

Partners in Health:

Implementing Supported Healthcare
Decision-Making for Users of Augmentative
and Alternative Communication in California



Office of Developmental Primary Care
Improving health outcomes for people with developmental disabilities

This guide is funded by:
Ability Central Philanthropy and the WITH Foundation



Published by:

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Plain Language Summary



People are healthiest when they:

- understand their conditions and treatments
- share in making decisions with their healthcare providers
- receive support from trusted helpers, and
- retain as much choice and control as possible.

In Supported Healthcare Decision-Making, you choose who supports you. You choose the type of support you want. You also make your own decisions. Your helper is there to support you.

Getting healthcare is complex. Many people with and without disabilities feel more in control when they bring supporters with them to appointments or to the hospital. People with disabilities may want to choose a trusted supporter to go to appointments. You can choose who you want to support you and the type of support you want.

If speech is not a reliable way for you to communicate, you may ask for accommodations and use the form of communication that works best for you. Supporters can help with communication. If desired, they can also help you:

- share your symptoms
- ask questions
- understand your choices
- tell the healthcare provider what treatment you choose.

Supporters can also help with other things if you want. For example, you can ask supporters to help you make appointments. They can help you get undressed and on the exam table. They can pick up your medicines.

You can sign an agreement. An agreement can help you, your healthcare provider, and your supporter know what type of help you want. It can include directions on how and when you want help. It can also tell your healthcare provider what to do if your supporter isn't able to help you.

Sometimes people are too sick or overwhelmed to make decisions. It is best if you can choose for yourself. But if you cannot make a decision, even with support, you can pick someone to make the decision for you. In the future, when you are able, you can make your own decisions. The person you choose is called a Power of Attorney. You can also write down what you would like to happen when you are very elderly or sick and can't be cured. Those instructions can be written on a paper called an Advance Directive. If you need help creating documents, you can get help from your Regional Center or State Council on Developmental Disabilities.

Families often worry about what will happen when they can no longer provide help like they once did. Supported Healthcare Decision-Making is a plan for support. The more you know about your health, the better choices you can make. The more you communicate directly with your healthcare provider, the better they will know you. They will understand your condition more, and give you better advice. The more times you make your own decisions, the better prepared you will be.



Supported Healthcare Decision-Making is a process where people with disabilities can name trusted supporters. Supporters can assist with communicating, accessing healthcare services, making decisions, and implementing healthcare plans.

Introduction

Background/Purpose

This consensus guide provides practical advice about implementing Supported Decision-Making in healthcare settings. It is based on input from healthcare providers, disability advocates, people with disabilities, and their supporters. It is not legal advice. Supported Healthcare Decision-Making is particularly useful for people with disabilities who require coordinated services and supports. This includes those with developmental disabilities. It also includes those for whom speech is not a reliable way to communicate. Communication is the foundation of patient care.

Definitions

Supported Healthcare Decision-Making. Supported Healthcare Decision-Making is a process where people with disabilities can name trusted supporters to assist them with communicating, accessing healthcare services, making decisions, and implementing their healthcare plan. Supported Healthcare Decision-Making:

- clarifies roles and responsibilities
- supports accountability and healthy boundaries
- ensures patients with disabilities have the support needed to partner effectively with healthcare providers
- prepares for when family members may be unable to provide the same level of support that they once did
- makes care more efficient
- avoids unnecessary expense and interference of the judicial system in private healthcare decisions

- may reduce fear of liability when understanding is unclear
- protects safety and civil rights

Augmentative and Alternative Communication. Navigating the healthcare system is challenging for everyone. However, it is particularly difficult for the estimated five million Americans for whom speech is not a reliable way to communicate. Speech is a complex motor skill. People with disabilities which impact speech have a full range of cognitive strengths and challenges. No assumptions can be made about a person's mental capacity based on how they communicate. Most people for whom speech is not a reliable form of communication use one or more forms of Augmentative and Alternative Communication (AAC). People who use AAC may also use speech at times, with some communication partners, in some environments, or for some purposes.

AAC includes all of the ways we share our ideas and feelings without talking. There are two main types of AAC: (1) unaided systems and (2) aided systems. (1) *Unaided Systems:* People do not need anything but their own body, e.g. using gestures, body language, facial expressions, and sign language. (2) *Aided Systems:* Uses some sort of tool or device, ranging from pen and paper or pointing to letters, words, or pictures on a board (basic aided systems) to selecting letters or pictures on a computer screen that speaks for you (high-tech aided system). They may be carried by the user, attached to their wheelchair, or held by a supporter. People use many different body parts and methods to activate these devices. Other AAC users have supporters or assistants who understand and can "revoice" their communication. Most people with and without speech disabilities use a combination of methods to communicate.

Process for Developing the Guide

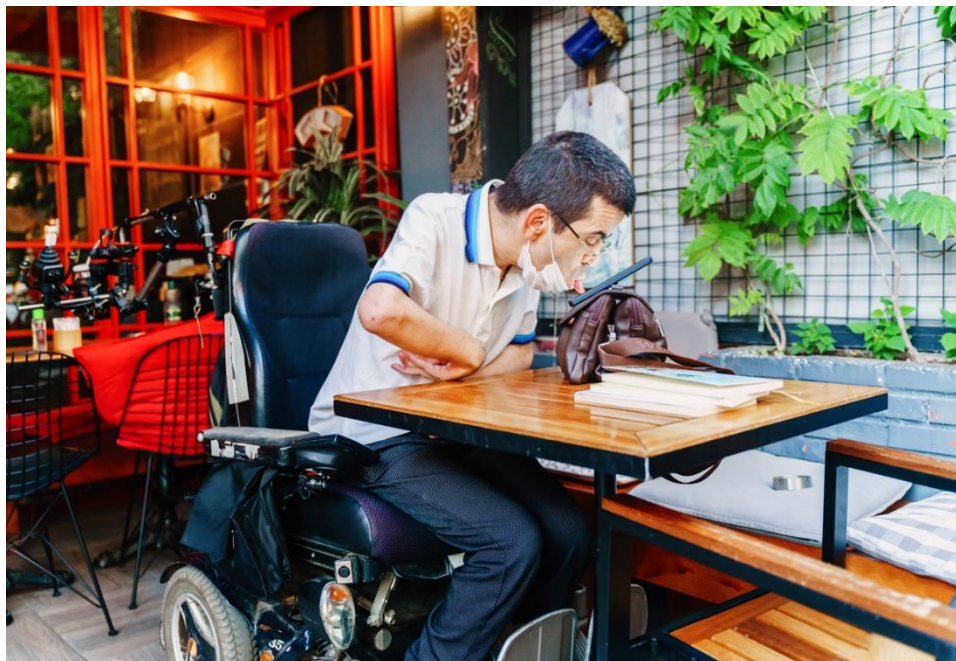
The Office of Developmental Primary Care is a program in the Department of Family and Community Medicine at the University of California San Francisco. We have fifteen years of experience providing primary care and consultation to people with complex disabilities. Most of the patients we serve are not conserved. Many have significant cognitive and communication challenges. This guide is based, in part, on our experience working within a Supported Healthcare Decision-Making framework.

In addition, we held two virtual discussion groups in the summer of 2020. We wanted to learn how Supported Decision-Making (SDM) applies to Augmentative and Alternative Communication users and their supporters in healthcare settings. Our goal for both groups was to understand what worked and what didn't.

The first group consisted of eight, active AAC users from Northern California. The members of this group represented a range of ages, genders, ethnicities, disabilities, types of communication, and decision-making abilities. We asked their communication supporters to remain in the background as much as possible. We provided accommodations to facilitate communication. For instance, a one-to-one interview was held with a participant who needed more support. The discussion group questions were sent in advance. The discussion was closed captioned. Also, a dedicated facilitator provided technical support and monitored the chat feature. A few participants submitted their responses in writing.

