

October 2022

Rhode Island Supported Decision-Making How-To Guide

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When you use Supported Decision-Making, **YOU DECIDE!**

*with help you need/want from an
eligible person or persons you choose*

REGIONAL RESOURCE CENTER
at the Sargent Rehabilitation Center



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Introduction

Rhode Island passed the Supported Decision-Making Act in 2019, both establishing Supported Decision-Making (“SDM”) and recognizing it as an alternative to guardianship.

By doing so, Rhode Island became part of a nation-wide and planet-wide shift toward supporting the decision-making rights of adults with disabilities and away from making decisions for them in an effort to protect them. This shift continues and both led to and was further prompted by the United Nations’ 2006 Convention on the Rights of Persons with Disabilities, which recognized, in Article 12, the legal capacity of persons with disabilities and the duty of states to provide them the support they may require to exercise their legal capacity. SDM is a way to provide persons with disabilities the support they may need with their decision-making.

Rhode Island proponents of SDM include Advocates in Action, the Alliance for Better Long-Term Care, CPN-RI, the Cross-Disability Coalition, Disability Rights Rhode Island, Looking Upwards, PLAN Rhode Island, PSN, the Rhode Island DD Council, RIPIN, and the Sherlock Center. Additional agencies testified in favor of the Rhode Island SDM Act. National groups that promote SDM include the federal Administration for Community Living, Department of Education, and National Council on Disability; the American Bar Association; the National Guardianship Association (promotes exploring it); and the Quality Trust; as well as advocacy groups such as ASAN, and the Center for Public Representation.

SDM is also consistent with Self-Determination and maximizing independence.

The Regional Resource Center (“RRC”) developed this guide to assist persons with disabilities to use SDM. The RRC is also available to provide training and assistance to groups regarding the information in this SDM “How-To” Guide.

Disclaimer

This guide contains practical information about SDM. The information in this guide is not legal advice. You may choose to consult an attorney about SDM; it is not required that you do so. Individuals seeking legal advice should consult an attorney.



Supported Decision Making (“SDM”) Summary

What is SDM?

SDM is a way for Rhode Island adults with disabilities to get help you need and want with your decision-making process. To use SDM, you must be able to express your decisions; such expression need not be verbal. You may get help with the decision-making process from an eligible person or from eligible persons you choose to help you, who have agreed to help you, called “supporters” in the Act. If you use SDM, by law, you are the one who makes the decisions. You are called the “principal” in the Act.

What is the decision-making process?

The decision-making process is what you do to make an informed decision. It includes gathering information about the decision, reviewing and understanding the information, and expressing the decision. You may get help with whichever part or parts of the process you choose.

Confidentiality:

Your supporter/s may only access confidential information about you with your written permission on proper forms; your supporters may help you obtain the forms for this purpose. If you authorize your supporter/s to access your confidential information, they must keep the information privileged and confidential.

*In Rhode Island, you have
decision making rights, and
a way to get help with your
decision-making process!*



Who is eligible to be a supporter?

Persons eligible to be your supporters may be family, friends or persons with experience and knowledge about you and your decisions, who agree to be your supporter/s.

Who may NOT be a supporter?

Supporters may not be your current service providers unless they are also your immediate family members. Your employer or employee may not be your supporter/s. Any person against whom you have obtained an order of protection from abuse or an individual who is the subject of a civil or criminal order prohibiting contact with you are also not permitted to be your supporter/s.

What may supporter/s do?

Supporter/s may help you with any or all parts of your decision-making process, but they are NOT allowed to make the decisions for you.

*Your supporters are eligible persons
you choose to help you and
who have agreed to help you.*



About which decisions can your supporter/s help you with the decision-making process?

Decisions covered by the Act include decisions related to where you want to live; the services, supports and medical care you want to receive; with whom you want to live; and where you want to work, without impeding your self-determination. Support services include the following: homemaker type services; companion type services, including transportation; visiting nurse and attendant care; healthcare provision; physical and psychosocial assessments; legal assessments and advisement; education and educational assessments and advisement; hands-on treatment or care; care planning; and, other services needed to maintain your independence.

As an alternative to guardianship, decisions covered would include relationship decisions in addition to health care, financial (Please note that *financial decisions are currently not specifically included, nor are they explicitly excluded from the Rhode Island SDM Act.*) and residential decisions.

You may need or want help with your decision-making process to make one, or some, or parts of, or all of your decisions within these areas of decision-making.

You may want or need help with the decision-making process

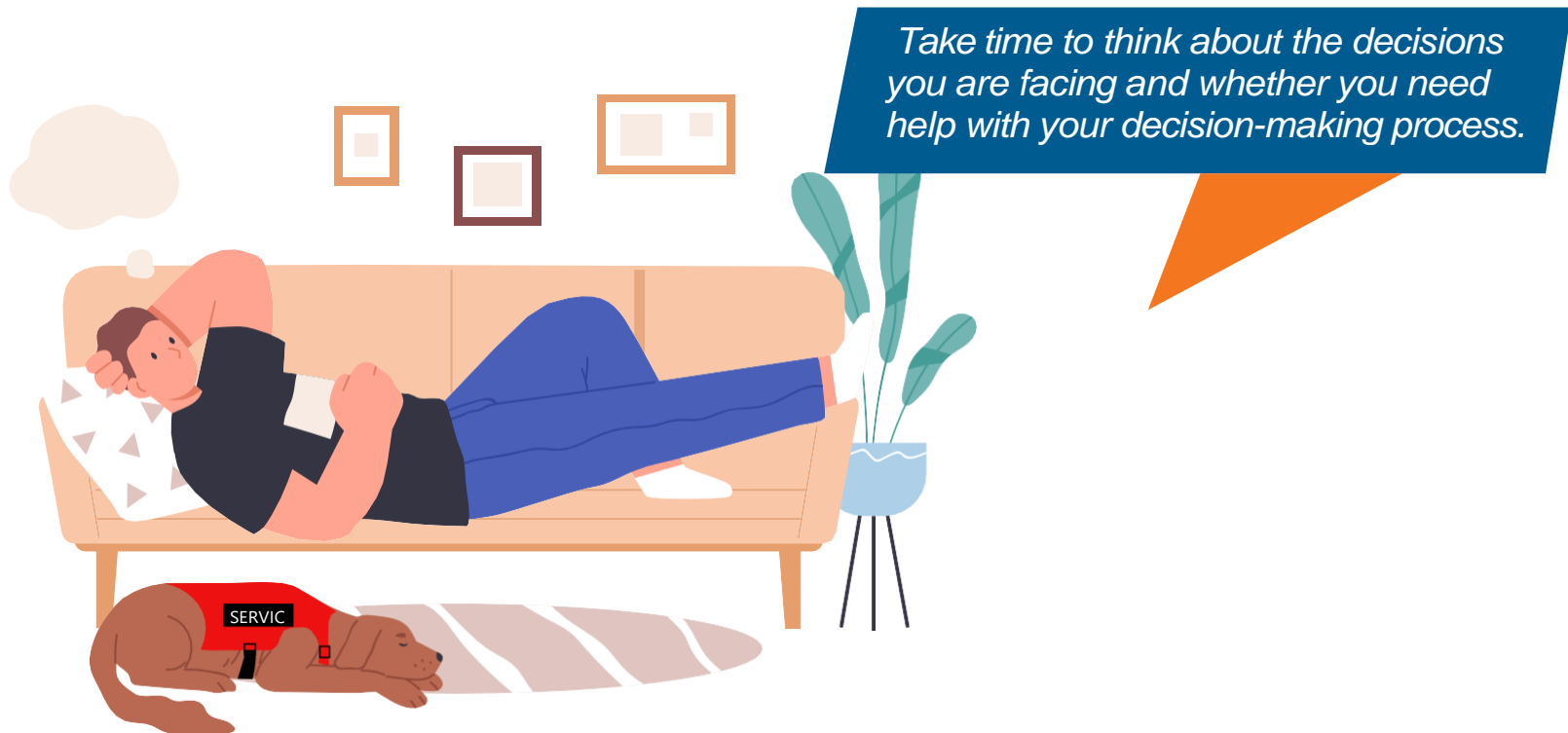


How do you use SDM?

There is some preparation recommended if you choose to use SDM. You should think about decisions you may face, who you want to help you with the decision-making process, what kind of help you may need and want, and how you will get the help you need and want from your supporter/s over time. You may also wish to think about how you make decisions to help you decide whether you need and want help with a particular decision and what kind of help you may need and want.

SDM Agreement required:

If you choose to formally use SDM and are as prepared as possible, you and the supporter/s you choose must enter an SDM Agreement. There is an SDM Agreement form in the RI SDM Act; a copy is attached beginning on page 14. You may modify it or create your own form or use a different form, as long as the form you use contains the elements of the form contained in the Act and is not inconsistent with the form in the Act or the other requirements of the Act.



Take time to think about the decisions you are facing and whether you need help with your decision-making process.



SDM Agreement must be witnessed by two witnesses OR notarized:

You and your supporters must date and sign the agreement in front of either two witnesses, witnesses may not be one of your supporters, or an employee or agent of one of your supporters, any of your paid service providers, or anyone who does not understand how you communicate, unless an individual who understands your means of communication is present to assist during the execution of the SDM Agreement; or, a Notary Public. An SDM Agreement is a legal document. You and your supporter/s should keep a copy in a safe place. You may wish to share a copy of the SDM Agreement with your providers and others who seek your decisions.

SDM implementation:

Once you sign the SDM Agreement, you and your supporters will work together to make the SDM Agreement work for you. You may decide how and how often you will discuss your decision-making needs. You may choose to meet in person, or by phone, or online. You may decide on a regular meeting schedule or to meet as needed, or both.



What if you change your mind?

If you change your mind about some parts of the SDM Agreement, you may amend the Agreement. You and your supporters would then have to date and sign the amended Agreement in front of two witnesses or a Notary Public.

If you change your mind about using SDM, you may terminate or cancel the SDM Agreement. Your supporter/s may also cancel the agreement.

Additional planning about decision-making:

You may wish to consult an attorney regarding future planning about decision-making to consider additional alternatives to guardianship, including advance directives, to put in place in the event that at some point in the future you are no longer able to express your decisions to use SDM. You may use SDM to make decisions about your possible future needs.

You may want to consider other alternatives to guardianship in addition to SDM.



Are you eligible to use SDM?

Are you eligible to use SDM?	Yes	No
· Do you live in Rhode Island?		
· Are you an adult (age 18+)?		
· Do you have a disability?		
· Can you express your decisions? (expression need not be verbal)		
· Do you need and want help with your decision-making process?		
If you answered YES to all of the above questions, you may wish to enter an SDM Agreement.		



Guide To Choosing Your Supporter/s:

Possible choices include adults who are:	Questions to think about:	The following are not eligible to be your supporter/s:
<p>1. Family</p> <p>2. Friends:</p> <ul style="list-style-type: none"> · Classmates · Co-Workers · Neighbors · Friends · Peers · Teammates · Others <p>3. Others who have knowledge or experience with the decisions you are making</p>	<ul style="list-style-type: none"> · Who do you know and trust? · Who is respectful of your decisions? · Who understands your communication? · Who shares your values? · Who has knowledge or experience about the decision/s you may be making? · Who is eligible to be your supporter? · Who is willing to help you with the decision-making process? · Are there other qualities that you want your supporters to have? 	<ul style="list-style-type: none"> · Your current service providers unless they are also your immediate family members, · Your employer or employee, · Any person against whom you have obtained an order of protection from abuse, or · An individual who is the subject of a civil or criminal order prohibiting contact with you. <div> <p>The Supporters you choose must be eligible and must agree to help you with your decision-making process. They must also date and sign the SDM Agreement Form with you in front of two witnesses or a Notary Public and acknowledge their responsibilities under the Act on the Form.</p> </div>

Supporter/s do not make the decisions, YOU do!



