

# BEST PRACTICES IN SUPPORTED DECISION-MAKING

## How to Be an Effective Supporter



# CESDM

CENTER FOR EXCELLENCE  
IN SUPPORTED DECISION MAKING



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# BEST PRACTICES IN SUPPORTED DECISION-MAKING: How to Be an Effective Supporter

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Nothing in this document should be construed as legal advice.

# BEST PRACTICES IN SUPPORTED DECISION- MAKING: How to Be an Effective Supporter

## I. Introduction

Whether it's a parent who's been diagnosed with dementia, a child with cognitive disabilities who's turning eighteen, or a friend or relative who needs extra support, helping the person to live their best life, to be happy, and to be safe is the goal. But balancing safety with quality of life can feel overwhelming. There's no roadmap and often no easy answer. A good place to start is by thinking through what the person *wants*, what they *need*, and how they make choices so they can have both. This is called *supported decision-making*; it's a newer approach for some people, for others it's an idea they really like but aren't sure how to do it, and still others have already been doing supported decision-making without even knowing it had a name.

These *Best Practices in Supported Decision-Making* recommendations are for supporters: families, friends, or others helping someone with decision-making, as well as anyone who wants to learn more about how to use supported decision-making. Professionals working with individuals and their supporters will find these best practices helpful too. Supporters and professionals can refer to these recommendations if complications arise in the future, can share the ideas with others, and are a resource if the person and the supporters need to change course if current approaches are not working. Remember, no two situations are the same; supported decision-making is as unique as the person and their supporters!

We hope you will find these *Best Practices in Supported Decision-Making* to be helpful suggestions and examples of approaches that may work well in your situation.

*Everyone* makes decisions based on wants, needs, history, relationships, education, culture, beliefs, and other very personal experiences.

When people feel *listened to* and that their supporters understand their perspectives, they are more likely to want to cooperate and hear what their supporters think about the choices they face.

## A. Terminology

*Decision-Making Options or Decision-Making Supports* refer to the whole spectrum of decision-making: from a person who is able to make decisions with minimal help, to the person who wants help from trusted others to sort out options, to people making decisions for the person through Health Care Directive or Power of Attorney authority, to guardianship and conservatorship.

*Guardians and Conservators* are court-appointed substitute decision makers who are granted decision-making authority over a person's finances (conservator) or personal and health care decisions (guardian). Guardianship and Conservatorship are expensive, involve removal of many of the person's civil rights, and can have a lot of unexpected downsides. Guardianship and Conservatorship are not appropriate if a specific decision cannot be identified that requires a guardianship, or there are no unmet needs.

### Did You Know?

#### **Health Care Directive (HCD)**

is a legal document, completed by a person with capacity to do so, which enables the person to: appoint a health care decision maker (health care agent), and/or to inform others about their health care. Experts agree that many people are legally capable of appointing a health care agent even if they cannot make other medical decisions.

**Power of Attorney (POA)** is a legal document, completed by a person with capacity to do so, which enables the person to appoint a person to manage some or all of their financial affairs. This person is called an Attorney-in-Fact. Many people who cannot manage their money are still legally able to appoint an attorney-in-fact.

*Less Restrictive Alternatives* (LRAs) refer to the variety of legal tools, programs and services, approaches and informal supports that could be used to meet the needs of a person without needing to turn to guardianship or conservatorship. Legal tools include *Power of Attorney* to appoint someone to manage a person's finances and *Health Care Directive* to appoint a health care agent (health care decision-maker) to make the person's medical decisions if the person couldn't make their own. A Health Care Directive can also express the person's health care wishes and preferences if they couldn't speak for themselves in the future. Representative Payees can be appointed by Social Security Administration or the Railroad Retirement Board to manage a person's benefits, and the Veterans Administration can appoint a VA Fiduciary to manage Veterans benefits.