The second group consisted of nine parents and paid supporters of people for whom speech is unreliable. Participants were from Northern and Southern California. These group members represented a range of ages, genders, ethnicities, unpaid (parents) and paid supporters of both un-conserved and conserved adults. The users of AAC they supported fell along a broad spectrum of ages and abilities. Not all invited participants could attend the discussion group. Other arrangements were made to collect their responses. Like the first group, they were asked questions about how they already used Supported Healthcare Decision-Making principles. In general, this group had many concerns and questions about implementation.

In addition to the two focus groups, a group of Thought Leaders representing organizations working on Supported Decision-Making met three times to discuss issues in how it should be implemented in California based on current organizations and laws. The group worked to achieve a consensus on as many concerns as possible.



What AAC Users and their Supporters Said

The healthcare system is challenging to navigate as an AAC user. In our AAC user and Supporter discussion groups, we learned that many are unfamiliar with the term, Supported Healthcare Decision-Making. Parents want their children to be independent and make their own decisions but worry they may not be able to without support. Discussion group participants were not always familiar with the options or felt pressure to pursue conservatorship. Healthcare settings are particularly difficult for making decisions, and more support is needed. A formal Supported Healthcare Decision-Making Agreement may address certain anxieties, but group members felt that they need guidance on what would go into a formal agreement. Supporters want checks and balances included in any agreement.

Below are key themes that emerged during our discussions.

What AAC Users and Their Supporters Said:

Theme A: Perceived Benefits and Uses of Supported Healthcare Decision-Making

1. Supporters enable and empower AAC users to make choices about their healthcare.

Quotes:

“Just because you get support doesn’t make your choice any less your choice.”

“When they find out that people aren't conserved, it's like what? They're not conserved? But they need to be conserved. And it's like, no.”

2. Supported Healthcare Decision-Making is a legal way of giving people with disabilities more control over their lives. It’s a way to get support and maintain decision-making authority.

Quotes:

“Why aren’t supports the norm for people with disabilities?”

“Supported Healthcare Decision-Making shifts some of the responsibility to the doctor to talk to you instead of just your support person.”

“This could evolve into a new profession – to guide and teach people how to step back and help people learn to make decisions.”

3. Joint decisions are made between supporters and AAC users. AAC users’ decisions are honored even when there is disagreement. Many participants used trusted family members to provide communication, logistical, and decision-making support.

Quote:

“My disability and side effects make my health complicated, so it’s useful to have a second set of eyes to track changes.”

Theme B: Challenges Using Supporters to Communicate with Clinicians

1. Clinicians frequently become impatient with slow communication.

Quotes:

“They’d rather get a quick verbal response from a supporter, so it helps to have trusted supporters to communicate your health decisions.”

“Being ignored is very frustrating especially when it’s a doctor.”

2. Supporters are there to assist, but doctors should speak directly to their patients.

Quotes:

“Doctors should prioritize listening to their patients with disabilities.”

“AAC users cannot and should not be penalized because they want to be part of the conversation and it takes them longer to communicate.”

3. Supporters and communication devices are not interchangeable. Supporters are not substitutes for AAC users. Participants feared losing access to communication.

Quotes:

“If the person supporting my son doesn't have his best interest in mind, then there's got to be a way of checking or protecting my son against that.”

4. AAC users can have unreliable verbal communication. Healthcare providers should seek confirmation by using the individual’s most reliable form of communication and, if unsure, check with trusted supporters.

Quotes:

“If you ask him something, he’ll agree with you. Because verbally, he’s been taught to say, yes, agree with the therapist. But that’s not necessarily how he feels.”

“They always give power to the verbal word. That must be the right thing. So I often feel I have to correct the doctor and say, no. Let's hear him type out his response.”

Theme C: Concerns Regarding Supported Decision-Making

1. Function depends on the environment as well as skills.

Quotes:

“Decision-making is harder when I’m anxious.”

“When he's stable...he's able to give his input a lot, and we encourage that a lot. But most of the visits to the doctor is when there's a crisis. In that time, he's not in any shape to communicate.”

2. The distinction between communication assistance and decision-making support is unclear.

Quote:

“I worry I won’t be presumed competent because I use communication support.”



In an Advance Directive, people can provide more information about their values, who they trust to make decisions if they are too sick to decide, and what they would want to happen at the end of life.

California Legal Context

All Californians are presumed competent (legally competent) when they become age 18 regardless of their communication and functional skills, unless a judge has determined otherwise.

California does not yet have specific [Supported Decision-Making statutes](#). However, current law supports the principles of Supported Decision-Making. Additional legislation could be helpful, but is not required for individuals to implement it. Anyone can develop a Supported Healthcare Decision-Making Agreement. Nobody is required to have one. [Model language](#) for such agreements are available from a number of organizations.

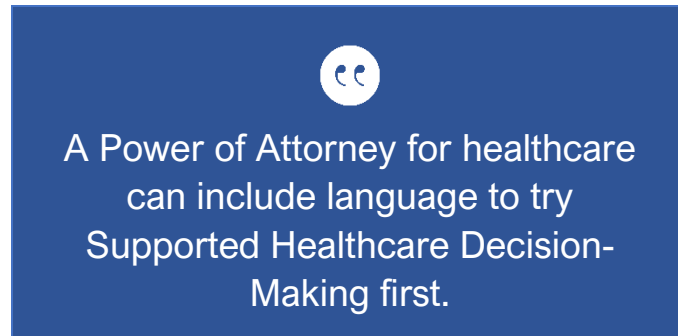
People with disabilities can use plain language [Supported Healthcare Decision-Making templates](#) which are freely available, and have them notarized, or can seek guidance from an estate lawyer familiar with Supported Healthcare Decision-Making.

In addition to a Supported Healthcare Decision-Making Agreement, people with disabilities can:

- Authorize [access to medical records and information](#);
- bring supporters to appointments or meetings as a disability accommodation;
- authorize someone to serve as a representative;
- develop an [Advance Directive](#) with explicit instructions or values statements;
- sign a [Power of Attorney](#) for healthcare which would enable a trusted person to make a substituted decision if the person lacked the mental or physical capacity to make a specific decision even with support.

Like everyone, people with disabilities may become too ill or overwhelmed to make a specific medical decision at a specific moment in time. People who use AAC may not have

the ability to communicate their decisions when they feel unwell, even with optimal support. A Power of Attorney for healthcare can include language to try Supported Healthcare Decision-Making first before the agent named in the document is authorized to make a decision. People with disabilities can also complete an Advance Directive. In an Advance Directive, people can provide more information about their values, who they trust to make decisions if they are too sick to decide, and what they would want to happen at the end of life. [Plain language Advance Directive](#) forms and training materials are available at no cost.



Regional Center System

People in California who meet the [state definition of developmental disability](#) have an entitlement to services and supports guaranteed by the [Lanterman Act](#), California Welfare and Institutions Code Divisions 4.1, 4.5 and 4.7 and Title 14 of the Government Code. This entitlement is administered through 21 [Regional Center agencies](#). Every county is served by one of these agencies. For those served by the Regional Center system, there are additional resources and protections. Regional Center agencies can fund supports or legal advice. Regional Center case coordinators can attend meetings to provide support. They can provide advocacy to ensure a client's agreements and rights are respected. The designee of the Regional Center's Executive Director can make a substituted informed consent decision for medical care for a client, if 1) the client is unable to make the decision even with support AND 2) if other arrangements have not been made AND 3) family, and supporters are unwilling or unable to do so.

Many parents are concerned that their Regional Center will exclude them from healthcare decision-making. This is not accurate. Section 4620.1 of the California Welfare and Institutions code states, "The Legislature recognizes the ongoing contributions many parents and family members make to the support and well-being of their children and relatives with developmental disabilities. It is the intent of the Legislature that the important nature of these relationships be respected and fostered by Regional Centers and providers of direct services and supports."

Section 4655 of the California Welfare and Institutions code authorizes the Regional Center or his/her designee to give consent for medical, dental, and surgical treatments ONLY if the person is an adult who is mentally incapable of consenting themselves, and their parent, guardian, or conservator who is a legally authorized representative doesn't respond. Even without any legal proceedings, parents can step in and provide decision-making support or even make substituted healthcare decisions, if needed, before Regional Center personnel are authorized to step in.

