Promoting Independence in Connecticut: Supported Decision-Making as an Alternative to Guardianship and Conservatorship

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By

The Supported Decision-Making Coalition of CT

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INTRODUCTION

CONNECTICUT SUPPORTED DECISION-MAKING COALITION

The Connecticut Supported Decision-Making Coalition (Coalition) is a collaboration between state agencies and nonprofit disability organizations, education agencies, individuals with disabilities and advocates. The Coalition was established to provide information about Supported Decision-Making to students and adults with disabilities, caregivers, families, educators, policymakers, and anyone interested in supporting the autonomy of adults with disabilities.

THANK YOU TO THE SOUTH CAROLINA SUPPORTED DECISION-MAKING PROJECT

This manual is adapted, with permission, from materials developed by the South Carolina Supported Decision-Making Project. The Project has graciously agreed to allow the Connecticut Supported Decision-Making Coalition to use these materials to support the independence of adults with disabilities in Connecticut.

PURPOSE OF THIS MANUAL

This manual is written for individuals who need support and those who support them. You will read how Supported Decision-Making in Connecticut can be used in place of more restrictive means, such as guardianship and conservatorship, to preserve a person's autonomy and independence, while still providing the person with support from his or her family, friends, and community.

Please be sure to read the entire manual. There are portions of this manual that are written in plain language, and other sections that are not. If there is something you do not understand, please ask for help from a trusted person. There are also resources in the back that can help you. The Appendices contain legal, resource, and support information about Supported Decision-Making. In addition to this manual, the Coalition, is developing materials, conducting webinars, and developing a website to provide resources, videos, and information about Supported Decision-Making Agreements.

DISCLAIMER

This manual contains 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 Connecticut, there is currently no law that specifically allows a Supported Decision-Making Agreement to be enforced but there is no law against having a Supported Decision-Making Agreement either. If you have questions about your legal rights, please speak with an attorney.

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. It is a concept that recognizes that none of us exist in a vacuum! We all need advice from time to time to help us make decisions.

The Quality Trust for Individuals with Disabilities and their partners define 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."*** They also say 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."***

In Connecticut, this would include Supported Decision-Making as an alternative to guardianship and conservatorship.

Supported Decision-Making can be used in many situations involving older adults and people with an array of disabilities. Keep in mind that when a person turns 18 in Connecticut, the law presumes that they have capacity to make legal, medical, educational, and other such decisions. Supported Decision-Making honors this concept as a tool that can be used to support older adults and adults with disabilities to make their own decisions.

In other words, if it is hard for you to make decisions, you may not need a guardian or conservator. You might just need some people you trust to help you make decisions. As a person with a disability, Supported Decision-Making emphasizes the importance of letting you decide, to the extent you are able, what your life should look like, and who should help you reach those goals.

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). You decide who will support you and how much support they will offer. You and the supporters may sign a Supported Decision-Making Agreement which will make your support formal. Typically, a Supported Decision-Making Agreement is a document that lists the areas in which you would like to be supported, how much support you want and when you want it and who should provide it. An example of a Supported Decision-Making Agreement can be found in **Appendix A** of this manual.

HOW DOES

Supported Decision-Making

WORK?

1

CHOOSE

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

2

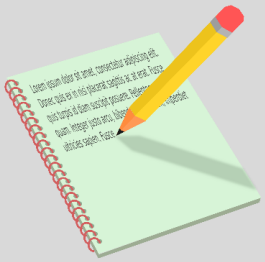
DISCUSS

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

3

MAKE A PLAN

The individual and supporters create a written plan that outlines how the individual will be supported. This is the Supported Decision-Making Agreement.



4

SIGN

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

For a complete copy of a Supported Decision-Making Agreement, please see Appendix A.

BENEFITS OF SUPPORTED DECISION-MAKING

Supported Decision-Making is part of ***self-determination***, meaning you direct the plan for your life. You decide what is important to you, set goals, and, with the support of those around you, work to achieve those goals 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 not 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, with any needed support, rather than never being allowed to make any decisions for themselves.

People who exercise more self-determination:

- were more likely to live independently,
- have greater financial independence,
- are 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).

