

PRACTICAL Tool for Healthcare Providers:

Putting Supported Decision Making in Action for Medical Professionals







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The PRACTICAL Tool was originally created by the American Bar Association for attorneys to help them identify and support implementing decision-making options for persons with disabilities that are less restrictive than guardianship. Like attorneys, healthcare providers may find themselves involved with families and patients as they navigate similar issues, and also like attorneys, little has been done historically to prepare them for attending to the full breadth of decision making support options available.

This manual begins with the PRACTICAL Tool, amended for use by healthcare providers, and then moves into a more detailed overview of patient-centered care (Part I) and other decision making supports that do not involve the removal of rights (Part II).

PRESUME GUARDIANSHIP IS NOT NEEDED.

- Consider less restrictive options like financial or health care power of attorney, advance directive, trust, or supported-decision making.
- Review state statute for requirements about considering such options.

REASON. CLEARLY IDENTIFY THE REASONS FOR CONCERN.

Consider whether the individual can meet some or all of the following needs:

Money Management:

- Managing accounts, assets, and benefits
- Recognizing exploitation

Health Care:

- Making decisions about medical treatment
- Taking medications as needed
- Maintaining hygiene and diet
- Avoiding high-risk behaviors

Relationships:

- Behaving appropriately with friends, family, and workers
- Making safe decisions about sexual relationships

Community Living:

- Living independently
- Maintaining habitable conditions
- Accessing community resources

Personal Decision-Making:

- Understanding legal documents (contracts, lease, powers of attorney)
- Communicating wishes
- Understanding legal consequences of behavior

Employment:

 Looking for, gaining, and retaining employment

Personal Safety:

- Avoiding common dangers
- Recognizing and avoiding abuse
- Knowing what to do in an emergency

Observations and Notes: (List supports needed)

Ask if a triggering concern may be caused by temporary or reversible conditions.

Are concerns the result of or related to temporary or reversible conditions such as:

- Medical conditions: Infections, dehydration, delirium, poor dental care, malnutrition, pain
- Sensory deficits: hearing or vision loss
- Medication side effects
- Psychological conditions: stress, grief, depression, disorientation
- Stereotypes or cultural barriers

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COMMUNITY.

Determine if concerns can be addressed by connecting the individual to family or community resources and making them accommodations.

Ask "what would it take?" to enable the person to make the needed decision(s) or address the presenting concern.

Might any of the following supports meet the needs:

Community Supports:

- In-home care, adult day care, personal attendant, congregate and home delivered meals, transportation
- Care management, counseling, mediation
- · Professional money management

Informal Supports from Family/Friends:

- Assistance with medical and money management
- Communication assistance
- Identifying potential abuse

Accommodations:

- Assistive technology
- Home modifications

Residential Setting:

- · Supported housing or group home
- Senior residential building
- Assisted living or nursing home

TEAM.

Ask the person whether he or she already has developed a team to help make decisions.

- Does the person have friends, family members, or professionals available to help?
- Has the person appointed a surrogate to help make decisions?

Observations and Notes:

IDENTIFY ABILITIES.

Identify areas of strengths and limitations in decision-making if the person does not have an existing team and has difficulty with specific types of decisions.

Can the individual:

- Make decisions and explain his/her reasoning
- Maintain consistent decisions and primary values over time
- Understand the consequences of decisions

CHALLENGES.

Screen for and address any potential challenges presented by the identified supports and supporters.

Screen for any of the following challenges: **Possible challenges resulting from guardianship:**

- Eligibility, cost, administrative burden
- Loss of Individual Rights
- Ability to secure employment or enroll in postsecondary education or training

Possible concerns about supporters and guardians:

- Risk of undue influence
- Risk of abuse, neglect, exploitation (report suspected abuse to adult protective services)
- Lack of understanding of person's medical/ mental health needs
- Lack of stability, or cognitive limitations of supporters
- Disputes with family members

Observations and Notes:

Advance supporter or surrogate consistent with person's values and preferences.