The Lanterman Act

The Lanterman Act is consistent with a Supported Healthcare Decision-Making framework. It prioritizes the decision-making of the client first. Unless other arrangements have been made, the family is prioritized second. Supported Healthcare Decision-Making is an option for all Regional Center clients regardless of support needs or cognitive and communication strengths or challenges. If the client does not have the mental or physical capacity to make a specific healthcare decision, their Advance Directive will be consulted. If more clarity is needed, a Power of Attorney chosen by the client can step in. If there is no Power of Attorney, parents or other family members may make decisions based on a hospital or health system protocol for such situations. If there is no family, the designee of the Executive Director of the Regional Center can step in to assist.

Graphic: If a client does not have the mental or physical capacity to make a specific healthcare decision:



Typically, in practice, if Regional Center personnel are called in to assist, they work collaboratively with the client and their supporters and healthcare providers to reach consensus on the best way to proceed.

Some Regional Center agencies have gone beyond the language in the Lanterman Act to specifically adopt policies promoting Supported Decision-Making. Clients and families can attend board meetings and get involved in helping to develop their Regional Center's policies.



Conservatorship permanently denies a person the right to make decisions about their lives.

Supporting the Rights of People with Disabilities and their Families

Professionals who assist with transition planning from child to adult services may provide [information about Supported Healthcare Decision-Making](#) to clients. Families complain that they are often steered towards the judicial system instead.

Unlike Supported Healthcare Decision-Making, conservatorship is not a voluntary agreement. It can't be changed or revoked by the conservator or person with a disability. In conservatorship, judges choose decision-makers. Conservatorship permanently denies a person the right to make decisions about their lives. Conservatorships remain in place even if a person's communication, function, relationships, preferences, or mental capacity evolve. Once in place, they are rarely reversed.

Judges can select family members to serve as conservators, but they are not obligated to do so. At any time, a judge can remove the rights of any family member to obtain information about their loved one or deny them involvement including visitation. Judges require regular reporting. If a conservator no longer wishes to have the significant responsibilities, a judge does not have to release them of the obligation. If they do agree to name a new conservator, judges do not have to select a preferred successor. Judges often replace family conservators with strangers. For families with immigration or legal disputes such as divorce, regular contact with the courts could negatively impact other legal proceedings. Involving the judicial system in private healthcare decision-making disempowers people with disabilities and their families. It often has unintended, long-term consequences. Consequences can't always be predicted.

General Principles

The Three S's of Decision-Making




Before the 1970's, healthcare decisions were typically made by doctors who used their professional judgement and ethics to make recommendations. Patients were socialized to trust their doctors. They mostly complied. Today, healthcare providers take a more person-

centered approach to care. Person-centered care requires healthcare systems to focus on the needs of the person. They should support their priorities and values. This is different than asking patients to adapt to the needs of the healthcare system.

Today, most healthcare decision-making is a dynamic process. It seeks to engage and empower patients and their representatives as much as possible. The only constraints are resources, patient knowledge and interest, and time. Common structures for decision-making can be described as shared, supported, and substituted decision-making. Shared decision-making is the most common model for people with and without disabilities.



Table: The Three S's of Decision-Making

 <p>Shared Decision-Making</p>	<p>Decisions are made jointly between a healthcare provider and a patient. This is how most medical decisions are made for both disabled and non-disabled patients. Patients and healthcare providers often consult others informally during this process. They draw on evidence, standards of care, guidelines and protocols, experience, and personal preferences.</p>
 <p>Supported Healthcare Decision-Making</p>	<p>For people with disabilities who are not yet able to independently share decision-making or who need support to access healthcare, arrangements can be made for support. In Supported Healthcare Decision-Making, the patient is involved in the decision-making process. They have access to the information and trusted support they need. Patients decide what type of support they need and who they want to provide it. Supported Healthcare Decision-Making acknowledges and welcomes the supporters into the shared decision-making process. In Supported Healthcare Decision-Making, patients can choose to come to their own decision independently or defer to the advice or opinions of their healthcare providers or trusted supporters. For patients with unreliable communication or cognitive disabilities, their known preferences are taken into consideration. Unlike a Power of Attorney or Conservator, in Supported Healthcare Decision-Making, legal responsibility and authority to make decisions is not transferred to another person.</p>
 <p>Substituted Decision-Making</p>	<p>Decisions are made by another person on behalf of the patient. Physicians may make substituted decisions in an emergency to save a life. A Power of Attorney is a substituted decision-maker chosen by the person. Other substituted decision-makers may be assigned by hospital protocol for unrepresented patients. These protocols usually list the priority for substituted decision-makers based upon their relationship to the patient such as child, parent, sibling, or friend. The protocols do not take into account the patient's preferences, the degree to which the patient shares values, or the quality of their relationship. Also, as a last resort, the delegate of the Executive Director of the patient's Regional Center agency is authorized to designate a decision-maker for people with developmental disabilities. A judge can assign a conservator or guardian to make substituted decisions for a person who they deem "incompetent." When a judge deems someone "incompetent" to make decisions about their life, it applies not only to their mental capacity to make the decision needed at the time, but also to all future decisions.</p>

No single structure can account for every healthcare situation, fluctuating abilities, or personal preferences. For example, most of the time, the situation is unhurried. If presented with information in the way they learn best, most people with disabilities have opinions and can express them. Shared decision-making is the best model. In an emergency where minutes matter or patients are too ill to engage, decisions may be more substituted. When patients are overwhelmed or distressed by too much information; their mental or physical capacity to process information is limited; or when they prefer to delegate decision-making to others; they may rely heavily on trusted supporters to make decisions.



Speech is not a required skill to provide informed consent for medical treatment.

What is an Informed Decision?

Informed consent means:

- The individual understands their condition and their treatment options.
- They understand the risks and benefits of accepting or declining treatment.
- They are able to weigh their options against each other.
- They can communicate their choice.

Speech is not a required skill to provide informed consent for medical treatments.

Speech is a complex motor skill. While people with speech disabilities are frequently presumed to also have difficulty with understanding or expressing themselves, this is not true. Speech, understanding, and processing information are separate brain functions. Furthermore, speech is only one way in which people express themselves.

The vast majority of healthcare decisions for both able-bodied and disabled people are made in the context of trusting relationships. The decisions are made informally through discussion and negotiation. Healthcare providers rarely perform formal assessments of mental capacity. They rarely initiate legal proceedings to ask a judge to find that someone is permanently “incompetent” and to assign a conservator.

Who Can Benefit from Supported Healthcare Decision-Making?

Many people with and without disabilities access informal support when navigating the healthcare system and making medical decisions through shared decision-making. Supported Healthcare Decision-Making is useful for people with disabilities who feel they need more formal structure to ensure they can:

- retain control over their healthcare
- access the support they need from people they trust
- define clear roles of supporters and healthcare providers
- collaborate effectively



Supported Healthcare Decision-Making Agreements are voluntary. They can ensure supporters understand and agree to their role. They help ensure that supporters are legally authorized to access protected healthcare information that is needed to provide support. They help ensure that supporters are able to accompany the person they support in the healthcare settings. It is a reasonable disability accommodation under the Americans with Disabilities Act. They can also help ensure the type and amount of support desired is consistently available when needed. Supported Healthcare Decision-Making Agreements

can serve as a tool for disability service systems and person-centered planning teams to identify and fill gaps in needed support. It can help healthcare providers work effectively with a patient who needs support to develop and implement an effective healthcare plan.

Supported Healthcare Decision-Making as a Process and Relationship Boundary Between Supporters, Service Providers, and People with Disabilities

The values that underlie Supported Healthcare Decision-Making include:

- People with disabilities have a right to control their own lives.
- The individual is the only person who can report on their internal thoughts, feelings, motivations, and sensations.
- Health and safety are protected when people have choice and control over their lives and bodies.
- People with disabilities are in the best position to decide who to trust, what support they need, and who they want to provide it.
- People with disabilities need clear boundaries with the people who support them.
- Everyone has a perspective that may not be the same as their family and supporters.
- Access to support and accommodation is a right.
- Communication access is a right.
- Everyone communicates.

Supported Healthcare Decision-Making is tailored to specific needs and desires of the patient. Supports can include decision and communication support. Supporters can also:

- communicate with clinicians
- help with remembering to take medication or follow up
- translate complex medical concepts into plain language
- weigh treatment options
- make and prepare for medical appointments
- transport to appointments
- take notes during appointments
- provide clinicians with a medical history and other information
- obtain medical and insurance information
- assist with physical tasks such as dressing or transferring onto exam tables
- pick up prescriptions or medical supplies

Preparing to Make Decisions

Maintaining a Circle of Support

A Circle of Support is made up of everyone interested in the well-being of a person or helping them meet their personal goals. These individuals do not usually represent a formal structure, but they do play an important role in the life of someone with a developmental disability. Every Circle of Support looks different, but may include family members, friends, personal care staff, case managers, coworkers, day program staff, housemates, classmates and teachers, and/or people from a shared place of worship, advocacy group, or exercise program.

A flexible, broad Circle of Support can offer opportunities, and serve as a safeguard against coercion. Individuals with developmental disabilities and their families should be strongly encouraged to develop a large Circle of Support and identify multiple healthcare supporters. A collection of supporters can assist the individual in a variety of situations. They can be available as back-up assistance in the absence of a primary supporter. For example, a person may want their brother to help them manage their medication, but might want their best friend to accompany them to medical appointments. Since these different supporters will enter and exit the life of the individual, a list of supporters should be reviewed and updated on a regular basis.



Communication is the foundation of patient care. Without communication there is no self-direction or informed consent.

Ensuring Continuous Access to Communication and Support

Communication is the foundation of patient care. Without communication, there is no self-direction or informed consent. Many people with disabilities do not have the ability to initiate a request for assistance without support. If they do not have support; their supporter does not agree to serve; or if they want to change supporters; they may not have the ability to alert someone who can help. Arrangements for communication support and decision-making should be listed in a person's disability services and supports.

Healthcare providers are responsible for accommodating disability and providing expertise and service. Except in emergencies, they should not make decisions on behalf of their patients. For Supported Healthcare Decision-Making to work, people with disabilities must maintain relationships with friends, family and professionals who can serve as supporters.

For people who are unable to independently request a revision to a Supported Healthcare Decision-Making Agreement, arrangements can be made to regularly review the agreement(s). A natural time and place to do this is in disability services planning meetings and documents. Disability planning meetings led by people with disabilities are called Person Centered Planning meetings. Disability services funding agreements written by Regional Center representatives are called Individual Program Plans. Clients, parents or advocates must agree to Individual Program Plans.

Specific strategies to ensure access to support and communication can include:

1. Instructions in the Supported Healthcare Decision-Making Agreement

- Include oversight or processes for paid supporters to ensure they are accountable.
- Have supporters sign the Supported Healthcare Decision-Making Agreement to confirm their commitment to serve and their understanding of the role.
- Include written instructions for what supporters should do if they no longer agree to serve.

2. Regular, planned review of the agreement(s)

- Review Supported Healthcare Decision-Making Agreement(s) at every Person-Centered Planning Meeting.
- Include funding for support in the patient's Individual Program Plan.

3. Back-up plans

- Name someone to ensure the Supported Healthcare Decision-Making Agreement is up-to-date and followed.
- Name multiple supporters.
- Name back-up or successor supporters.
- If the patient is unable to name a supporter, ask the [State Council on Developmental Disabilities](#) to assign an authorized representative.

4. Maintenance of a strong social network who will notice problems and intervene

- Healthcare providers, family or friends can alert Regional Center case coordinators to unmet support needs.

- When appropriate, Individual Program Plans or Person-Centered Plans should include assistance with maintaining a robust Circle of Support.
- Include criteria for the adequacy of the Circle of Support in the Individual Program Plan. If the criteria are not met, include services designed to develop it.

Who Can Serve as a Supporter/Managing Competing Interests?

All people who provide or fund services and supports for people with disabilities have competing interests. This is true whether they provide or fund services formally or informally, voluntarily, or professionally. Healthcare providers cannot serve as supporters, power of attorney, or conservators for the patients they treat. While people who provide or fund services may be some of the best candidates to serve as supporters, competing interests should be discussed and considered when people with disabilities select their supporters.

If necessary, a Supported Healthcare Decision-Making Agreement can include information about competing interests and instructions about what to do if those interests seem to be impacting the quality of the support. For example, an alternate supporter can be named for some types of decisions. A team meeting can be called that includes advocate(s) without competing interests whose role is to ensure the decision is not coerced. Members of the team can fill out a chart regarding [what is important for](#) and [what is important to](#) each member of the team. This can help identify competing interests so they can be discussed and managed.



Competing interests should be discussed and considered when people with disabilities select their supporters.

Examples of potential supporters who have strong competing interests include:

- A person who can get money from a legal case that involves a person with a disability.
- Someone who is planning to go to court to become the conservator or guardian of an adult with a disability.
- A person who owes money to an adult with a disability.
- Someone who is trying to get control of a person's property.

- Someone who gets paid to help an adult with a disability with personal or medical tasks or their relatives.
- Someone who works at a nursing home, group home, or home in the community that another person runs as a business where the adult with a disability lives or gets services.

Education in How to Make Decisions

Like everyone, people with developmental disabilities learn to make increasingly complex decisions with practice and experience. Family members and other supporters can start building decision-making skills early by allowing younger children to have some agency over their everyday lives. Even small decisions like what to have for dinner or wear to school can help build skills and confidence. If an open-ended decision is too overwhelming, try offering a few simple choices. Remember, like everyone, people with disabilities can make decisions that others oppose or believe are unwise. They learn from the consequences of those decisions. Advice for parents who want to raise disabled children with the skills to direct their lives and their support can be found in the [What's Next: A Self-Advocate's Guided Tour through Transition for Parents and Other Supporters](#) guide.

Formal Supported Healthcare Decision-Making Agreements

Formal documents describing Supported Healthcare Decision-Making Agreements can help clarify roles and responsibilities for everyone involved. Like Advance Directive and Power of Attorney documents, there are simple and detailed templates that can be customized. Copies of formal documents should be given to people who may need to reference them such as healthcare providers, Regional Center agency case coordinators, supporters, and first responders.

Healthcare providers should respect the role of a supporter. The role of a supporter is analogous to a translator or cultural broker for people with disabilities. While the patient makes the final decision, the healthcare provider can rely on the supporter to help them interpret communication and to work effectively with their patient. The supporter is there to help healthcare providers succeed and to achieve a good outcome by accommodating the patient's disability, self-determination, values, and culture. Healthcare providers should ask their patient for permission before seeking information from another person, and should not ask supporters to make decisions on their patients' behalf. They should also respect the agency of their patient, rather than insisting on substituted decisions when the patient has made and communicated an informed decision.



People have a right to take risks, to make decisions that are not recommended, and to learn from it.

Support for Supported Decision-Making

Supported Decision-Making has been advanced by disability rights organizations around the world. Thus far, Supported Decision-Making has primarily been available for people with developmental disabilities, but increasingly, as the definition of support evolves, it is gaining traction for people with physical and communication disabilities, psychiatric disabilities, traumatic brain injuries, and age-related cognitive decline.

Over the past several years, Supported Decision-Making has increasingly gained recognition in state statutes, case law, and social services. As of 2019, nine states have passed laws that define Supported Decision-Making Agreements as legally enforceable arrangements. The United Nations Convention on the Rights of Persons with Disabilities endorses Supported Decision-Making for all people with disabilities. It was adopted in December of 2006. The American Bar Association adopted a resolution in support in 2017.

Role of Supported Healthcare Decision-Making in Healthy Lifestyle and Prevention

Healthy Lifestyle

In addition to providing support when accessing healthcare services, if desired, helpers can provide support for healthy lifestyles. This can include decisions regarding exercise, healthy foods, sleep, taking medications, documenting signs, symptoms and side effects of treatments, or help remembering to follow through on healthcare plans. The [Office of Developmental Primary Care has forms](#) for tracking information about health care.