EFFECTS OF GUARDIANSHIP AND CONSERVATORSHIP

While many families seek guardianship or conservatorship out of a desire to protect their family member with a disability, what they do not realize is that a person under full guardianship or conservatorship 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 (U.S. House of Representatives, Select Committee on Aging, H.R. Rpt. 100-641). A guardian or conservator may remove the person's right to make decisions about many types of important issues. For example, a guardian or conservator can prevent an individual from receiving money, paying bills, choosing where to live, and developing friendships. The process to obtain and also to reverse guardianship or conservatorship can be expensive, time-consuming, and may damage relationships. Overly restrictive measures can limit the development of important independent living skills (Quality Trust for Individuals with Disabilities et al., 2015).

In some cases, guardianship or conservatorship may be used as a last resort when no other measure sufficiently protects a person with a disability. Guardians and conservators have a profound responsibility to the person under guardianship or conservatorship including decision-making that allows the person to live as independently as possible. If a person is unable or unwilling to serve as a guardian or conservator in the future (due to illness or death, for example) additional legal hurdles will need to be addressed.

FOR FAMILY MEMBERS OR OTHER RESPONSIBLE PEOPLE

WHAT TO CONSIDER WHEN PLANNING FOR THE FUTURE

Planning for the future, particularly when the individual has a disability, can be a daunting task. Many families or responsible parties avoid such planning until after there is a problem or crisis. They worry about who will care for their family member or the person for whom they are so responsible, often fearing that outsiders will take advantage of, or otherwise harm, the person with a disability. This can also happen if a guardian or conservator is appointed.

Beginning in elementary or middle school, and sometimes even earlier, families are strongly encouraged to seek guardianship or conservatorship for their child with a disability once the person with the disability turns 18 years old. They are told if they do not seek guardianship or conservatorship, they will not be able to participate in medical care or financial and educational decision-making. Families also worry the individual will be susceptible to sexual or emotional abuse. Guardianship or conservatorship may be a solution to ease a family's worries, but on its own it may do little to adequately address those concerns.

Have Conversations

It is never too early to begin having conversations with a family member or person for whom you are responsible. As a child grows, a family should encourage simple decision-making such as "what color shirt do you want to wear" or "what would you like for breakfast?"

As a child grows up, decisions should become more complex and as they approach their teenage years, you may want to ask questions like:

- Where would you like to go with friends?
- What kind of chores would you like?
- What kind of job would you like?
- With whom would you like to live?
- Where would you like to live?

Practice the idea of consent by allowing the person to make decisions for themselves and taking responsibility for the consequences. This should be coupled

with an appropriate amount of responsibility and freedom. Often, people with disabilities are "excused" from behaving in socially acceptable ways or are shielded from rules, responsibility, and expectations. **Just because an individual makes some *poor* decisions does not mean he or she is unfit to make other decisions. Everyone makes poor decisions at some point in their lives.** 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 so many other skills that are necessary for anyone to live independently.

Start with the Least Restrictive Measures

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. You may be pleasantly surprised at what they can accomplish! Put informal supports in place and seek assistance from disability agencies that may offer skill building and technical assistance.

There are many people who can formally or informally support a person with a disability such as case managers, self-advocacy groups and advocates who can help connect you and the individual with the disability with job training and other supported employment services, independent living skills training, and other resources. When considering the barriers to independence a person faces, ask yourself if they can be improved with things like assistive technology, training, opportunities to socialize, role-playing, and other means. Look at all the individual's personal and environmental circumstances in determining the barriers to decision-making and create opportunities to help develop decision-making skills.

Promoting Independence – A Comprehensive List

Appendix B is a 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.*

> **With a Supported Decision-Making Agreement, the person with a disability, along with his or her supporters, will decide which tools can be used to retain the highest level of independence while still providing appropriate levels of guidance.**

Example: John has autism and anxiety and just turned 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 is 18, John 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 John's parents and his medical providers. John is nervous about dating, making new friends, and adjusting to the changes that college will bring. He thought about who might support him including a trusted friend, his case manager, his next-door neighbor, his coach, and his aunt. John chose his aunt to support him. He talked with her about approaching girls he is interested in, as well as what a healthy relationship and friendships should look like. John asked his aunt and uncle 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 OR CONSERVATORSHIP

In some cases, an individual may want supporters to help him or her with finances, medical treatment, or other areas, and he or she may want formal means for obtaining this support. Below are common legal alternatives to guardianship and conservatorship that preserve an individual's civil rights while allowing supporters to assist in making important decisions.

This is by no means an exhaustive list of all legal alternatives to guardianship or conservatorship and is not intended to be legal advice. If you have further questions, be sure to contact an attorney familiar with the various alternatives to guardianship and conservatorship or Disability Rights Connecticut. (Contact information is in Appendix E).

Power of Attorney

A Power of Attorney (POA) is a legal document that allows an individual to act for you. The individual does not have to be an attorney. The POA document details the types of decisions, called powers, that the individual has the authority to make on

an individual's behalf such as education, finances, real estate, and other specifically listed powers. These can be limited to one or two types of powers or can be broad and allow the individual to do almost anything you would do for yourself**. It is important to note that the document does not take away the individual's right to make those same decisions for him or herself.**

For more information on Power of Attorney, please visit a publication by Connecticut Legal Services called "*Frequently Asked Questions About Power of Attorney."* The website link is:

https://ctlawhelp.org/en/power-of-attorney

HIPAA Release

The individual with the disability can choose one or more a family members, friends, or other trusted persons with whom health care providers may discuss the individual's medical condition and treatment plan. This release, for example, might allow a parent to enter an examination room with an adult child. 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.

Advanced Directives (Living Will and Healthcare Agent)

Advanced Directives are other legal documents through which an individual can express preferences about medical care. In Connecticut, there are two types of Advanced Directives, a Living Will and Appointment of a Health Care Representative.

1. **Living Will** - A Living Will is a legal document used to express an individual's wishes regarding any kind of healthcare, including treatment, the individual may receive in case they become unable to make or communicate decisions about his or her own healthcare. The Living Will also addresses end of life decisions such as life support, treatment, or other measures to prolong the individual's life.

2. **Appointment of a Health Care Representative.** (Sometimes called a healthcare proxy.) A health care representative (HCR) is a person authorized to make health care decisions on behalf of an individual and can include whether to withhold or withdraw life support systems. The HCR is

designated in writing and does not act unless the individual is unable to make or communicate decisions about their medical care. The HCR will make decisions based on the individual's wishes, as stated in a living will or as otherwise known to the individual's HCR. In the event the wishes are not clear or a situation arises that the individual did not anticipate, the HCR will make a decision in the individual's best interests, based upon what is known of their wishes.

More information about Advanced Directives can be found on the website for the Office of the Connecticut Attorney General at:

https://portal.ct.gov/AG/Health-Issues/Connecticuts-Living-Will-Laws

Supported Decision-Making Agreement

This publication focuses on Supported Decision-Making and how it can be used to promote independence for people with disabilities. A Supported Decision-Making Agreement is a tool that can be used to help an individual with a disability to maintain maximum decision-making in his or her own life. The Agreement is a written document between an individual with a disability and one or more persons who act as supporters by providing advice in different areas of the individual's life such as financial decisions, medical, educational, and vocational. The supporters provide advice to help with making a decision but **may not make the decision** for the individual. This publication provides information about the benefits of Supported Decision-Making, considerations in developing a Supported Decision-Making Agreement and a model Agreement.

FOR INDIVIDUALS WITH DISABILITIES

WHY IS IT IMPORTANT TO MAKE MY OWN DECISIONS?

Making your own decisions is important because you know your interests, likes and dislikes, and goals for your future better than anyone else. You are the most qualified person to make decisions about your life! Making decisions can be tough and it takes practice. The more decisions you make, the easier it gets to tell others what you want. Practicing decision-making can help you become more independent so that you rely less on others.

Some decisions are tougher than others. For tough decisions, people with and without disabilities talk to others and get advice before making that decision. You should not be afraid or embarrassed to ask for help or for more information when deciding. Asking for help when needed means you are a wise decision-maker! Just remember, it is okay to disagree with the advice others give you. You make the final decision.

You are the Best Expert About You!!

ADVOCATING FOR YOURSELF

Know Your Rights

Advocating for yourself means letting others know what you want and need. People with disabilities have rights just like everyone else. You have the right to make decisions about your life, including where you work, live, and with whom you spend time. You have the right to vote and get married and have a family if you choose. You have the right to make decisions about medical treatment and medication.