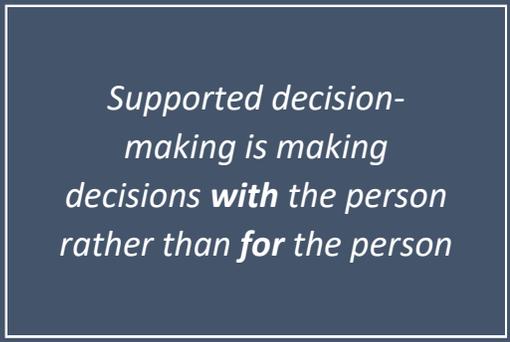
Programs and Services include arranging for home care services, a move to a care setting with an array of services provided on-site, a case manager helping to coordinate services, and more.

Approaches such as supported decision-making and informal supports such as families or trusted others helping with banking, budgeting, housekeeping, medication management and other decisions and supports are all

examples of less restrictive alternatives to guardianship or conservatorship.

*Person-Centered Practices* (also, person-centered thinking, approaches, services) are based on the principle that “government, service providers [and supporters] must listen to people about what is important to them to create or maintain a life they enjoy in the community...[it] is not driven by professional opinion or limited-service options. Instead, planning looks at services and supports in the context of what it takes for a person to have the life they want. The person along with [their] support team identifies effective support and services that will help the person live, learn, work and participate in preferred communities on [their] own terms.”<sup>1</sup>

*Supported Decision-Making* is “a recognized alternative to guardianship where people with disabilities use trusted 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.”<sup>2</sup> We all turn to trusted others to help us with decisions and choices; it’s how we all make decisions. Supported Decision-making is the term that most people use when they talk about helping someone better understand and make their own decisions. It may be informed by a formal, written document (Supported Decision-making Agreement) or it may be informal approaches and conversations with trusted others to help the person make a decision or arrange for needed assistance.



*Supported decision-making is making decisions **with** the person rather than **for** the person*

*Supportive Decision Making*: though many people use this term to refer to *supported* decision-making, it is actually an umbrella term that includes the full spectrum of decision-making from making decisions with a person to making decisions for a person based on that person’s current and previously expressed goals, wishes, and current needs.

*Supporters* are the people who help a person understand their situation and the choices they face. Supporters are chosen, or accepted, by the person, and might be family members, friends, or even professionals such as a case manager.

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<sup>1</sup> MN Department of Human Services, [Person-centered Practices](#)

<sup>2</sup> Blanck and Martinis, 2015

## B. Supported Decision-Making

Supported Decision-Making (SDM) is built around the concept that everyone needs occasional help to make decisions, and that even though someone cannot make decisions independently, they are still able to participate in decision-making. SDM is a person-centered intervention where a person is empowered to make decisions with the support of trusted family, friends, and/or professionals, rather than others making decision for the person, and in most situations can avoid more restrictive approaches such as guardianship.

For those who have never heard of it, supported decision-making might sound like a confusing, or brand-new idea but actually, many families, friends, and professionals are already using supported decision-making when they are helping a person figure out the best care and service options and how to make sure needs are met, all while balancing what the person wants.

*“Supported Decision-Making is just a fancy way of describing how we all make choices. We all need help making decisions, every single day.”* Jonathan Martinis

Supported decision-making is simply making decisions with the person, not for the person, to ensure they are safe, happy, and living their best life. All the ways that supporters are currently helping a person are examples of supported decision-making, as long as the person is the one ultimately agreeing to, or declining, the choices. It’s about being creative in helping people achieve their wants (goals, desires, wishes, hopes) while ensuring their needs are met. It’s about finding the balance: being as safe as necessary not as safe as possible.

When there are concerns that the person’s decisions or actions will result in danger, unacceptable levels of risk, or other actual harm to the person, supporters help the person to understand the consequences of their decisions. Person-centered approaches and supported decision-making are not about just doing whatever the person wants, but rather, taking the time to help the person make the best decision for their situation, accommodating for wants as well as needs.

If a person intends to make a “bad decision” or a “poor choice”, supporters might have conversations with the person to find out more about why something is important to the person and help them understand how it might cause them to lose out on other things that are important.