Healthy Boundaries Between People with Disabilities and Supporters

Naming trusted supporters is voluntary. Providing support is also voluntary (although people can be paid for their time). Supporters should sign any formal Supported Healthcare Decision-Making Agreements. They should be encouraged to include any personal

boundaries about when they are willing to make themselves available; how they are to be contacted; and decisions or activities they are not willing to support.

People have a right to take risks, to make decisions that are not recommended, and learn from it. For people who have care and custody of a person with a disability, they should review laws which prevent abandonment. Supporters who are unable or unwilling to serve for any reason should help ensure a backup plan and facilitate a smooth transition to another supporter. A commitment to do this can be included in a formal Supported Healthcare Decision-Making Agreement.

Preparing for Interactions with the Healthcare System

Best Practices for Medical Providers



Sometimes a small change in the physical environment...can make a huge difference.

Barriers to accessing healthcare for people with disabilities can be physical, sensory, financial, attitudinal, programmatic, or involve communication. Barriers to access can occur at any point in the system from parking, untrained office staff and medical assistants, and inaccessible scales and exam tables. Ask for feedback from patients with disabilities. Sometimes a small change in the physical environment, such as a less distracting exam room, or a subtle shift in an interaction between a patient and healthcare provider can make a huge difference.

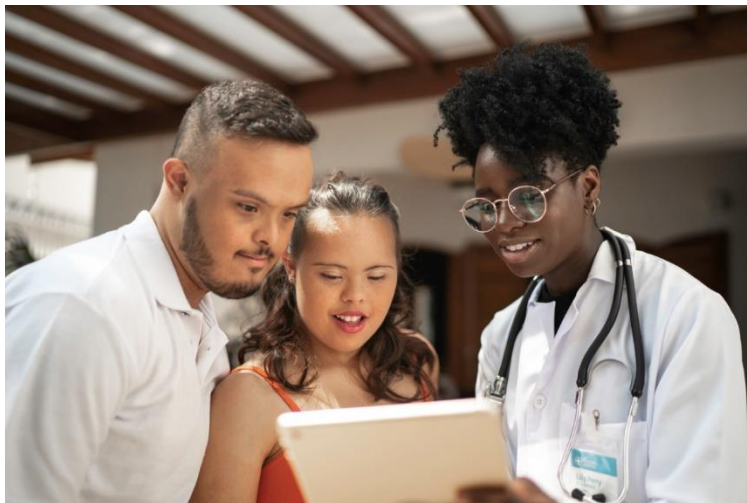
Healthcare providers should both comply with requirements of the Americans with Disabilities Act and routinely ask patients about their accommodation needs. For users of AAC, phone triage systems are often inaccessible. Longer appointment times may be needed to accommodate slower communication styles. Offer alternative ways to contact the office such as email or a direct phone number to a clinician or a staff person. Patients can be given questions in advance of the appointment so they can prepare or follow up to provide responses after.



Patients should be asked if they have a Supported Healthcare Decision-Making Agreement at the same time they are asked about Power of Attorney, or Advance Directive.

Healthcare providers are obligated to provide information in accessible formats such as large print, audio, and Braille, and use appropriate literacy levels and other individualized methods that their patient can understand.

Patient's should be asked if they have a Supported Healthcare Decision-Making Agreement at the same time as they are asked about Power of Attorney, or Advance Directive. As with all patients, presume patients who do not use speech to communicate are competent to make their own decisions unless informed otherwise. Give people uninterrupted and unpressured time to answer.



Some respectful ways to ask about supports include:

- Do you have any legal documents such as a Supported Healthcare Decision-Making Agreement, Power of Attorney, or Advance Directive?
- Do you have a trusted supporter who helps you make decisions?
- How do you make decisions? Is there someone who assists you with that?
- Is there someone you would like to consult to help you make your decision?

- Do you need more time to make a decision?
- Do you want to think about it at home, and tell me later?
- Do you have a health passport, accommodation letter, or medical summary that describes how to work with you best?

Here are some specific tips to support decision-making in health care settings for supporters and healthcare providers:

- Speak directly to the person with the disability.
- Respect the role of a supporter by allowing them into the exam room.
- If appropriate, ask the patient or supporter to explain, and if possible, demonstrate how the person communicates decisions.
- Check for understanding.
- Give the person time to process.
- If an immediate decision is not needed, allow the person to research options, consult with others, and process information.
- Ensure access to appropriate communication devices and support.
- Follow-up to address any questions or concerns.
- Respect and honor their decisions.

If a patient does not have an effective form of expressive communication, consider referring them for an assessment. [A guide to accessing communication](#) can be found on the Office of Developmental Primary Care website. If a patient does not have the mental or physical capacity or communication skills to make a specific decision at a specific moment in time, a substituted decision may be necessary. However, do not presume that will always be the case for all decisions in the future. People learn to make decisions by making decisions. Even if ultimately unsuccessful, attempts to engage patients in shared decision-making helps build skills. Lack of experience, opportunity, education, or communication skills is not the same as lack of potential.

Communication skills can take many years to develop. The field of Augmentative and Alternative Communication is in its infancy. New technologies and communication methods are advancing rapidly. People who are unable to communicate effectively when feeling poorly or in a healthcare facility may be more capable in a less stressful environment.

Clinicians should be skeptical of diagnoses of intellectual disability in people who do not have a fluent method of expressive communication or who have sensory and movement differences. They may have been misdiagnosed. Family or supporters may have been misinformed by professionals about a person's intellectual capacity and potential. Assessments that were developed for people with typical sensory processing and movement

control often provide misleading results in people with sensory-movement differences. Also, people can gain and lose cognitive skills, so past results may not reflect the current situation.



Patients and families report that professionals often steer or even pressure them to pursue conservatorship.

Patients and families report that professionals often steer or even pressure them to pursue conservatorship rather than working with them to provide the needed support. Healthcare professionals can help their patients to retain their legal right to make decisions and to build the skills to exercise their rights.

Accommodations

Patients should provide written information about any accommodation needs they have. However, it is helpful to know basic [disability etiquette](#). Below are a few recommendations.

- Speak normally using a normal rate, volume and tone of voice unless asked to do otherwise.
- Speak directly to your patient rather than their supporter.
- Ask, before addressing a supporter.
- Mobility and communication devices are often highly customized and critical to the daily functioning of people with disabilities. Respect these devices and ask permission before handling any adaptive device or specialized equipment.
- Non-traditional communication is typically slow. When interacting, expectantly wait for a response without speaking. Don't interrupt or complete sentences.
- More can be found on the [Office of Developmental Primary Care website](#).

Forms and Tools for Patients

Eighty percent of diagnosis is based on medical history. It is the responsibility of patients to provide an accurate and complete history. Sometimes people with disabilities need support to complete logs to track signs and symptoms; body functions such as vital signs, sleep, menstruation, behaviors; fluids and food intake; and/or medication administration. To assist people with disabilities and their supporters to collect and organize information, [templates for tracking body functions](#) can be used.

Patients should also be prepared to provide detailed information about baseline traits, characteristics and function. Understanding the baseline will help with diagnosis. Illness often presents as a change in behavior or function, so it is critical that doctors understand what is normal for the patient. This information may be summarized in disability or educational assessments or Individual Program Plan documents.



Illness often presents as a change in behavior or function.

It is also the responsibility of patients and their supporters to tell their doctors how best to accommodate their communication and disability. It is helpful to create a succinct note with information. This is sometimes called a [Health Passport](#), Medical Summary, or [Personalized Accommodations Report](#). These documents will explain a patient’s disability needs, preferred communication and learning methods, and any special tips for helping them in healthcare settings. Patients should provide this information again when they see new healthcare professionals or go to the emergency department. Patients should consider keeping a copy of this document in a wallet, backpack, or something that travels with them at all times.