You Have Rights! Know Them!

In the past, and still sometimes today, the rights of people with disabilities are not always respected. You may have been in situations where others were talking about you without asking what you think. You may have had people decide what

classes you should take or what type of job you should do or what type of help or support you need. These are the times when it is important to speak up and let others know how you feel. It is up to you to make sure people know what you want.

Make Sure People Know What You Want and Need!

Most of us need help making decisions, so we turn to those we trust to guide us. For example, you might want your parents to be able to come into the exam room with you at the doctor so they can ask any questions you may forget to ask. Or you may want a family friend to help you with finances because paying the bills and keeping track of how your money is spent can be complicated. You do not have to have a written agreement for people to help you in decision- making, but it may be helpful so everyone is clear on how you want to receive this support. The next section will discuss how to use a Supported Decision-Making Agreement to let others know who will help you and what areas you need support. ***Remember, just because you may need help in some areas does not mean you are unable to make decisions for yourself!*** Like any skill, decision-making takes practice.

It's Okay to Have Support with Making Decisions!

REMEMBER!
• **You are the Best Expert About You**
• **You Have Rights**
• **Know Your Rights**
• **Make Sure People Know What You Want and Need**
• **It is Okay to Have Support with Making Decisions**

What kind of support do I need?

People can support you in many different ways. Here are some examples:

- Changing complicated information to words that are easier to understand.
- Helping you make a list of the good and bad sides for each possible choice.
- Using pictures or videos to help explain something.
- Looking up information to compare different options.
- Teaching how to use technology (apps, communication devices, phones, and computers) to increase independence.
- Making a calendar to remember appointments.
- Working together to make a list of questions to get ready for meetings.
- Helping advocate and making sure your wishes are respected by everyone.
- Helping you practice the best way to communicate your choices.

Use this information to help you fill out the first part of the Supported Decision-Making Agreement. You can fill it out on your own or ask someone for help.

THINGS TO CONSIDER WHEN MAKING A SUPPORTED DECISION-MAKING AGREEMENT

WHEN DO I NEED SUPPORT?

There are many areas of life where a person may need help with making decisions. Some examples are below:

FINANCES

- Do you need help paying bills (cell phone, electricity, rent, internet, etc.)?
- Do you need help buying things (understanding what is a good deal, which products are best, can you afford it)?
- Do you need help with banking?

HEALTHCARE

- Do you need help making and keeping doctor's appointments?
- Do you know what medicines you take, how to find out the dosage amount, and understanding what the side effects may be?
- Do I need help making medical decisions?
- Do you understand how your health care costs are covered (Medicaid, private insurance) and what your co-pays are?

EDUCATION

- Do you know what you need to learn as you leave school?
- Do you need help deciding what college you should attend?
- Do you know what accommodations you need?

WORK

- Do you know what accommodations you need at work and how to ask for them?
- Do you need help understanding your employee responsibilities or work policies?

LIFE PLAN

- Do you know where you want to live and what you should know before choosing a home?
- Do you know how to find transportation to places in your community?
- Do you know the difference between healthy and unhealthy relationships?
- Do you know how to plan for an emergency?

LEGAL MATTERS

- Do you need help understanding your rights?
- Do you know what to do if you think someone is violating your rights?

These are just some examples. You may think of other times you need support in these areas, or you or you may think of new areas not listed above.

Choosing Supporters

The most important part of any Supported Decision-Making Agreement is the people involved. You are at the center of the Supported Decision-Making Agreement; you are the **decider.** You choose people to support you who you trust to help you make the best decisions possible. They are called your **supporters**.

You should know your supporters well. They can be family members, friends, neighbors, service coordinators, advocates, members of your faith community, or professionals. It is good to have more than one supporter in case something happens to one of your supporters. You can fire any of your supporters at any time, and they have the option to quit as well. No one should force you into choosing someone as a supporter.

You are at the center of the Supported Decision-Making Agreement at all times! YOU MAKE THE DECISIONS!! A supporter should not help make decisions in areas that you did not agree to, and they should NEVER make decisions FOR you.

Talking to your Supporters

Once you decide who you would like to be your supporter, you need to talk with them one-on-one to see if they will agree to help. Bring a copy of a sample Supported Decision-Making Agreement with you. Let the person know the areas where you would like their support and talk through what that support might look like. Do not worry or get upset if they say no to being a supporter. You only want supporters who have the time and want to help! If they say yes, then have a longer discussion about the specific support you will need. Take notes or record the meeting so you both can remember what you decided. Then set a time when the two of you can fill out the Supported Decision-Making Agreement.

Who needs a copy of the Supported Decision-Making Agreement?

All your supporters and your service providers (school, doctor's office, vocational rehabilitation office, etc.) should have a copy of this Agreement. Store the original document in a safe place for your records. You can make changes or add things to the Supported Decision-Making Agreement to make it work better for you. Note that you may also change the Agreement anytime in the future if needed. Just make sure everyone gets a copy of the updated Agreement.

Supported Decision–Making Guide
For
Individuals

1

Choose Supporters

Think about people you trust and ask them to support me. They have to agree to support me.

2

Thinking About Support

Think about how you want them to support you. Think about the areas that you want support in, like healthcare, education, money, getting a job, or relationships. Ask for support in other areas too.

3

Discussion with Supporters

You and your supporters discuss how they will support you. You and your supporters agree in the ways you will be supported. You might have to ask for other professionals to help you too.

4

Sign the Agreement

You and your supporters sign the agreement. You can change your mind at any time. Your supporters can change their minds too.

REMEMBER

You are always at the center of your Supported Decision-Making Agreement!

APPENDICES

Appendix A – Sample Supported Decision Making Agreement

Appendix B – Comprehensive List of Ways to Provide Support

Appendix C – Frequently Asked Questions About SDM?

Appendix D – Support Areas to Consider When Making A Supported Decision-Making Agreement

Appendix E – Additional Resources

Appendix F - References

APPENDIX A - Sample Supported Decision-Making Agreement

Supported Decision-Making Agreement

This supported decision-making agreement is to support and accommodate an individual with a disability to make life decisions, including decisions related to where and with whom the individual wants to live, the services, supports, and medical care the individual wants to receive, and where the individual wants to work, without impeding the self-determination of the individual with a disability.

This agreement may be revoked by the individual with a disability or his or her supporter at any time. If either the individual with a disability or his or her supporter has any questions about the agreement, he or she should speak with a lawyer before signing this supported decision-making agreement.

Appointment of Supporter(s):
I (Name of Adult with Disability), _____ am entering into this agreement voluntarily.

I choose (Name of Supporter) _____ to be my Supporter as noted below.
Supporter's Address: _____
Phone Number: _____
E-mail Address: _____

I choose (Name of Supporter) _____ to be my Supporter as noted below.
Supporter's Address: _____
Phone Number: _____
E-mail Address: _____

I choose (Name of Supporter) _____ to be my Supporter as noted below.
Supporter's Address: _____
Phone Number: _____
E-mail Address: _____

I choose (Name of Supporter) _____ to be my Supporter as noted below.
Supporter's Address: _____
Phone Number: _____
E-mail Address: _____

I choose (Name of Supporter) _____ to be my Supporter as noted below.
Supporter's Address: _____
Phone Number: _____
E-mail Address: _____

My Supporter(s) may help me with life decisions about:

Yes ___ No___ obtaining food, clothing, and a place to live (Supporter(s) _____)

Yes ___ No___ my physical health (Supporter(s) _____)

Yes ___ No___ my mental health (Supporter(s) _____)

Yes ___ No___ managing my money or property (Supporter(s) _____)

Yes ___ No___ getting an education or other training (Supporter(s) _____)

Yes ___ No___ choosing/maintaining my services and supports (Supporter(s) _____)

Yes ___ No___ finding a job (Supporter(s) _____)

Yes ___ No___ Other: _____ (Supporter(s) _____)

My Supporter does not make decisions for me. To help me make decisions, my Supporter may:

1. Help me get the information I need to make medical, psychological, financial, or educational decisions.
2. Help me understand my choices so I can make the best decision for me; or
3. Help me communicate my decision to the right people.

Yes____ No____ My Supporter(s) _____ may see my private health information under the Health Insurance Portability and Accountability Act of 1996. I will provide a signed release.

Yes____ No____ My Supporter(s) _____ may see my educational records under the Family Educational Rights and Privacy Act of 1974 (20 U.S.C. Section 1232g). I will provide a signed release.

This agreement starts when signed and will continue until _____ (date) or until my Supporter(s) or I end the agreement or the agreement ends by law.

Signed this _____ (day) of _____ (month), _____ (year)

_____ _____

(Signature of Adult with Disability) (Printed Name of Adult with Disability)

Consent of Supporter(s);

I (Name of Supporter), _____ consent to act as a Supporter under this agreement.

(Signature of Supporter) (Printed Name of Supporter)

I (Name of Supporter), _____ consent to act as a Supporter under this agreement.

(Signature of Supporter) (Printed Name of Supporter)

I (Name of Supporter), _____ consent to act as a Supporter under this agreement.

(Signature of Supporter) (Printed Name of Supporter)

I (Name of Supporter), _____ consent to act as a Supporter under this agreement.

(Signature of Supporter) (Printed Name of Supporter)

I (Name of Supporter), _____ consent to act as a Supporter under this agreement.

(Signature of Supporter) (Printed Name of Supporter)

This agreement must be signed in front of two witnesses or a Notary Public.

(Witness 1 Signature) (Printed Name of Witness 1)

(Witness 2 Signature) (Printed Name of Witness 2)

OR Notary Public
State of _____
County of _____
This document was acknowledged before me on _____
(date)
By _____ and
_____
(Name of Adult with a Disability) (Name(s) of Supporter(s))

_____
(Signature of Notary) (Printed Name of Notary)

(Seal, if any, of notary)
My commission expires: _____

Attention: Protection for an Adult with a Disability - If a person who receives a copy of this agreement or is aware of the existence of this agreement has cause to believe that the adult with a disability is being abused, neglected, or exploited by the supporter, the person shall report the alleged abuse, neglect, or exploitation CT Department of Social Services by calling the toll-free In State referral line at 1-888-385-4225, Out of State call Infoline at 1-800-203-1234.

Duty of Certain Persons with Respect to Agreement - A person who receives the original or a copy of a supported decision-making agreement shall rely on the agreement. A person is not subject to criminal or civil liability and has not engaged in professional misconduct for an act or omission if the act or omission is done in good faith and in reliance on a supported decision-making agreement.

What does a provider need to know if an adult has a supporter?
A supporter is different from a legal guardian appointed by a court. A supporter cannot force an adult with a disability to make a decision or make a decision on behalf of an adult with a disability. A supporter can only help an individual gather information, consider options, and communicate the decision. The person with a

disability retains the exclusive right to make these decisions.
When an individual has chosen a supporter and has a supported decision-making agreement, the individual may give a copy of the agreement to the provider if the individual wants the supporter involved in making decisions related to any services provided by the provider.

If a supporter is gathering information for an adult, the supporter must have the adult's written consent to get the information. For example, a provider may have confidential information about an individual such as medical information, school records, and Medicaid case records. A supporter may have access to this information only with written consent of the individual. In providing a supporter with access to confidential information, a provider should follow its usual practice for releasing an individual's confidential information to another person.

A supporter must ensure that the information from the provider is kept confidential and cannot release the information to anyone without the consent of the adult with a disability. A supported decision-making agreement does not prevent an adult with a disability from seeking confidential information on his or her own without the assistance of the supporter.

If the provider has knowledge of a supported decision-making agreement in which the adult with a disability states he or she wants the supporter to assist him or her with decisions about services, the provider must ask the individual if he or she wants the supporter invited to service-planning meetings or other meetings that are convened by the provider. The individual may include in the agreement that the supporter will attend such meetings.

APPENDIX B – Comprehensive Ways to Provide Support

Ways to Address Support Needs for an Individual With a Disability

Needs	Tasks	Ways to Address the Needs
Employment	• Looking for, gaining, and retaining employment	• Seeking appropriate support to obtain and maintain employment. • Support competitive integrated employment while in high school and beyond. • Use educational programming to build skills. • Using Vocational Rehabilitation, Medicaid waiver services, or other Employment providers.
Health Care	• Making decisions about medical treatment • Taking medications as needed • Obtaining and using medical equipment and supplies • Maintaining hygiene and diet • Avoiding high-risk behaviors	• Obtaining Advance Directives • Having individual sign HIPAA release • Using apps or devices to help remember to take medication and perform hygiene tasks. • Visiting a healthcare professional to discuss information regarding prevention and safety. • Allowing someone to help in daily living tasks. • Getting advice from healthcare professionals • Using apps to remind about maintaining devices, calling for supplies and who to call. • Aide to help in daily living tasks. • Getting advice from professionals

