list includes spouses or domestic partners, siblings, adult children and grandchildren, parents, and an adult relative or close friend.

Under this law, the patient can let their health care team know who they would want to make decisions for them.

The assignment of decision making can last no more than 60 days.

Whether a person decides to use independent, supported or shared decision-making is their decision. PWD chooses who they want to support them and the type of support they want.

They may find that certain documents, like a permission to exchange information or an SDMA, may make their process clearer to medical personnel.

Making a plan for medical visits (as well as for emergency situations) can help the decision-maker meet their needs and priorities.

QUESTIONS ?

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