Emergency Preparedness

It is helpful to have a healthcare “Go Bag” in case of an emergency. It should include copies of key health documents, including Supported Healthcare Decision-Making Agreements, Advance Directives, Authorizations, information about needed accommodations, and Power of Attorney documents. It can also include comfort items which can help a person stay calm, anything needed for communication, or other items that might be needed in an emergency department or shelter. For people who can’t be left alone, there should be a backup plan if a supporter is unable to serve. For people who are medically fragile, who have a history of mental health or behavioral crises, it is helpful to have a crisis and backup plan for medical or behavioral emergencies. Disability crisis services should be used instead of law enforcement for crisis that do not involve criminal intent. For people who require special equipment or transportation for their disability or communication, there should be plans in place for power outages or natural disasters.

Insurance

Navigating health insurance and copayments for care can be complex. If support is needed, patients may need to complete health plan paperwork to allow a supporter to serve as an Authorized Representative to provide assistance.



A diagnosis of a cognitive or speech disability does not determine whether or not someone has the mental capacity to make an informed decision.

Interactions with the Healthcare System (Roles and Responsibilities)

Recommendations for Healthcare Providers

Ask your patient:

- How do we communicate best?
- What can I do to accommodate you?
- Do you use any services or supports?
- What information would you like shared with others?
- Would you like more [information about Supported Healthcare Decision-Making](#) or a referral to social, legal or disability services?
- Presume competence and start with your usual shared decision-making process.
- Move to supported and finally substituted decision-making processes as needed.

There are two situations when it is challenging to obtain informed consent from a patient. The first occurs when a patient does not have the mental or physical capacity to make an informed decision. The second is where a patient has the capacity, but it is overlooked. The later situation is far more common than the former. A diagnosis of a cognitive or speech disability does not determine whether or not someone has the mental capacity to make an informed decision. The fact that someone uses services or supports or is a Regional Center client also does not determine their mental capacity to make an informed decision. Some people with developmental disabilities fear clinicians may assume the need for support is the

same as less capacity to direct their lives. Capacity can fluctuate. It can be improved with accommodations and a supportive environment. It can be adequate for some decisions at some points in time and not for others at other points in time. People can gain or lose capacity. It is not a fixed trait. Mental capacity must be assessed for each decision at the time the decision must be made.

People are presumed to have legal capacity to make decisions for themselves unless a judge has found them “incompetent.” Legal capacity means the ability to execute valid legal documents. Like able-bodied people, by using shared, supported, and when needed substituted decision-making processes, people with disabilities can retain their legal capacity, even when they don’t yet have the mental or physical capacity to make some healthcare decisions some or most of the time. Retaining legal capacity and engaging in decision-making gives people the opportunity to develop their decision-making skills, take responsibility for the outcomes, and learn from both good and bad experiences. People are safest when they retain control.

Research shows that able-bodied patients of all educational backgrounds frequently have incomplete understanding of their conditions, and the treatment options that they have been offered. Communication and health education could be improved for all patients. Able-bodied patients also frequently make decisions against the advice of their doctors and are given the dignity of taking risks. People with disabilities should not be held to a different standard for their participation in the informed decision-making process than other patients.

Recommendations for Supporters

Supporters should try to anticipate the specific type of support a person will need based on the general type of support the person has requested. For example, some people may need help remembering to bring their insurance cards, health passports or accommodation letters. Others may need help writing down their questions, concerns, or symptoms, collecting information from caregivers, remembering what medications they take, bringing documents, arranging transportation, or navigating the paperwork at the front desk. If possible and appropriate, speak to the person before the appointment to determine their specific need for support. Supporters should feel comfortable asking healthcare providers for assistance and accommodations. For example, a supporter may request extra time or an accessible exam room when they schedule an appointment. Supporters can ensure that AAC users have access to their preferred method of communication and the vocabulary they will need. During the appointment, supporters can keep the focus on the person with a disability and assist or model communicating directly with the client. If the healthcare provider does not direct their communication to the person, the supporter can redirect them.



Recommendations for AAC Users

People who use AAC have the right to make decisions about their body and their health. With this right comes certain responsibilities.

- To the greatest extent possible, AAC users should have the power to name and set boundaries with supporters.
- They should ask for the type and amount of help they need in order to make informed decisions. This may also include granting each supporter permission and access to specific medical information.
- AAC users should be engaged in the planning of their own healthcare. This might mean thinking about questions to ask a doctor or partnering with a supporter and healthcare professional for effective communication.
- AAC users and all people with disabilities have the right to ask questions and either take the advice of a clinician, ask for a second opinion, choose a different path, or ask for an alternative plan.
- Once a decision has been made and communicated, AAC users are responsible for the consequences.

Follow Up After Healthcare Interactions

Assigning Responsibility for Follow Up

Following through on a healthcare plan and monitoring the outcome can include navigating complex systems. Doctors may recommend referrals, lab tests, procedures, and

medications. Working with pharmacies to fill prescriptions and ensure a complete understanding of directions and side effects may require support.

Some healthcare plans can't be implemented without new services and supports. Healthcare providers and supporters can help request and advocate for changes to a person's Individual Program Plan, if needed. It is important to ensure that it is clear who will follow up and what type of support is needed. Healthcare providers may need to be more proactive than usual to ensure that patients with disabilities can navigate the healthcare system. For example, providers may need to schedule specialist appointments for their patient or call ahead to ensure important information is accurately transmitted.



People with communication challenges might not be able to alert their healthcare professional about a problem without support.

Data Collection about Health Status/Results of Treatment

Sometimes healthcare professionals assume that patients will call them if treatments don't work or if there are side effects. People with communication challenges might not be able to alert their healthcare professional about a problem without support. Discuss what data should be collected regarding the response to treatment and how quickly problems need to be reported. Make sure there is a plan for timely follow up.

Medical problems tend to be identified later for AAC users than for people without communication challenges. Healthcare professionals should ensure that patients with communication challenges have efficient ways to contact them that will receive a prompt, prioritized response. Patients may need a direct line or email address of a staff person who understands their communication and accommodation needs. Supporters can also assist in the follow up process. For example, they can help to keep the lines of communication open between the patient and healthcare professionals. The supporter who provides assistance with follow up care may be different from the supporter at the appointment. Ask who will provide this help.

Informed Consent Process

Except in emergencies, all decisions should be informed. This means the patient, supporter, or representative understands their condition, the treatment options, the risks and benefits of each option, has weighed them against each other, and communicates a choice. Healthcare providers are obligated to provide accessible information and to try to communicate in a way their patient can understand. They are also obligated to honor informed decisions, even if they disagree with them. However, if a decision is not fully informed or if the patient's mental or physical capacity is compromised or unclear, it is helpful to include information on what to do in an Advance Directive or Supported Healthcare Decision-Making Agreement.

If a clinician does not believe a supported decision is informed, the next steps for healthcare providers are:

- See if accommodations or communication can be improved.
- Work with the supporter to assess the patient's mental and physical capacity.
- Review any Advance Directive or Supported Healthcare Decision-Making Agreement.
- If the patient assents and the decision is fairly low risk/low stakes or there is a clear best standard of care or option most people would choose, accept a supported decision even though mental capacity or communication is not completely clear.
- Consult the patient's Power of Attorney.
- Request the [Regional Center](#) for the county in which the client resides to appoint a designee. If there is time, convene a team meeting of those in the patient's Circle of Support to help the Regional Center designee make the decision.
- If there is not assent and consensus, the client should also have an advocate at the meeting who does not have a competing interest such as the Client's Rights Advocate or an Authorized Representative appointed by the State Council on Developmental Disabilities.
- If there is not consensus among the members of the patient's Circle of Support, the team can consult an ethics committee, the Client's Rights Advocate, Ombudsman, Patient Relations and/or Risk Management officers to assist the team to reach a consensus.
- If there is still not consensus, as a last resort, parties can consider a legal case to resolve the decision at hand (not necessarily all future decisions). This is very rarely necessary.

With both able-bodied and disabled patients, it is not always completely clear that the patient fully understands the risks and benefits. Truly informed consent is more of an aspiration than

a reality. Assent means that the person affirms the decision, even if it is not clear if the patient fully considered the risks and benefits of all alternatives. There is a risk that the healthcare provider or supporter is substituting their decision for the patient's, but at least the patient participated in the decision-making up to their capacity. For people whose expressive communication is very limited, assent can mean that they don't actively protest verbally or through body language.