For example, supporters could:

- Make sure the person understands that the supporter wants to help with decision-making, not take over decision-making.
- Help the person understand likely outcomes or consequences of “bad” decisions.
- Find out what is important to the person, using non-judgmental, curious approaches:
  - Give them space to explain their desire and rationale for the decision
  - Let them explain the reasoning behind their desires to make the decision: what is at the root of the decision? Often, once we find out why it’s important, it is much easier to discuss how to address what’s important to the person while also considering health and safety concerns.
- Talk through all the possible outcomes, including good, bad, or neutral, and consider how likely these outcomes are to occur.
- Recognize that sometimes people just want to dream out loud, but actually have no real intention or ability to act on these choices. Supporters don’t always need to spend energy or worry about something scary that in all likelihood will never happen.
- Recognize that people express their frustrations in ways that may sound angry or self-defeating, but really, the person just needs to vent or let their feelings out and may not have the ability in the moment to express their feelings with words. They likely just need to let it out, talk it out, scream it out. Give them space and come back later to discuss when the person feels calmer.

There are endless examples of what supported decision-making is: as long as the person is substantially involved in the decision, and ultimately is the one who decides (even with a lot of input from others), that is supported decision-making.

It’s also important to understand what supported decision-making is not. It is not:

- Making decisions for the person
- Telling the person what others think they need to do
- Focusing only on safety and not looking at what is important to the person
- The person making decisions without any input from others

## Foundations of Supported Decision-Making

- ✓ Rooted in respect for the person's autonomy
- ✓ Requires self-reflection by the supporter; be aware of one's own biases
- ✓ Balances what is important *to* the person with what's important *for* the person
- ✓ Recognizes that everyone has the right to self-determination
- ✓ All people need help with decision-making sometimes: no one is an island
- ✓ Supporters and the person being supported *will* disagree, just like all people. Communication is the key
- ✓ Think "outside the box" to identify and try creative approaches to balancing wants and needs, safety and quality of life

## II. Best Practices for Creating Supported Decision-Making Agreements

### *Written Supported Decision-Making Agreement*

Supported Decision Making can be as informal as a single or ongoing conversations to help a person understand the choices they face. Or it can be as formal as writing down the names of supporters and areas of support they offer, when the person wants help, and anything else the person wants. When these preferences are written down, it is called a Supported Decision-Making Agreement (SDMA).

Minnesota does not require a written form in order for a person to receive support in making decisions or arranging for care and services. Unfortunately, some health care and social service providers are less familiar with supported decision-making, and because there is not a form described in law, they might not accept an SDMA. Or the opposite may be true: they may feel more comfortable interacting with a person's supporters only if there is an SDMA. It is important to remember that all people, all patients, all clients have the legal right to ask providers to include people of their choosing in conversations about the person's care and services. Either way, extra conversations with health care, residential, and social service providers may be necessary to help remind them that people needing or wanting support have the right to include their trusted family or friends involved in appointments and with decision making if they choose.

### *Creating a Written Supported Decision-Making Agreement*

Because there are no required forms, the options for creating a written Supported Decision-Making Agreement (SDMA) are many! The National Resource Center on Supported Decision-Making<sup>3</sup> website provides several templates for [forms](#). The Center for Excellence in Supported Decision Making in partnership with Estate and Elder Law Services at Volunteers of America MN has also developed an SDMA which can be completed and attached as an addendum to a Health Care Directive (see Appendix B). This is recommended because health care professionals who are not familiar with supported decision-making may not be willing to accept a supported decision-making agreement. However, because Health Care Directives are often part of a patient's medical record, health care professionals are familiar with them and when a Supported Decision-Making Agreement is attached to the Health Care Directive, providers might be more comfortable receiving and accepting the agreement.

Some people find it helpful to work with a facilitator to develop an agreement. This might be a professional, such as a social worker, a case manager, or an attorney. Or, it might be another family member or friend, who is not the supporter. A facilitator can help keep the conversation

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<sup>3</sup> National Resource Center for Decision Making, [www.supporteddecisionmaking.org](http://www.supporteddecisionmaking.org)

## Helping the Person Choose Supporters?

If you're helping the person choose supporters and they don't know who they want, consider some of these conversation prompts:

*When you're having a bad day and want to vent to someone, who do call?*

*If you're confused or worried, who do you usually talk to?*

*When you're having a really great day, or something exciting happens, who do you tell first? Second?*

*Who are the people in your life that you really trust?*

and planning flowing when the person and their supporters find that they are running into barriers because of heightened emotions due to the supporter's fears and worries or the person's frustrations.

A facilitator will help keep the focus on the person being supported and can be a resource later if there is conflict between the supporter and person, or if extra advocacy is needed to convince professionals that the SDMA is valid and acceptable.

Whether it will be written down or not, the first step in developing supported decision-making agreements or practices is for the person to decide who the supporter or supporters will be. For some people, that will be easy as they are already turning to people in their lives when they need some extra help or discussing their lives. For others, this will not come as naturally: they might immediately think of their best friend or another family member, forgetting that this person doesn't always listen to them or otherwise wouldn't be a helpful supporter. The most important thing is that the person chooses supporters who they trust and who will commit to listening to them, helping them make decisions but not making decisions for them. A good supporter helps the person think through all the options, the pros and cons of each, to help the person identify the best decisions for that person.

Next, the person and their supporter(s) should talk about what areas the person wants support in, and whether they want help on a regular basis, or just when something arises. For some people, it works best to set up regular touchpoint or check-in meetings, maybe weekly or every other week, for example.

The person and the supporter(s) should discuss what the relationship will look like, such as how involved the supporter will be: almost all the time for most decisions, or only major decisions, or somewhere in between. Only when the person asks for help or runs into trouble, or with more day-to-day decisions as well? Remember, the person will be most likely to turn to

supporters and ask for help if they feel they won't be judged or "punished" for bringing problems to the supporters.

For some people, it might be hard to list ways they need or want help. A very helpful guide is the ACLU's *How to Make a Supported Decision-Making Agreement*. This document encourages the person to think about a recent decision: how was the decision made, alone or with help, and then provides more prompts to think about decision-making, which can guide the person and their supporters to think about supporting the person in future decisions:

*What did you **like and dislike** about making this choice?*

- *Did you understand your choice?*
- *Did you understand all of your options (different choices you could make)?*
- *Could you communicate your choice? Did anyone help you?*
- *Did you have enough time to make sure you were happy with your choice?*
- *Did you know what to do if you had questions?*
- *Did you feel like you could say "no" if you didn't want help?*
- *Are you happy now with the choice you made?*
- *Could you change your mind if you wanted to make another choice?*

How to Make a Supported Decision-Making Agreement, ACLU<sup>4</sup>

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<sup>4</sup> [www.supportmydecision.org/assets/tools/ACLU-how-to-make-a-SDM-Agreement.pdf](http://www.supportmydecision.org/assets/tools/ACLU-how-to-make-a-SDM-Agreement.pdf)

## GETTING STARTED WITH SUPPORTED DECISION-MAKING

- Talk with the person to identify areas of life the person wants or needs help with
- Include others the person trusts and who know the person well
- Encourage the person to identify and talk to trusted others (supporters) for each area of help desired
- Talk with person about their needs as well as goals, hopes, desires: what would it take for the person to be successful in getting their wants and needs met?
- Writing it down or making a formal supported decision-making agreement is a good idea, but is not required

## Supporting a Person's Decision

- Gather relevant information; then explain it in ways the person can understand.
- Help the person understand the various options and choices, and the pros and cons of each
- Help the person identify possible negative or unintended consequences that may arise because of a particular choice
- If needed, be prepared to communicate the person's preferences and decisions to others; and coach them to develop skills in doing this themselves.

## III. Best Practices for Providing Ongoing Support

### A. Providing Support

For some, helping a person learn to make better decisions instead of making decisions *for* the person is a continuation of how they have always done it. For others, it can feel like a scary idea. It can be challenging for supporters to gain new skills and approaches in helping the person; they may feel challenged and might find they have to confront their own approaches, biases, and fears about vulnerability and safety, as well as their habits and patterns of communication that may no longer work in supporting a person.

For parents helping their young adult children with disabilities, it may be extra challenging to move from making decisions for their child to recognizing their child is now an adult. The role for parents now has shifted from decision making *for* the child to decision-making *with* their child, such as ensuring the person has all the information and support, they need to make decisions.

For families who are caregivers (also called care partners) with aging parents with illnesses related to neurocognitive disorders (dementia), it may seem impossible to think about making decisions with the person rather than for the person. Experience and research tell us otherwise: when people of all ages and abilities have the information they need presented to them in ways they can understand, and

when supported by trusted others, most can make decisions in their own best interest.<sup>5</sup>

There are many ways families and others can be effective in supporting the person's decisions. In any given decision, supporters should help by gathering any additional relevant information the person may need, and then explaining it in ways the person can understand. Together, the

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<sup>5</sup> O'Conner & Vallerand, Canadian Journal on Aging, 1994; Haberstroh, et al, 2014; Powers et al, 2012; Shogren, Wehmeyer, Plamer, Rifenbark & Little, 2014; Wehmeyer & Palmer, 2003

supporters and the person should list the various options and choices, and then discuss the pros and cons of each option. It is perfectly acceptable, and even advisable, to help the person understand possible negative, or unintended consequences, that may arise as a result of a particular choice.

Effectively supporting someone in decision-making may take many attempts to figure out what will work. It may require creativity and thinking outside the box or thinking differently about how to approach the situation in ways that work for the person, while also addressing safety concerns that others may have.

### *Do's and Don'ts of Supporting a Person in Decision-Making*

- Do listen to the person when they tell you about their intent, question, or concern: find out what the person is thinking about regarding the issue at hand. What's important to them about this? What else have they considered?
- Do listen with an open mind so you can really hear what the person is telling you.
- Do find out what they know about options.
- Do offer options and alternatives as you understand them, after listening to the person. Offer these in ways that show you understand what's important to the person and that you are on the same page with them.
- Do share your own thoughts of how you made a similar choice: your own decision-making process, what factors you considered, what influenced you to make the decision, why you did what you did.
- Do talk through the action and ways to carry out the decision.
- Don't presume you already know: really listen to them and ask follow-up questions to get to the root of their thinking. Sometimes what they really want hasn't been expressed or identified yet.
- Don't offer your opinion or answer for them...unless they ask
- Don't continue the conversation if you feel yourself becoming scared, worried, or anxious about their choices, or if the person is feeling frustrated or upset; instead, take a break and come back to the conversation when you both feel calmer.

It is important for all of us to have people we can turn to for small and big decisions in our lives.

### *Communicating the Decision to Others*

Sometimes, the person may need the supporter to communicate their preferences and decisions to others. Being shy and intimidated by professionals such as doctors, surgeons, social workers, and attorneys is natural, but this shyness may be misinterpreted as inability to make or communicate decisions. With the person's permission, the supporter may need to speak for the person.

### *Preparing for Hard Conversations*

When there is potential for these conversations to be emotionally unsettling or even explosive due to conflict between what the person says they want and what supporters feel they need, it is critical that supporters themselves feel calm, open-minded, and ready to temporarily set aside their own worries and fears about the person's safety or vulnerability.

Spend a few minutes alone, thinking about the upcoming conversation. Some people call this "centering themselves"; others think of it as checking in with themselves before walking into a challenging situation. Consider arriving early, if it's an in-person conversation; use this time to collect your thoughts before going into the meeting location. Try to avoid entering the conversation if you're feeling rushed, or anxious or upset.

Think about your own emotions and worries; consider whether your fears are based in reality. How likely is it that your concern or worry will happen? How likely is it that the person will experience serious harm? What is the likelihood the person is just "dreaming out loud" and not actually planning to take the action you're worried about?

Consider delaying the conversation. Maybe it would be helpful to first talk with a friend, or another supporter of the person, to be sure you are calm (sometimes called "grounded"), and that you are able to keep the focus on the person, not your own emotions, fears, and history. Be sure you are able to be fully present for the person, focused on them, rather than your own anxieties.

Presume the person's competence: they know what they want, and why they want it. If they feel they have your trust and confidence that the right decision or solution will be found, they may be much more likely to hear your thoughts and opinions.

Think about what works best for the person being supported; if you don't know, ask them. Do they value hearing how someone else dealt with the situation? They may want to continue talking about how it applies to them. Are they reluctant to directly say what they want? Would they feel more comfortable expressing through a drawing? Writing it down? Confiding in a friend with the intention that they can then tell you? Use your knowledge of, and experience with the person to understand what they are communicating.

It's okay if there is no immediate resolution. Sometimes, people need to say things out loud, have a conversation, and then step away for some time to let the ideas develop.

If the conversation gets too heated because of disagreements, take a break, regroup, and reapproach the conversation at another time. Plunging through an emotion-filled discussion can lead to people taking sides, digging in deep to hold their position and stop listening to the other person. Trust and willingness to work together could be forever damaged by having conversations based on anger, fears, and other strong emotions.



Sometimes, it's best to "plant a seed", or an idea, and let it take root in the person's thoughts.

After consideration, they may then make the same decision you hope they would. And if they feel like it was their own idea, they're more likely to stick to it.

*In 2018, CESDM held a series of Listening Sessions with young people with disabilities to hear what they had to say about making decisions.*

People want to make good decisions.



“When you think about getting help making decisions, what would you like to change?”

*Help getting the words out*

*Feeling like we made good decisions*

*Overcoming being nervous*

*Feeling more confident and strong to make decisions*

*Overcoming fears*

*Getting help working through emotions*

*Ensuring choices are honored*

*I need people to know me better and know my values*

## B. Sample Language and Conversation Guide

Just starting the conversation may be the hardest part. Families may be anxious about how to talk about decision-making, choices, and areas of vulnerability because they haven't had much practice, or they fear a negative response from the person.

Remember that the person is the center of the discussion. Rather than imposing ideas on them, encourage them and give them space to express their opinions, hopes, and worries without feeling pressure about what they think others want them to say. Consider encouraging the person to write down ideas that excite them. This can be a good visual reminder to orient them back to what is most important.

It is normal to fear for the person's safety; this is hard work for families to transition from being the parent of a child with a disability to the parent of a young adult with a disability who wants to be independent. Or for the adult children of a parent with dementia to shift from doing things *for* the person to doing *with* the person.

This sample language may be helpful in prompting and guiding conversations.

- *To me it sounds like this is overwhelming you. Can we talk together about it?*
- *Let's make a list of your choices. Once we list your choices, we can talk about what you do or don't like about these options.*
- *How can I help you with this?*
- *How do you think we can work through this?*
- *What do you think we should do next?*
- *Can I tell you what it looks like from my perspective?*
- *What do you think is going well? What are you having a hard time with?*
- *Would you like to hear what happened to me when I faced a similar choice?*
- *I'd like to hear in your own words what you think is going on/what you're worried about/why we are talking today.*
- *I know this can be a touchy subject, but I'd like to understand why I see another overdraft fee on your account. We talked last month and decided on a plan, but maybe we need to try something else. What do you think?*
- *It sounds to me like you know it's important to clean your apartment but that your friends come over a lot and you'd rather go out with them. I know it's important to you keep this apartment, and it was really hard to find a place you liked, that allowed you to smoke and let you have your cat. It will be important to keep this on track so that you don't get in trouble with your landlord or lose your apartment. Maybe we can talk about creating a cleaning schedule so that it doesn't get out of hand?*
- *Tell me what's exciting to you about the idea of buying a car. It's great to have a goal to buy a car: can you tell me how you'll pay for it? Shall we talk about how to get a job? Let's look*

*for driver's education services to help you get your driver's license. And if you'd like, we can talk about how to start saving money to put toward the car.*

### C. Tips

- If you've identified something that you think could be problematic to the person, consider how they may take the information. