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INTRODUCTION

PURPOSE OF THIS MANUAL

This manual was written by partners of the South Carolina Supported Decision Making Project to provide information about Supported Decision Making to providers serving people with disabilities. You will read how Supported Decision Making can be used in place of more restrictive means, such as guardianship, to preserve a person's autonomy and independence, while still providing the person with support from his or her family, friends, and community, and how your organization can best promote Supported Decision Making.

Keep in mind that when a person turns 18 in South Carolina, it is presumed that the individual has a capacity to make legal, medical, educational, and other such decisions. Supported Decision Making is in line with this concept. It is a tool that can be used to support adults with disabilities to make their own decisions.

COLLABORATING AGENCIES

This manual was created through funding received from the South Carolina Developmental Disabilities Council. It represents a collaborative effort between:

- Able South Carolina
- Protection and Advocacy for People with Disabilities, Inc.
- Family Connection of South Carolina
- The Arc of South Carolina

Together, these agencies form the South Carolina Supported Decision Making Project.

DISCLAIMER

This manual provides legal information, but is not intended to be legal advice. The information is based on the law at the time this manual was produced. In South Carolina, there is currently no law that specifically says a Supported Decision Making Agreement can be enforced. There is no law against having a Supported Decision Making Agreement either. If you have questions about your legal rights, please talk with an attorney.

WHY PROVIDERS SHOULD KNOW ABOUT SUPPORTED DECISION MAKING

In your work with individuals with disabilities, you have most likely found there are a variety of methods that individuals and families use to make decisions; some formal, others informal, and many in between.

You and your staff may encounter clients and families who have questions about guardianship, Supported Decision Making, or other future planning. It is unlikely that you or your staff are in a position to offer legal advice to families and individuals regarding guardianship, Supported Decision Making, and other alternatives. However, you will most likely find yourself faced with questions and requests for more information and, depending on your core functions as a provider, offering services, referrals, and other supports for people with Supported Decision Making Agreements. As a provider, you are also in a unique position to advocate for and alongside individuals while promoting self-determination among those you serve.

It is crucial for providers to respect the choices and rights of the individuals they serve, while fostering an environment of self-determination and independence. Providers should respect an individual's informal and formal agreements regarding decision making. More detail on potential arrangements can be found in "Possible Alternatives to Guardianship" and "Legal Alternatives to Guardianship." While this manual is focused on the concept of Supported Decision Making, please keep in mind that the options listed in this manual do not represent all available arrangements that individuals may choose.

Please review the Supported Decision Making Agreement located in the appendix to fully understand the nature of the document.

WHAT IS SUPPORTED DECISION MAKING?

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 quardian (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.

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 make medical decisions). 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.

THE SUPPORTED DECISION MAKING MODEL

HOW DOES

Supported Decision Making





choose

The individual decides who will be involved in supporting him or her. The supporters must also agree to be involved.





discuss

The individual and supporters talk about how the individual will be supported, which can include finance, healthcare, education, employment, and others. The individual can choose to have support in some areas but not others.





make a plan

The individual and supporters create a document that outlines how the individual will be supported. This is the Supported Decision Making agreement.





sign

The individual and supporters sign the Supported Decision Making agreement. The agreement can be revised if necessary in the future. Everyone receives a copy of the agreement.



For a complete copy of a Supported Decision Making Agreement, please see the appendix.

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).

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. In fact, it has been said that a prisoner has more rights than a person under guardianship (House Select Committee on Aging, H.R. Rpt. 100-641). A guardian may remove a person's right to vote, sign contracts, receive money or pay bills, or get married. 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.

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).

INTRODUCING THE SUPPORTED DECISION MAKING CONCEPT

During your intake process, you should assess the supports in place to help individuals make decisions, if there are any at all. Depending on the nature of your work, you may already have certain elements of Supported Decision Making in place (such as encouraging clients to sign a HIPAA agreement). More examples of such elements can be found in "Possible Alternatives to Guardianship."

Keep in mind that many families receive very little information about the concept of Supported Decision Making, and are often encouraged to seek guardianship. They may have misconceptions about the nature of decision-making as it relates to people with

disabilities.

Providers should encourage such clients 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 include providing or altering assistive technology, adjusting medication that interferes with cognition, and addressing mental health status.