Optimizing Knowledge, Attitudes and Beliefs

AAC User. Only the patient can know their own internal experiences. It is critically important that supporters and healthcare providers hear directly from patients. Patients usually understand and can communicate more than it is assumed they can if we listen and observe carefully. Like everyone, AAC users have the ability to change and learn. A single interaction is not necessarily indicative of all future interactions.



Not all agitation, failure to respond, or unusual responses are related to a person's disability. They can also be a sign of delirium or severe illness such as stroke or side effects of medications.

Supporter. The role of being a supporter is different than being a substitute decision-maker. Supporters must be proactive and advocate without becoming overly involved or speaking for, or over, the person they support. This is often a delicate balance between caring for a person with a developmental disability and silencing their voice or taking away their autonomy.

Healthcare Professionals. It may be helpful to have some basic knowledge of disability history and disability rights. For example, women with disabilities have had a long history of being denied their reproductive rights. They have been sterilized against their will, or had their children removed from their custody. People with disabilities also carry the fear of institutionalization. They have often received negative messages about their bodies and abilities. These practices and negative messages still occur today. A patient may be leery of medical advice rooted in perceptions about disability.

Not all agitation, failure to respond, or unusual responses are related to a person's disability. They can also be a sign of delirium or severe illness such as stroke or side effects of medications. To avoid making dangerous assumptions, a careful history of a person's baseline behavior and function can help identify changes to baseline function, behavior, and communication which could indicate illness. It may be helpful to use a [tool for evaluating a change in behavior](#).

Supporting Communication

Everyone should be respected and involved in decisions about their health to the greatest extent possible. Use the patient's preferred method of communication. Keep in mind, speech is not the only form of communication. Some patients with communication or cognitive disabilities may not respond using words. In some cases, their spoken words may not accurately represent their true will and preference. However, a trained supporter or careful observer may be able to interpret body or facial gestures or vocalizations. Even if someone's expressive communication is minimal and substituted decisions will be necessary, patients should be in the room when information and decisions that impact them are discussed. Speak directly to the patient, even if unsure if they understand and if they do not respond.



Speak directly to the patient, even if unsure if they understand and if they do not respond.

Optimizing Settings to Support Power Sharing

Optimize the environment. Reduce sensory distractions as much as possible. Accommodate communication needs. Presume competence. Don't make assumptions. Provide adequate time.

Preventing, Identifying, and Managing Ability Bias

Ability bias may be conscious or unconscious. The lives of people with disabilities are meaningful and valuable regardless of traits, characteristics, or functional status. People with disabilities lead full complex lives. They feel joy, sorrow, and have dreams and goals. People with disabilities rate their quality of life higher than others presume they do. Merely having a disability is not an indication of a poor quality of life. Lack of services and supports,

opportunity, choice and control, or negative attitudes can diminish quality of life. The right services in a supportive, welcoming environment can dramatically improve function.

Managing Uncertainty

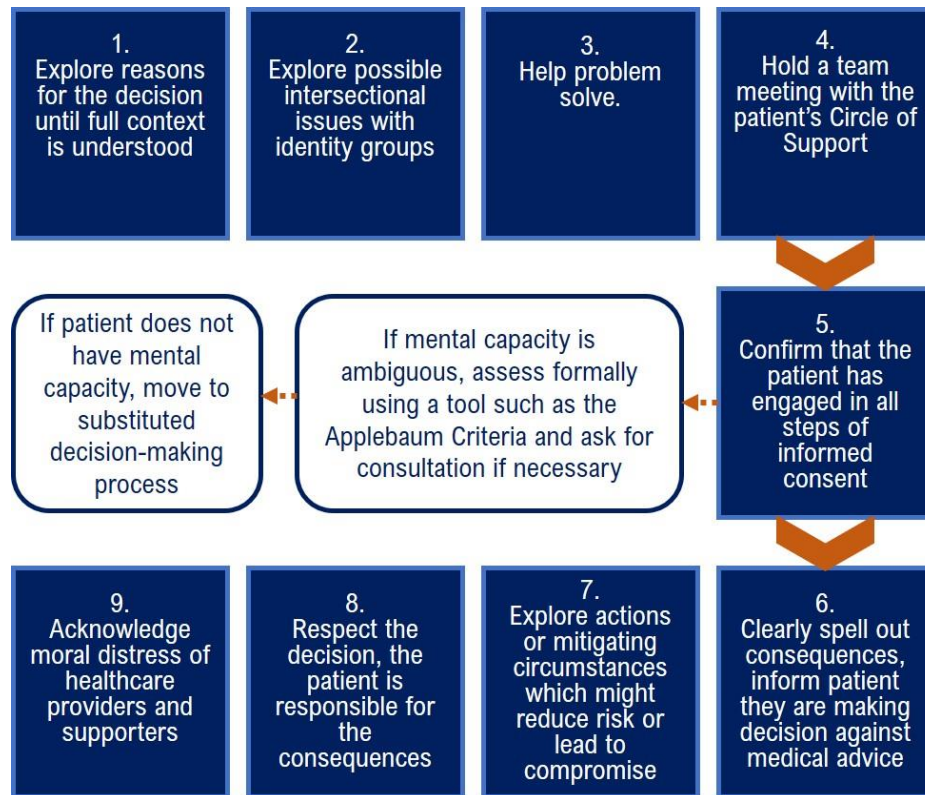
Deliver timely care. While it is important to optimize the opportunity for the patient to make a decision, it is also important to secure timely informed consent. Delaying or denying care because of difficulties with obtaining valid informed consent is a decision. Use the least restrictive means possible. If you act in good faith, and do your best, your best is good enough. Work through the process to deliver timely care.

What to do when a decision is outside the range of what reasonable people might choose. Try to gain a deeper understanding of the reasons behind a particular decision. People with developmental disabilities are complex just like their non-disabled peers. Understanding personal histories and motivations may go a long way towards arriving at a compromise with a patient. When a patient has a communication disability, clinicians often need to find alternative ways of gathering this information. If the decision can be delayed, perhaps the patient can prepare a written explanation at home. A clinician may obtain permission to speak with a trusted supporter who may possess relevant information. There might be a reason behind a decision that seems outside the norm. Steps to follow include:

1. Explore the reasons for the decisions until the full context is understood. For example, a patient may be trying to exert power by not going along with the recommendation of an authority figure.
2. Explore possible intersectional issues with identity groups such as gender identity, race, ethnicity or religion which may inform the patient's decision-making differently than the healthcare provider who doesn't share the same identity or culture.
3. Help problem solve.
4. Hold a team meeting with the patient's Circle of Support.
5. Confirm that the patient has engaged in all steps of informed consent and is not merely assenting or resisting.
6. If mental capacity is ambiguous, assess it formally using a tool such as the Applebaum Criteria, and ask for consultation, if necessary. If the patient does not have mental capacity, move to a substituted decision-making process.
7. Clearly spell out the consequences, and inform the patient they are making a decision against medical advice.
8. Try to come up with compromises or mitigating actions which might reduce the risk or lead to compromise.

9. Acknowledge moral distress of healthcare providers and supporters.
10. Respect the decision and the patient is responsible for the consequences.

Graphic: What to do when a decision is outside the range of what reasonable people might choose.



What to do when a decision is unclear. The nature of some people’s disability is that they may say things verbally that they do not mean. Confirm by using their strongest form of communication and be aware of the risk of triggering automatic verbal or motor responses. To reduce the risk of influencing a response, use techniques such as teach back, asking in different ways, and creating a safe, calm environment. Check with supporters to confirm that the response is authentic. Parents reported challenges with interpreting communication in people for whom speech is unreliable:

Quotes:

“The [doctors] would say were you doing cocaine? And she would say, yes. And that's not the case.”

“...verbally, he's been taught to say, yes, agree with the therapist. But that's not necessarily how he feels.”

“The doctor may not know that whatever my son says, that doesn't always apply.”

Usually, the assessment of mental capacity will be implicit. If there isn't a reason to question a patient's decision-making, presume competence. Merely having a disability, using an alternative to speech to communicate, or using service or supports is not evidence of lack of mental capacity. Unless a patient is conserved by a legal proceeding, they retain their legal capacity, even when they lack mental capacity to make decisions. This is a common situation when people are ill, whether they have a disability or not, and can be handled in a similar fashion.



Steps to follow when decisions are unclear are:

1. Make sure that the person's preferred supporter and communication methods are being accommodated. Supporters and communication devices are not interchangeable.
2. Make sure the patient's mental capacity is not being overlooked because of their appearance, behavior, physical limitations, or communication style.
3. Use supporters to clarify. Supporters are similar to translators or cultural brokers. The healthcare provider doesn't always need to be able to independently communicate, but can work with others to obtain informed consent.

4. Healthcare providers can rely on what they would do in a similar situation with a non-disabled person whose decision-making is compromised.

What can you do if a healthcare provider is misinterpreting or ignoring a supported decision?

1. Ensure adequate communication supports.
2. Remind the healthcare provider of the requirement to provide effective communication.
3. Provide information about Supported Healthcare Decision-Making, communication rights, and the patient's preferred communication method.
4. Ask for advocacy from a trusted primary care provider.
5. Bring in additional members of the patient's Circle of Support.
6. Ask for a Regional Center representative, Ombudsman, Patient Representative, Advocate, or Client's Rights Advocate to get involved.
7. Switch healthcare providers.

What can a supporter or healthcare provider do if they suspect a decision is coerced?

1. Speak to the patient alone.
2. Make competing interests explicit.
3. Refer to an Advance Directive.
4. Offer to help them name a different supporter.
5. Ask for support from a case manager, patient advocate, ombudsman or disability advocate.
6. Call Adult Protective Services if abuse or neglect is suspected.

Definition of Terms

- **Assent** means that the person agrees with the decision, even if it can't be determined if they fully understood all of the options, risks and benefits.
- **Augmentative and Alternative Communication** includes all of the ways we share our ideas and feelings without talking. There are two main types of AAC: (1) unaided systems and (2) aided systems. (1) *Unaided Systems*: People do not need anything but their own body, e.g. using gestures, body language, facial expressions, and sign language. (2) *Aided Systems*: Uses some sort of tool or device, ranging from pen and paper or pointing to letters, words, or pictures on a board (basic aided systems) to selecting letters or pictures on a computer screen that speaks for you (high-tech aided system). Most people with and without speech disabilities use a combination of methods to communicate.
- An **Authorized Representative** is a supporter. Different organizations such as Health Plans, Regional Center agencies, the Social Security Administration, and Medi-Cal allow people with disabilities to authorize someone to assist them with paperwork, support or represent them at meetings, or file a complaint on their behalf. The State Council on Developmental Disabilities can appoint an authorized representative to provide support to a Regional Center client. An Authorized Representative can speak on behalf of the represented individual and support them to sign legal documents, but cannot make decisions for them or sign legal documents for them.
- A **Circle of Support** is the support network of all the people invested in supporting the person's goals and looking out for their wellbeing. It can include significant others, friends, community members (e.g. people from work, school, clubs, teams, interest groups) and service providers (e.g. teachers, social workers, aides, therapists, hairdressers, mechanics, tradespeople).
- **Coercion** is convincing or forcing a person to do something against their will or not in their best interest.
- **Consent** is agreeing to a decision while understanding and being able to weigh options.
- **Conservator** is what a guardian is called in California. A judge decides the abilities and needs of the person with a disability based on what they can do without assistance and assumes their needs will stay the same for life. The judge decides who to appoint to make decisions on behalf of the person with a disability and supervises them.
- **Guardian** is a person who a judge grants the right to make all final decisions about their ward's life. Changes to guardians must go through the court. A court can replace a guardian if they think it is best or grant more powers than requested. In California, guardians are called conservators.

- **Incompetent** means someone who is judged in a formal hearing to lack the ability to make or carry out important decisions about their own affairs. A judge can appoint a permanent conservator or guardian to make decisions for a person who has been deemed incompetent.
- **Individual Program Plan** is a Regional Center agency document which identifies the goals and needed supports and services for a specific client. It is a contract that authorizes funding.
- **Influence** is the ability to sway someone's decisions. People influence each other when they communicate and discuss.
- **Limited Conservatorship** gives a court-appointed person the right and responsibility to make decisions for another adult in some, but not all, realms of life such as healthcare, finances, or housing.
- **Legal Capacity** means that a person is legally able to enter into a contract such as signing a will or a Power of Attorney. A Supported Healthcare Decision-Making Agreement is an authorization, not a contract, and does not require the same degree of mental capacity.
- **Mental Capacity** is sufficient understanding and memory to comprehend in a general way the situation in which one finds oneself and the nature, purpose and consequence of a proposed act or transaction. Mental capacity can change over time and in different circumstances or environments.
- **Natural Support** is a type of support available outside of the paid, disability support system. This type of support can be available to people with and without disabilities. An example of a natural support is someone who accompanies a friend to a medical appointment.
- **Patient Centered Care** focuses on the needs of the patient. In this model, the healthcare system adapts to these needs. The patient is a crucial partner in their healthcare. It takes into account their values, preferences, and respects their decisions.
- **Person Centered Planning Team** is a group of people chosen by the person to assist with future planning and developing a plan for disability services and supports. It focuses on the preferences of the person with a disability.
- **Power of Attorney** for healthcare is a legal document where a patient identifies who will make a decision on their behalf if they are too sick to provide consent to medical treatment. It is a more complex document than a Supported Healthcare Decision-Making Agreement since it is giving someone else the legal right to make decisions. The person needs to understand it to execute it validly.
- **Regional Center** agencies are one of 21 agencies in California that provide services to qualifying people with developmental disabilities. These centers coordinate and fund

services and supports. They are funded by the California Department of Developmental Services.

- **Shared Decision-Making** means decisions are made jointly between healthcare provider and patient. This is how most medical decisions are made for both disabled and non-disabled patients. Patients and their health care providers work together to make decisions.
- **Substituted Decision-Making** decisions are made by another person on behalf of a patient. Physicians may make substituted decisions in an emergency to save a life. A Power of Attorney is a substituted decision-maker chosen by the person. Other substituted decision-makers may be assigned by hospital protocol for unrepresented patients or by a judge after a legal hearing.
- **Supported Decision-Making Agreements** are documents that identify the person(s) who will support an individual in making their own decisions. It is not a contract, but an authorization. It should be easy to understand and validly executed.
- **Supported Healthcare Decision-Making** is a process where people with disabilities can name trusted supporters to assist them with communicating, accessing healthcare services, making decisions, and implementing their healthcare plan.



Resources

General Information

- [Supported Healthcare Decision-Making](#)
- [Plain Language Advance Directive](#)
- [State Definition of Developmental Disability](#)

Agencies & Organizations

- [Listing of Regional Centers by County](#)
- [Regional Center and Other Advocacy Organizations](#)
- [State Council on Developmental Disabilities](#)

Documents & Forms

- [Authorization to Access to Medical Records and Information](#)
- [Advance Directive Tools & Resources](#)
- [Health Passport \(English\)](#)
- [Health Passport \(Spanish\)](#)
- [AASPIRE Personalized Accommodations Report](#)
- [Health Tracking Forms](#)
- [Managing Competing Interests \(What is Important To, What is Important For\)](#)
- [Power of Attorney Form](#)
- [Supported Decision-Making Model Agreements](#)
- [Supported Healthcare Decision-Making Templates](#)

Guides

- [Everybody Communicates: Toolkit for Accessing Communication Assessments Funding, and Accommodations](#)
- [What's Next: A Self-Advocate's Guided Tour through Transition for Parents and other Supporters](#)

Laws & Statutes

- [Lanterman Act](#)
- [Supported Decision-Making Statutes by State](#)

Optimizing Attitudes & Beliefs

- [Disability Etiquette](#)
- [Evaluation of Behavior Change Tool](#)
- [Tips for Interacting with Non-traditional Communicators](#)