Could any of these appointments meet the needs:

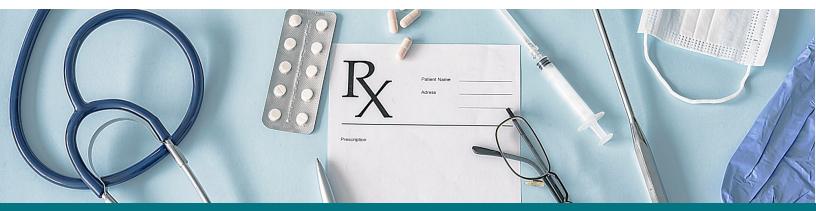
- Agent under health care power of attorney or advance directive
- Health care surrogate under state law
- Agent under financial power of attorney
- Trustee
- Social Security representative payee
- VA fiduciary
- Supporter under representation agreement

LIMIT YOUR RECOMMENDATIONS FOR GUARDIANSHIP OR FINDINGS OF INCAPACITY.

If a guardian is needed:

Limit recommendation to guardianship to what is absolutely necessary, such as:

- Only specific property/financial decisions
- Only property/finances
- Only specific personal/health care decisions
- Only personal/health care decisions



Part I

Why Should Medical Professionals Know about Supported Decision Making?

Patient-Centered Care

How you, as a practitioner, talk about disabilities to your patients may set the tone for the expectations they have for their lives. Your words matter and have an effect on your patients' attitude, perspective, and life choices.

You and your colleagues most likely encounter family members of patients and patients themselves who inquire about guardianship, Supported Decision Making, or other future planning. You are in a position where you likely find yourself faced with questions and requests for information regarding decision making supports for your patient or even statement requests for filing a guardianship petition.

As a Medical Provider, you are in a unique position to write a Physician's Statement or affidavit regarding an individual's capacity in the support of a petition for guardianship or to be an advocate for and alongside your patients with disabilities while promoting self-determination and independent living.

Physicians have a duty to protect every patient, including the patient's privacy, consent, and right to self-determination. Preservation of legal capacity is a priority for all individuals and retains guardianship as an extreme last resort (The Arc of the US).

Your patients should not have their decision-making abilities questioned because they have a disability. The decision-making abilities of individuals with disabilities is often too quickly questioned or discounted due to their disabilities, yet individuals regardless of a disability may make choices deemed good or bad.

As a physician, you should only recommend guardianship after all other less restrictive alternatives have proven to be ineffective or unavailable (American Bar Association & NGA).

25%

of South Carolinians have a disability (CDC).

This 25% of South Carolinians who have disabilities see you as their physician and need optimal care that maximizes their dignity and autonomy.

Disability alone, including but not limited to intellectual, physical, emotional, psychiatric, or developmental disability, is not an adequate indicator of an individual's ability to live independently or make informed decisions about their lives.

How individuals with disabilities are treated by their families, medical providers, and community affects how they view themselves, their abilities, and their lives. The model of care you use as a practitioner could either empower your patient to live an autonomous, independent life or render them powerless to the individuals around them.

Individuals with disabilities want their medical providers to recognize the role that the social model plays in their care. That is, they want their doctors to understand that any limitations to their independence can be addressed by connecting the appropriate supports and removing barriers. Individuals with disabilities, just like individuals without disabilities, want to make their own decisions and have the decisions honored regardless of the outcome. Guardianship should be restricted to an extreme measure because it may substantially limit one's liberty to make their own decisions.

The American Bar Association states, "In many cases, courts appoint guardians for people who could continue to make their own decisions with the right supports and services." In between an individual completely making decisions on their own and having a guardian appointed to make decisions is Supported Decision Making. Supported Decision Making may be used in a formal or an informal capacity to support an individual making decisions without making decisions on behalf of that person.

What is Supported Decision Making?

Almost everyone has relied on someone else to help them make a decision. People with and without disabilities occasionally need support in the decision making process. Supported Decision Making is "a recognized alternative to guardianship through which people with disabilities use friends, family members, and professionals to help them understand the situations and choices they face, so they make their own decisions without the 'need' for a guardian."

In Supported Decision Making, individuals can choose "Supporters" to assist them in different areas of their lives - employment, education, services, finances, health, etc. The Supporters and their duties are listed in an agreement that is shared with all of the individual's medical and service providers to ensure that the Supporters are included in discussions surrounding important decisions. The Supporter does

NOT make decisions for the individual or discuss matters without the individual present. Instead, the Supporter helps explain information in an understandable way, guides the individual in weighing the courses of action, and advises the individual on the consequences of the decision.