Guide To Identifying Decisions You May Need Help With:

From SDM Act and Guardianship Law:		General decisions:
Disability-related support services decisions: <ul style="list-style-type: none"> · Homemaker-type services · Companion-type services, including transportation · Visiting nurse and attendant care · Legal assessments and advisement · Hands-on treatment or care · Care planning · Other services to maintain your independence · Proposed physical or psychosocial assessments · Proposed diagnostic testing 	Healthcare decisions: <ul style="list-style-type: none"> · Proposed treatment <ul style="list-style-type: none"> » Medication » Therapy » Surgery » Other Residence: <ul style="list-style-type: none"> · Where will you live? · With whom will you live? Relationships: <ul style="list-style-type: none"> · With whom will you associate? Finances: <ul style="list-style-type: none"> · How will you manage your money? Employment: <ul style="list-style-type: none"> · What type of work are you interested in? 	<ul style="list-style-type: none"> · Individualized Education Program · Individual Service Plan · Other plans · Your goals · Daily activities · Recreation · Travel · Career Development Plan · Individualized Plan for Employment · Person Centered Planning Process · Other



Possible Areas for Assistance With Your Decision-Making Process:

Do you need help:	Yes	No
· Gathering and reviewing information related to the decision?		
· Understanding the information?		
· Weighing your options (risk/benefit analysis)?		
· Identifying alternative options?		
· Understanding any responsibilities and possible consequences?		
· Finding, obtaining, making appointments for and implementing your support services or plans for support services?		
· Monitoring information about your affairs or support services, including keeping track of future necessary or recommended services?		
· Communicating your wishes and decisions to other persons, and advocating that your wishes and decisions are implemented?		

You may also state what help you do NOT want.

Remember, your supporter/s may help you with the decision-making process, but YOU make the decisions!



How Will You Make SDM Work for You?

How and where will you meet?	How often?
<p>In Person?</p> <ul style="list-style-type: none"> · How and where will you meet? <ul style="list-style-type: none"> » Your home? » Your supporter/s home? » Somewhere else private to preserve your confidentiality? · By phone? · By Zoom or other online meeting? · All of the above? · Some of the above? · Other? _____ _____ _____ _____ 	<ul style="list-style-type: none"> · As Needed? · On a Schedule? <ul style="list-style-type: none"> » Weekly? » Bi-Weekly? » Monthly? » Quarterly? » Other? <p>Who will reach out about meeting?</p> <ul style="list-style-type: none"> · Will you contact your supporter/s? · Do you need or want your supporter/s to contact you?



SDM Preparation Chart

List decisions you may need/want help with the process:	Which supporter/s will help?	Describe help needed/wanted:	State how supporter/s will help:
(Example) Proposed Surgery	(Example) All Supporters	(Example) Meeting with the surgeon with me and gathering and understanding information and weighing options	(Example) One or more in person meeting/s with me, expressing my decision



Supported Decision-Making Agreement

Appointment of Supporter

I, _____, (insert your name)
make this agreement of my own free will.

I agree and designate that:

Name: _____

Address: _____

Phone Number _____

E-mail Address: _____

Is my supporter. My supporter may help me with everyday life decisions relating to the following:

Y / N Obtaining food, clothing, and shelter

Y / N Taking care of my health

Y / N Other (specify) _____



I agree and designate that:

Name: _____

Address: _____

Phone Number _____

E-mail Address: _____

Is my supporter. My supporter may help me with everyday life decisions relating to the following:

Y / N Obtaining food, clothing, and shelter

Y / N Taking care of my health

Y / N Other (specify) _____



My supporter(s) is (are) not allowed to make decisions for me.

To help me with my decisions, my supporter(s) may:

1. Help me access, collect, or obtain information that is relevant to a decision, including medical, psychological, educational or treatment records;
2. Help me gather and complete appropriate authorizations and releases;
3. Help me understand my options so I can make an informed decision; and
4. Help me communicate my decision to the appropriate persons.

Effective Date of supported decision-making agreement

This supported decision-making agreement is effective immediately and will continue until

_____ (insert date) or until the agreement is terminated by my supporter(s) or me or by operation of law.

Signed this _____ day of _____, 20_____
date month year



Consent of Supporter

I, _____ (name of supporter), consent to act as a supporter under this agreement, and acknowledge my responsibilities under chapter 66.13 of title 42.

(Signature of supporter) _____

(Printed name of supporter) _____

My relationship to the principal is: _____

I, _____ (name of supporter), consent to act as a supporter under this agreement, and acknowledge my responsibilities under chapter 66.13 of title 42.

(Signature of supporter) _____

(Printed name of supporter) _____

My relationship to the principal is: _____



Consent of the Principal

(My signature)_____

(My printed name)_____

Witnesses or Notary

(Witness 1 signature)_____

(Printed name of witness 1)_____

(Witness 2 signature)_____

(Printed name of witness 2)_____

or

State of _____

County of _____

continued on next page



This document was acknowledged before me on _____(date)

by _____

and _____

Name of adult with a disability: _____

Name of supporter: _____

Signature of notarial officer _____

(Seal, if any, of notary)

Notarial officer printed name _____

My commission expires: _____

*Congratulations! You've completed
the SDM Agreement!*



Resources

ACLU - SDMResources: www.aclu.org/other/supported-decision-making-resource-library

CPR - SDM Information and Resources: www.supporteddecisions.org

National Resource Center for Supported Decision-Making: www.supporteddecisionmaking.org

RI SDM ACT: R.I. Gen. Laws. Ann. §§ 42-66.13-1 to 10

Bibliography

acl.gov/programs/consumer-control/supported-decision-making-program

ACLU's Brainstorming Guide to Supported Decision-Making; How to Make a Supported Decision-Making Agreement, A Guide for People with Disabilities and Their Families; and, Supported Decision-Making Frequently Asked Questions

American Bar Association's 2017 Supported Decision-Making Resolution

ASAN's The Right to Make Choices: International Laws and Decision-Making by People with Disabilities

Campanella, Tina M., CEO, Quality Trust for Individuals with Disabilities, Principle Investigator, National Resource Center on Supported Decision-Making, Supported Decision-Making and the Role of Siblings

centerforpublicrep.org/initiative/supported-decision-making/

Charting the LifeCourse documents

Colorado Developmental Disabilities Council, Supporting Individuals with Disabilities to Take Charge of Their Lives, Self-Determination and Supported Decision-Making

Cooper, Travis and Alaska Governor's Council on Disabilities and Special Education, Agency Guide for Crafting Supported Decision-Making Agreements



CPR's SDM Pilot Project Reports: *Supported Decision Making Pilot: A Collaborative Approach, Pilot Evaluation Year 1 Report; and, Pilot Program Evaluation, Year 2 Report*

Disability Rights Maine's *Supported Decision-Making: A User's Guide for People with Disabilities and Their Families*

Disability Rights Texas' *The Right to Make Choices, A Supported Decision-Making Toolkit for People with Disabilities and their Supporters*

Francisco, Suzanne M., Special Education and Disability Rights Advocate, with Martinis, Jonathan G., Esquire: *Supported Decision-Making Teams: Setting the Wheels in Motion*

Gimson, Sarah, Quality Enhancement Specialist, The Council on Quality and Leadership, *Supported Decision Making*

Hunter/CUNY, NY Alliance, DRNY, The Arc Westchester, *sdmny, Supported Decision-Making New York*

Maine Parent Federation Presents *Supported Decision-Making*

Martinis, Jonathan, Senior Director for Law and Policy, Burton Blatt Institute at Syracuse University and Policy Director, National Resource Center for *Supported Decision-Making, Supported Decision-Making From Theory to Practice: Special Education Planning and Supports*

Missouri Stoplight Tool

National Guardianship Association's 2017 *Position Statement on Guardianship, Surrogate Decision Making, and Supported Decision Making*

Office of the Public Advocate, *Supported Decision-Making in Victoria*

Quality Trust's *Brainstorming Guide: How Are we Already Using Supported Decision-Making?*

Rhode Island SDM Act: *R.I. Gen. Laws. Ann. §§ 42-66.13-1 to 10*



supporteddecisionmaking.org

supporteddecisions.org

The Arc of Northern Virginia and the Burton Blatt Institute at Syracuse University, *“I learned that I have a voice in my future”, Summary, Findings, and recommendations of the Virginia Supported Decision-Making Pilot Project*

The South Carolina Supported Decision Making Project, *Independence. Together. Promoting alternatives to guardianship that preserve autonomy and wellbeing*

UN Convention on Rights of Persons with Disabilities, 2006, Article 12

Volunteers of America Minnesota and Wisconsin, *CESDM Guide to Supported Decision Making in Minnesota: A Resource for Families and Other Supporters, 2019*

Wisconsin BPDD et al.'s *Let's Talk About Supported Decision-Making SDM Toolkit*