Relationships	• Interactions with friends, family, co-workers, and other members of the community • Making decisions about friendships, social events, and intimate relationships	• Teaching and practicing appropriate behavior • Visiting a health center to learn more about contraception. • Speaking trusted supporters about healthy relationships.
Community Living	• Living in a place of your own to call home. • Maintaining habitable conditions Accessing community resources	• Incorporating adaptive and assistive technology • Find room mates or house mates, cooperative housing. • Setting reminders to complete home maintenance tasks • Making a list of community resources, such as transportation • Introduce yourself to first responders
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

Appendix C – Frequently Asked Questions

FREQUENTLY ASKED QUESTIONS ABOUT SUPPORTED DECISION - MAKING

1. **I, or my loved one, would like to begin the process of creating a Supported Decision-Making Agreement. How can I get started?**

   Since you are reading this booklet, you have already started! The Connecticut Supported Decision-Making Coalition has information and resources about Supported Decision-Making in Connecticut including a helpful chart on various formal and informal decision-tools, videos, and upcoming events. There are also links to websites of other national organizations that have helpful information and stories about Supported Decision-Making.

2. **I have been told that if I do not obtain guardianship or conservatorship, I will not be able to help my child make medical, financial, educational, or other decisions. Is this true?**

   No. Many families are told that the only way to protect their children is to pursue guardianship or conservatorship. However, guardianship and conservatorship severely restrict a person's civil rights and can create unforeseen complications when a guardian or conservator is unable or unwilling to serve in this capacity (for example, if the guardian or conservator dies). Many alternatives to guardianship and conservatorship exist that allow a person with a disability to receive support while still maintaining freedom, civil rights, and self-determination. See *Legal Alternatives to Guardianship and Conservatorship*, above for more details.

3. **Is a Supported Decision-Making Agreement legally enforceable?**

   At this time, the legislature and the courts in Connecticut have not addressed Supported Decision-Making Agreements. However, if an individual has not been deemed incompetent or incapacitated, providers should be 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 legal 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 Appendix B, note that either the individual or a supporter can end the Agreement at any time.

4. **How can I stop my family member or person for whom I am responsible from being taken advantage of?**

Unfortunately, many of us "had to learn the hard way" when it came to money, relationships, and other areas of our lives (and some of us are still learning!). In life some risk is inherent. This is no different for a person with a disability. For example, depending on the disability, he or she may have a harder time recognizing someone's true intent, understanding the content of a contract fully, or budgeting money for the month. However, this does *not* mean a person with a disability should not be given opportunities to make decisions. Sometimes, financial management training, or repeated discussions about what an abusive relationship looks like, can be enough to support the individual adequately. It is important to understand that sheltering a person to the extent they never exercise any freedom may leave them unable to handle responsibility.

5. **My child has a profound disability, and I do not think he has the capacity to make sound decisions or communicate his wishes. How can Supported Decision-Making help our family?**

Guardianship and Conservatorship should always be a measure of last resort even for people with profound disabilities!!! Often other less restrictive measures can adequately ensure the safety of an individual. If your child has trouble communicating, consider assistive technology that may enable him or her to do so. Complex topics can often be broken down into simple

yes or no questions, or even by pointing at pictures of different scenarios. Consider the effect of medications your child may be taking that makes it hard for them to think clearly. A Supported Decision-Making Agreement allows for a network of trusted supporters to help the individual make decisions, including formal and informal methods, while preserving civil rights and freedoms.

6. If my adult child signs a Supported Decision-Making Agreement, can I still seek guardianship or conservatorship later?

Signing a Supported Decision-Making Agreement and attempting to allow a person with disabilities to make their own decisions and retain all their rights will not prevent or restrict the ability of anyone to later file a petition for guardianship or conservatorship. However, if the person with a disability can show that they were successful at using supports to accommodate their disability, the person may use that as evidence to demonstrate that they have capacity and do not need a guardianship or conservatorship.

Appendix D – Support Areas to Consider

SUPPORT AREAS TO CONSIDER WHEN DEVELOPING AN SDM AGREEMENT

Check the boxes to say if you need support in each area. You can skip the boxes where you feel that you do not need support. When you check the "I can do this with support" box, you should think about who you might want to support you. Write what kind of support you need in the box. You can use the information in this form to help you fill out a Supported Decision-Making Agreement.

	I can do this	I need some support	What kind of support do I need?
Finances			
Paying the rent and bills on time (for example, cell phone, electricity, internet)			
Keeping a budget so I know how much money I can spend.			
Making big decisions about money (for example, opening a bank account, signing a lease).			
Making sure no one is taking my money or using it for themselves			

	I can do this alone	I need some support	What kind of support do I need?
Health Care			
Deciding when to go to the doctor or the dentist			
Taking care of my health needs (for example, getting check-up, medicine from the drug store)			
Making medical decisions in serious situations (for example, surgery, serious injury)			
Making medical decisions in an emergency			
Understanding how health care costs are covered (for example, Medicaid, private insurance, etc.)			
Making choices about birth control or pregnancy			
Remembering to take medicine			

	I can do this alone	I need some support	What kind of support do I need?
Legal Matters			
Help understanding my rights			
Signing contracts and formal agreements			
Talking to an attorney if I need one			
Education			
What classes I will take?			
What accommodations I need at school			
Deciding what college to attend or what to do after high school			
Work			
Deciding what I want to do for a job			
Understanding my work choices			
Choosing classes or training I need to get a job I want, and taking these classes			
Applying for a job			
Going to my job every workday			

	I can do this alone	I need some support	What kind of support do I need?
Knowing what accommodations, I need at work and how to request them			
Understanding the employee handbook or work policies			
Life Plan			
Choosing where I live			
Choosing with whom I live.			
Choosing what to do and who to see in my free time			
Keeping my room or home clean			
Knowing who to call to fix things that break in my home like plumbing or appliances.			
Finding support services and hiring and firing support staff			
How to plan for an emergency			

	I can do this alone	I need some support	What kind of support do I need?
Other			
Telling people what I want and do not want			
Telling people how I make decisions			
Choosing what I wear			
Getting dressed			
Taking care of my personal hygiene (for example, showering, bathing, brushing teeth)			
Choosing what to eat, and when to eat			
Learning how to live safely in my space (for example, turning off the stove, having fire alarms)			
Getting help if I am being treated badly (abused or neglected)			
Making healthy choices about alcohol and drugs			

	I can do this alone	I need some support	What kind of support do I need?
Choosing if I want to date, and who I want to date			
Making healthy decisions about sex			
Making choices about marriage			
Transportation to work, doctor appointments, community activities, stores, to visit friends			
Choosing to register to vote and deciding who to vote for and voting!			

Adapted from the ACLU, *How to Make A Supported Decision-Making Agreement*

Appendix E – Supported Decision-Making Resources

I. Connecticut Supported Decision-Making Resources

Connecticut Supported Decision-Making Coalition
University of Connecticut, Center for Excellence in Developmental Disabilities
MC6222
270 Farmington Ave.
Farmington, CT 06032
(860) 679-1500

Disability Rights Connecticut
Information and assistance with Supported Decision-Making
Phone: (800) 842-7303 (toll-free in CT, TDD) or (860) 297-4300 (local)
Website: www.disrightsct.org

Connecticut Legal Rights Project
Information, forms, and assistance related to Advanced Directives
Phone: (877) 402-2299
Website: http://clrp.org

II. National and Other Resources

National Resource Center for Supported Decision-Making
National and local resources and information about Supported Decision-Making.
Website:
http://supporteddecisionmaking.org
Phone: 202-448-1448

Center for Public Representation – Supported Decision-Making Initiative
Focuses on exploring alternatives to guardianship for people with intellectual and developmental disabilities
Website: http://supporteddecisions.org
Phone: 413-586-6024

PRACTICAL Tool for Lawyers: Steps in Supported Decision-Making
Helps lawyers identify and implement decision-making options for persons with disabilities that are less restrictive that guardianship.
www.ambar.org/practicaltool

Appendix F – Resources

REFERENCES

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