Everyone relies on help and guidance from family, friends, co-workers, and others in the community when making big decisions, such as which car to buy or where to live. Supported Decision Making is not something specific to those with disabilities. Supported Decision Making is a concept that recognizes none of us exist in a vacuum! We all need advice from time to time in order to make decisions.

Some legal scholars and advocates have defined Supported Decision Making as "a less restrictive alternative to guardianship that empowers people with limitations in decision-making to express their own preferences, make their own decisions, and direct their own lives without the need for a guardian." (Quality Trust for Individuals with Disabilities et al. 2015, p.1).

A similar definition holds that this process is a recognized alternative to guardianship through which people with disabilities use friends, family members, and professionals to help them understand the situations and choices they face, so they may make their own decisions without the need for a guardian (Blanck & Martinis, 2015).

Supported Decision Making emphasizes the importance of letting the person with a disability decide, to the extent she is able, what her life should look like and who should help her reach those goals. In this way, a person with a disability can fully access the opportunities they need to become increasingly independent, learning about their own affairs and building critical skills as they move through life.

Methods of support can be informal (asking a relative for help making financial decisions) or formal (signing a HIPAA release so a parent can help break down complex medical information). The individual decides who will support her and how much support they will offer. The supporters and individual may sign a Supported Decision Making Agreement. Typically, a Supported Decision Making Agreement is a document that lists the areas in which an individual would like to be supported, along with the extent that this support should occur, and who should provide support. An example can be found in the appendix of this manual.

Benefits of Supported Decision Making

Supported Decision Making is an extension of self-determination, meaning an individual directs the plan for his life. He decides what is important to him, sets goals, and, with the support of those around him, he works to achieve those goals in order to live the most fulfilling life possible. Ask people with disabilities what they want for their lives, and most will tell you they desire independence, gainful employment, friendships, and romantic relationships. This is no different from what anyone else would want. And, as is true for anyone else, life is full of risks. An individual with a disability must learn to manage and avoid risks, as opposed to never being allowed to make any decisions for themselves.

Several studies have found that people who exercise more self-determination were more likely to live independently, have greater financial independence, be employed at higher paying jobs, and make greater advances in their employment (Wehmeyer & Palmer, 2003). In addition, self-determination has been shown as a predictor of post- high school success in employment and independent living (Test et al., 2009).

Utilizing a Supported Decision Making Agreement, unlike Guardianship, increases positive aspects of health, integration into the community, and quality of life. Compared to guardianship, a Supported Decision Making Agreement may increase:

- Psychological health
- Self-determination
- Self confidence
- Seeking + maintaining employment
- Likelihood of higher pay
- Money management
- · Independence in daily life
- Successful transition to adulthood

Implications of Guardianship

While many families seek guardianship out of a desire to protect their loved ones, what they fail to realize is that a person under full guardianship cannot make any decisions for him or herself. The process to obtain guardianship can be expensive, time-consuming, and may damage relationships. It also represents a profound responsibility on behalf of the guardian. If this person is unable to or unwilling to serve as a guardian in the future (due to illness or death, for example) additional legal hurdles will need to be addressed, and the court has the ultimate authority to determine who the guardian should be.

In some cases, guardianship may be used as a last resort when no other measure sufficiently protects a person with a disability. However, overly restrictive measures can limit the development of important independent living skills (Quality Trust for Individuals with Disabilities et al., 2015).

Guardianship may take away an individual's right to:

- Marry
- Vote
- Drive
- Seek or maintain employment
- Manage money or property
- Decide where to live
- Consent to medical treatment or medical decisions
- · Choose friends or who to spend time with

Guardianship may also be difficult to terminate because of costs, time, and the number of cases in the courts.

Individuals under guardianship may be more likely to experience:

- Abuse
- Neglect
- Financial exploitation
- Decrease in ability to function

The Supported Decision in Action

During the process of working with patients with disabilities, you may need to assess the supports in place to help individuals make decisions, if there are any at all. You most likely already have certain elements of Supported Decision Making in place in your practice, such as encouraging clients to sign a HIPAA agreement should the patient want a loved one's support in any capacity. More examples of such elements can be found in the "Possible Alternatives to Guardianship" section of this manual.

Keep in mind that many families receive very little to no information about the concept of Supported Decision Making. Often, parents of individuals with disabilities are seeking you as a physician to recommend guardianship (in writing) for their child. The parent or guardian may have already determined that guardianship is the best option for their child yet they may be unaware of less restrictive alternatives. Parents, guardians, and the patients may have misconceptions about the nature of decision-making as it relates to people with and without disabilities.

Medical providers should not sign off on documents stating that a patient needs guardianship solely because of the parents' or guardians' encouragement or persistence. Encourage such patients and parents/guardians to contact Able South Carolina (please see the appendix for contact information) and/or an attorney. Providers should never provide legal advice unless they are licensed to practice law. In addition, providers should identify and address, to the extent they are able, potential barriers to the decision-making process. Examples of addressing barriers include providing or altering assistive technology, adjusting medication that interferes with cognition, and addressing mental health status.

Signing a legal document stating that a patient does not have the ability to make decisions on their own should not be taken lightly or without exhausting all resources and possible supports.



Part II

Communicating Options with Patients and Families

The Continuum of Decision Making Supports

Decision making is a process that varies greatly from person to person. Most would agree, however, that the process of making decisions, especially complicated or life altering decisions, is something that should suit the individual affected by the decision.

For many, that process can and should involve information and support from sources trusted by the decision maker. We must ask: what decision-making supports are currently in place, and where are there opportunities for education? Instead of focusing on what a person is unable to do, we pay attention to their strengths. Allow an individual with a disability to experience responsibility instead of shielding them from decision-making, and you may be pleasantly surprised at what they can accomplish.

When considering the barriers to independence a person faces, ask yourself if these can be lessened by measures like assistive technology, training, opportunities to socialize, role-playing, and other means. Consider the person's mental state, nutrition, access to stimulating environments, and side effects from medication before determining that an individual is unable to make decisions. Does your setting offer a quiet location free from distraction? Would simple edits to a manual, documents, or test results, such as adding pictures or easier to understand language, help individuals with understanding and decision-making?

There are a number of existing state statutes, federal laws and policies, and practices that tie in to supporting individuals in being at the center of their own decision making. Supports tend to fall into two categories of decision making: surrogate and supported. Surrogate decision making, as in guardianship or a health care power of attorney, is when some with the legal authority to do so gives decision making authority to a 3rd party. Supported decision making involves supports that empower a decision maker formally or informally to remain at the center of their own decisions. The following chart explores some of the options at hand for surrogate or supported decision making.

Additional guidance on decision making supports can be found on the "Resources" page of https://scsupporteddecisionmaking.org/resources/.

A **Supported Decision Making Agreement** allows individuals 18 years and older to have legal supports in making life decisions without the restrictions of guardianship. With a Supported Decision Making Agreement, decisions remain in the individual's power, but they have accessible designated supporters to go to for support as needed. A Supported Decision Making Agreement allows designated supporters access to supporting the individual in the following areas including but not limited to healthcare, education, housing, and finances.

Each Supported Decision Making Agreement is unique to the individual and tailored to the areas that an individual needs supports. Some may choose to have their agreement written up in a durable power of attorney, while others may elect to forgo a written agreement formalizing the nature of their support.

Power of Attorney and Living Will

A Power of Attorney allows one person to make decisions on behalf of another person (called a principal). Decisions can be about medical treatment (Health Care Power of Attorney), finance (Financial Power of Attorney), real estate, and other matters. The agent does not need to be an attorney to be authorized to make such decisions. Health Care Power of Attorney and other documents such as a living will (where an individual makes end-of-life decisions and documents those decisions in case they become incapacitated) are some of the most common examples of an advance directive.

HIPAA Release

An individual can choose a family member, friend, or other trusted person with whom health care providers may discuss the individual's medical condition and treatment plan. This can allow a parent to enter an examination room with an adult child, for example, without needing Health Care Power of Attorney. Typically, each medical provider provides a HIPAA release to the patient. It can be changed or revoked at any time by letting the provider know.

Adult Health Care Consent Act

Many family members may worry about what happens in a medical emergency if a person with a disability uses a Supported Decision Making Agreement. First, if an individual has the ability to consent to medical care, they will do so. However, in an emergency where the person cannot communicate due to the emergency or a situation where the proposed health care and the decision to be made is so complicated that the person is not competent to make the decision, the Adult Health Care Consent Act might apply if two licensed physicians find that the person is unable to consent to health care. In those situations, the Act would identify a surrogate decision maker for the person, usually the next of kin.

Adult Students with Disabilities Educational Rights Consent Act

As the Adult Health Care Consent Act operates for health care decisions, the Adult Students with Disabilities Educational Rights Consent Act provides alternative processes to ensure a student with a disability's education is not side-railed by the lack of having someone to consent to the education process. First option, the student can manage education decisions independently; second option, the student can use a supporter to assist with their decisions about their education; third option, the student can appoint a decision maker through a power of attorney; and fourth option, if the student cannot communicate, a decision maker can be appointed for that student.

Trusts

Trusts allow a third party to hold money and assets on behalf of someone else (usually called a beneficiary). There are many different ways to set up a trust, and some are tailored specifically for those with disabilities so as not to impact other benefits. Because of the many different ways a trust may be arranged, it is best to speak with a financial manager who can more accurately assess your needs.

Representative Payee Program

Offered through the Social Security Administration, this program allows a representative to manage a beneficiary's SSI or SSDI payments. A representative may be responsible for using benefits to pay an individual's expenses and keeping track of expenditures. Typically a family member or other trusted adult is chosen to act in this role; however, one may be appointed through the Administration.

Laws Protecting Vulnerable Adults

In South Carolina, the Omnibus Adult Protection Act (the Act), is designed to protect vulnerable adults from abuse, neglect, and exploitation (S.C. Code § 43-35-5 et seq.). The Act provides both criminal and civil remedies for individuals who have been or who are at risk of abuse, neglect, or exploitation, including self-neglect. Id. Adult Protective Services is available to assist individuals and families with finding ways to protect the health and welfare of adults with disabilities.

Guardianship determines that the individual lacks the ability to meet essential requirements for physical health, safety, or self-care, even with the appropriate supportive services, technological assistance, or other supports. Guardianship determines a person is unable to receive and evaluate information or communicate decisions. Guardianship may take away the right to marry, vote, drive, seek or maintain employment, manage money or property, decide where to live, consent to medical treatment or medical decisions, and choose friends or who to spend time with. Individuals under guardianship may be more likely to experience abuse, neglect, financial exploitation, and decrease in ability to function.

Family Dynamics

In some cases, families have assumed the role of decision-maker even when the individual has demonstrated his or her ability to make reasonable decisions consistent with his or her morals and values over time. Families often act out of concern for their loved one, fearing that the individual might make poor decisions. Note that because an individual makes a poor decision does not mean he or she is unfit to make decisions altogether. People with and without disabilities should have opportunities to learn from failure, and sound decision-making is a skill that must be learned and practiced over time, like many other skills that are necessary for independence. Family dynamics are complex. "That's the way we've always done things," might be a phrase you've grown accustomed to hearing from concerned family members. As a medical provider, you are in a unique position to advocate for Supported Decision Making, but this is not without its challenges.

Assume that individuals can make decisions.

Although a family might insist that an individual is incapable of making their own decisions, as a provider you should assume that the individual can make decisions for herself unless given compelling evidence to the contrary. Keep in mind that in South Carolina, it is assumed that a person 18 years or older has the capacity to make decisions, regardless of disability.

Always talk directly to the patient you are serving, even if a family member, guardian, or caregiver is helping you communicate with the individual. Consider assistive technology devices (which may be as low-tech as a dry erase board or simple pictures to aid in understanding) which may help the individual communicate. Be aware of family members, guardians, and caregivers who insist on answering for the individual. If necessary, speak to the individual alone.

Sound decision-making reflects primary values that remain consistent across time, and the individual's ability to explain his or her reasoning and understanding of consequences. Again, keep in mind that a poor decision or one that is unpopular with the individual's family, does not mean the individual is unable to make decisions. Decision-making should be coupled with an appropriate amount of responsibility and freedom; oftentimes, those with disabilities are "excused" from behaving in socially acceptable ways or are shielded from rules, responsibility, and expectations.

How Do Medical Providers Determine the Decision Making Ability of a Patient?

Currently, there is no universal method for determining the decision making capacity of a patient. Due to the lack of universal method for determining the decision making capacity for the patient, the final determination of the decision making capacity is solely up to the treating physician.

Therefore, it is important for the physician to be objective during the assessment and not make a face value judgement of a patient's decision making capacity. On the next page is a checklist for physicians to ensure they are giving the patient adequate opportunities to reflect their decision making abilities.

Medical Provider Checklist:

Have you provided accommodations for your patient's specific disability? Examples of accommodations may include but are not limited to assistive technology, an interpreter, a dimly lit room, etc.
Has the patient been able to practice utilizing decision making skills in the areas of question? Patients need to be given adequate opportunity to grow in their decision making abilities. The patient should be given chances to practice their decision making skills before a final decision about their decision making capacity is made.
Have you had adequate opportunities to see the patient's decision making capacity utilized before a final decision is made?
Has a rapport been established with the patient before the decision making assessment is conducted? An assessment with a patient before rapport has been established could make the patient more nervous and not perform as well under the stress of an evaluation with a physician they do not know well.

If a physician determines that a patient does not have the capacity to make decisions, the legal decision making capacity of the patient may be completely taken away by a court in all major aspects of their life.

A structured approach should be used when determining a patient's decision making capacity. The assessment should be made accessible to the patient depending on the presenting disability or barriers for the patient with adequate time for the patient to strengthen their decision making skills before a final decision is made.

Supported Decision Making Resources

Recommended Health Care Transition Timeline

It is important to begin the transition process early in adolescence preparing youth for adult health care, so they have practice utilizing the necessary skills and are prepared for the responsibility of their own healthcare. Below is the recommended healthcare transition timeline to adequately prepare patients with and without disabilities for the transition into healthcare as an adult. For more on recommendations for how to address the timing of healthcare transition considerations, visit https://www.gottransition.org/providers/index.cfm.

Recommended Health Care Transition Timeline

14 16 18 18-22 23-26 Make youth and Initiate health care Prepare youth and Transition to adult Transfer care to Integrate young family aware of transition planning parents for adult model of care adult medical home adults into adult transition policy model of care and and/or specialists care discuss transfer with transfer 18 package

Transition Readiness Assessment

Got Transition recommends that doctors "conduct regular transition readiness assessments, beginning at age 14, to identify and discuss with youth and parent/caregiver their needs and goals in self-care" and "jointly develop goals and prioritized actions with youth and parent/caregiver, and document regularly in a plan of care." An English and Spanish version of a transition assessment can be found by visiting https://www.gottransition.org/providers/staying-3.cfm.

Making My Own Healthcare Decisions: A Letter for My Doctors

The Arc of the United States created a great template for individuals to plan for and communicate the nature of their Supported Decision Making arrangements for healthcare providers. It is a tool that may greatly aid patients in beginning to think through how SDM can work for them in a way that lends itself to better communication with providers on what works best. The tool can be found by visiting https://www.thearc.org/file/Making-My-Own-Health-Care-Decisions--A-Letter-for-to-My-Doctors.pdf.

SC SDM Agreement

Like "A Letter for My Doctors," the SC Supported Decision Making Project has created a tool to help decision makers plan for and document the manner in which they will receive support in making and communicating decisions. The SC Supported Decision Making Agreement can be found by visiting http://scsupporteddecisionmaking.org/wp-content/uploads/2017/07/SDM-Representation-Agreement7.28.17. pdf.

Dr. Nathan Bradford on SDM

In 2017, the SC Supported Decision Making Project had the pleasure of interviewing Dr. Nathan Bradford of AnMed Health on his perspective of SDM. A video of the short interview was filmed and can be viewed by visiting https://www.youtube.com/watch?v=30Q6L3hklck.

SDM Manuals

In addition to this manual, the SC Supported Decision Making Project has also published manuals on the topic of SDM and alternatives to guardianships for individuals and families, attorneys, and service providers. Links to those manuels as well as a host of other resources can be found by visiting http://sc-supporteddecisionmaking.org/resources/.

NRC-SDM

The National Resource Center for Supported Decision Making is at the fore of best practice regarding SDM in the US. They offer a great broad perspective on issues in SDM, and you can learn more about their work by visiting http://supporteddecisionmaking.org/.

For more on how the SC Supported Decision Making Project can support you in your work, contact info@able-sc.org.