COMMUNICATING WITH INDIVIDUALS AND FAMILIES

Addressing Challenges

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 provider, you are in a unique position to advocate for Supported Decision Making, but this is not without its challenges.

Assume the Individual Can Make Decisions

Although a family might insist that an individual is incapable of making her 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 individual 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 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.

Assess Barriers and Consider Solutions

Determine the individual's goals and needs as it relates to your practice. 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, 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 they 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, such as adding pictures or easier to understand language, help individuals with understanding and decision-making?

Below is a more comprehensive list of ways to promote independence within the Supported Decision Making framework. Some measures are formal, legal processes, while others are informal. Note that this table does not include all possible alternatives. As a provider, you may already have some of these in place, or be in a position to recommend them to your clients. You can also use <u>The Stoplight Tool worksheet</u> to identify alternatives to guardianship.

POSSIBLE ALTERNATIVES TO GUARDIANSHIP

Need	Tasks	Can this be accomplished by:
Money Management	 Managing accounts, assets and benefits Learning to recognize and prevent exploitation 	 Conservatorship or trust Seeking financial counseling Representative Payee Program Money-managing app on phone
Health Care	 Making decisions about medical treatment Taking medications as needed Maintaining hygiene and diet Avoiding high-risk behaviors 	 Obtaining Health Care Power of Attorney or Living Will Having individual sign HIPAA release Using Adult Health Care Consent Act for areas of health care beyond the person's ability to understand (read more about this in the "Alternatives to Guardianship" section) Using apps to help remember to take medication and perform hygiene tasks Visiting a health care professional to discuss information regarding prevention and safety Allowing a home health aide to assist in daily living tasks Getting advice from professionals
Employment	 Looking for, gaining, and retaining employment 	 Enrolling in job coaching services, such as supported employment programs Using Vocational Rehabilitation, Medicaid waiver services, or other employment providers to become job-ready
Relationships	 Behaving appropriately with friends, family, and co- workers Making decisions about sexual relationships 	 Role-playing and practicing appropriate behavior Visiting a health center to learn more about contraception Speaking with loved ones

Need	Tasks	Can this be accomplished by:
Community Living	 Living independently Maintaining habitable conditions Accessing community resources 	 about healthy relationships Incorporating adaptive and assistive technology Setting reminders to complete home maintenance tasks Making a list of community resources, such as
Personal Decision Making	 Understanding legal documents (contracts, leases, powers of attorney) Communicating wishes Understanding legal consequences of behavior 	 Allowing supporters to help explain contracts and other legal documents Having the individual demonstrate understanding of consequences, such as through role-playing Seeking advice from professionals
Personal Safety	 Avoiding common dangers Recognizing and avoiding abuse Knowing what to do in an emergency 	 Role-playing scenarios, such as what to do in case of fire Discussing signs of healthy and unhealthy relationships and abusive behaviors Writing down emergency numbers

Adapted from: American Bar Association, 2016

With a Supported Decision Making Agreement, the person, along with his or her circle of support, will decide which tools can be used in order to retain the highest level of independence while still providing appropriate levels of guidance.

Example: Johnny has autism and is about to turn 18. He is excited to begin classes at a community college next year. He, his family, and those close to him sit down together to form a Supported Decision Making Agreement. Even though he will be 18, Johnny still wants his parents to attend doctor's appointments with him, and to be able to discuss any medical issues with his doctors. Together, they decide to sign a HIPAA release form to allow communication between Johnny's parents and his medical providers. Johnny is also nervous about dating, making new friends, and adjusting to the changes that college will bring. Johnny's pastor agrees to support Johnny by talking to him about approaching girls he is interested in, as well as what a healthy relationship and friendships should look like. Johnny's aunt and uncle agree to check in with him regularly once he starts college to make sure he is spending time studying and completing assignments.

LEGAL ALTERNATIVES TO GUARDIANSHIP

Unless you are licensed to practice law, it is most likely beyond your scope of practice to offer legal advice to clients. However, being aware of legal alternatives can allow you to support individuals and families in a more comprehensive manner.

This is by no means an exhaustive list of all legal alternatives to guardianship, and is not intended to be legal advice. If you have further questions be sure to contact an attorney or Protection and Advocacy (information is located in the appendix).

Power of Attorney and Living Will¹

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), finances (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 doctors 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

Like the 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

¹ In South Carolina, a living will is called a "Declaration of Desire for Natural Death," but is still commonly referred to as a "living will."

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.

Trust

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 Social Security or SSI 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.

APPENDIX

WHO CAN I CONTACT FOR MORE INFORMATION?

South Carolina Supported Decision Making Project

For more information on the SC Supported Decision Making Project and resources, including a downloadable copy of this manual, visit www.scsupporteddecisionmaking.org

Able South Carolina

803-779-5121

Toll-free: 800-681-6805 TTY: 803-779-0949 www.able-sc.org

Family Connection of South Carolina

803-252-0914

www.familyconnectionsc.org

The Arc of South Carolina

803-748-5020 www.arcsc.org

Protection & Advocacy for People with Disabilities, Inc.

803-782-0639

Toll-free: 866-275-7273 TTY: 866-232-4525 www.pandasc.org

South Carolina Developmental Disabilities Council

803-734-0465

TTY: 803-734-1147 www.scddc.state.sc.us

FREQUENTLY ASKED QUESTIONS

1. My clients would like more information in Supported Decision Making. Are there any resources I can provide?

Clients interested in learning more about the Supported Decision Making process may contact Able South Carolina at 803-779-5121, or visit www.scsupporteddecisionmaking.org.

2. How can providers best promote Supported Decision Making?

Providers can promote this concept by doing the following: being aware of Supported Decision Making and how it works; referring clients and families to Able SC to learn more about the Supported Decision Making Process; assuming clients have the ability to make decisions unless given a reason otherwise; and putting supports in place to promote self-determination and person-centered decision making. Please see "Communicating with Individuals and Families" for more information.

3. Is a Supported Decision Making Agreement legally enforceable?

At this time, courts in South Carolina have not addressed Supported Decision Making Agreements. However, if an individual has not been deemed incompetent or incapacitated, providers are obligated to respect the individual's wishes in how services are delivered. It is also important to note that at age 18, a person, regardless of disability, is presumed to have decision-making capacity. Going through the Supported Decision Making process also allows individuals and families to have important discussions about an individual's goals, dreams, and priorities. As you review the sample Supported Decision Making Agreement in the appendix, note that either party can end the agreement at any time.

THE SUPPORTED DECISION MAKING AGREEMENT



SUPPORTED DECISION MAKING AGREEMENT

READ THIS: This agreement is a sample of a Supported Decision Making Agreement. Having this sample is not a substitute for seeking legal advice from an attorney. In South Carolina there is no law that specifically says that a Supported Decision Making Agreement can be enforced. There is no law against having a Supported Decision Making Agreement either. If you have questions about your legal rights, please talk with an attorney.

This is the Supported Decision Making Agreement of Name: ______Date of birth: _____ Address: _____ Telephone: _____ Email: ____ **A.** Lunderstand: I can talk to an attorney before I sign this agreement. П П This agreement is because I want supporters to help me make decisions. My supporter cannot make decisions for me. П I can end this agreement when I want it to. I can change this agreement when I want to. I can change my list of supporters when I want to. My supporter(s) can quit if they want to.

	If I end this agreement or change this agreement, I must let my supporters know about the change. Anyone with a copy of the agreement needs to get a copy of the change in writing.
В.	I need supporter(s) to help me make decisions about:
	Taking care of my financial affairs, like banking (Finances)
	My health care, including big and small health care decisions (Health Care)
	Talking to an attorney if I need one and working with the lawyer (Legal Matters)
	My education, including what classes I will take and what accommodations I will have (Education)
	My employment, including what work I will do and what accommodations I need to do it (Work)
	Where I live, what I do, the services I receive, and who helps me day to day (Life Plan)
	□ Other matters:
C.	I expect my supporter(s) to help me in the following ways:
	Giving me information in a way I can understand
	Discussing the good things and bad things (pros and cons) that could happen if I make one decision or another
	Telling other people my wishes
П	

D. I express myself and show what I want in the following ways:
☐ Telling people my likes and dislikes.
☐ Telling people what I do and do not want to do.
E. I designate the following individual(s) to be part of my Supported Decision Making Network to assist me in making decisions.
Network Supporter #1
Name:Date of birth:
Address:
Telephone: Email:
Relationship:
I want this supporter to help me with:
□ Finances
□ Health care
with a form to let this supporter see my private health information
without a form to let this supporter see my private health information
□ Legal Matters

□ Education
with a form to let this supporter see my private education information
without a form to let this supporter see my private education information
□ Work
□ Life Plan
□ Other (please specify):
Areas I don't want Supporter #1 to assist me with:
Network Supporter #2
Name:Date of birth:
Address:
Telephone: Email:
Relationship:
I want this supporter to help me with:
□ Finances
□ Health care
with a form to let this supporter see my private health information
without a form to let this supporter see my private health information

□ Legal Matters		
☐ Education		
with a form to let the information	nis supporter see my private education	
without a form to le	et this supporter see my private education	
□Work		
□ Life Plan		
☐ Other (please specify):		
Areas I don't want Supporter #2 to assist me with:		
Network Supporter #3		
Name:	Date of birth:	
Address:		
Telephone:	Email:	
Relationship:		
I want this supporter to he	elp me with:	
□ Finances		
☐ Health care		
with a form to let the information	nis supporter see my private health	

	without a form to let this supporter see my private health information
□ Le	egal Matters
□Ec	ducation
	with a form to let this supporter see my private education information
	without a form to let this supporter see my private education information
□ W	ork
□ Lit	fe Plan
□ o	ther (please specify):
Area	as I don't want Supporter #3 to assist me with:
F.	If I have more than one Supporter (Optional, but if you do not fill out this section, your Supporters will act "Successively".)
	My Supporters will act (choose one)
	☐ Jointly (work together to help me)
OR Supp	☐ Successively (For example: Supporter #2 helps me if corter #1 is not available)
Sign	ature Date

G. Notary Certification

State of South Carolina County of	_
On this day of undersigned notary public, perso	
	ry evidence of identification, which
	, to be the person whose name is ched document in my presence.
(seal)	Notary Public Signature

H. Network Supporters' Statements

Network Supporter #	<u>^Ł1</u>	
express his/her wish information in a way cons of decisions; ar know that I may NOT	consent to act as and that my job as supporter is to honor les. My support might include giving him he/she can understand; discussing prosend helping him/her communicate her chor make decisions for him/her. I agree to the best of my ability, honestly, and in g	n/her s and bice. I support
Signature	Date	
Network Supporter #	<u>‡2</u>	
express his/her wish information in a way cons of decisions; ar know that I may NOT	consent to act as and that my job as supporter is to honor les. My support might include giving him he/she can understand; discussing prosend helping him/her communicate her chor T make decisions for him/her. I agree to the best of my ability, honestly, and in g	n/her s and bice. I support
Signature	Date	
Network Supporter #	<u>‡3</u>	
express his/her wish information in a way cons of decisions; ar know that I may NOT	consent to act as and that my job as supporter is to honor les. My support might include giving him he/she can understand; discussing pros nd helping him/her communicate her cho T make decisions for him/her. I agree to the best of my ability, honestly, and in g	n/her s and bice. I support
Signature	Date	

ADDITIONAL RESOURCES

Center for Disability Resources

Provides resources, programs, and self-advocacy opportunities for people with intellectual and developmental disabilities.

http://uscm.med.sc.edu/cdrhome/index.asp

803-935-5231

I'm Determined Project

Focuses on providing direct instruction, models, and opportunities to practice skills associated with self-determined behavior. Look under the "resources" tab for activities and worksheets.

http://www.imdetermined.org

National Resource Center for Supported Decision-Making

National and local resources and information about supported decision-making.

http://supporteddecisionmaking.org

202-448-1448

Identifying Alternatives to Guardianship Stoplight Tool

A tool to help assess a person's ability to make decisions and manage different life skills. http://moguardianship.com/

South Carolina Assistive Technology Program

Provides access to assistive technology and devices, including device lending programs, training, and demonstrations.

http://scatp.med.sc.edu

803-935-5263; Toll-free: 800-915-4522

South Carolina Department of Disabilities and Special Needs (SC DDSN)

The state agency that plans, develops, oversees and funds services for South Carolinians with severe, lifelong disabilities of intellectual disability, autism, traumatic brain injury and spinal cord injury.

www.ddsn.sc.gov

803-898-9600; Toll-free: 1-888-DSN-INFO (376-4636)

TTY: 803-898-9600

South Carolina Vocational Rehabilitation

Provides job training and readiness skills to those who qualify, including some individuals with disabilities. May also provide workplace adaptations and assistive technology.

www.scvrd.net

803-896-5500; Toll-free: 800-832-7526

TTY: 803-896-6533

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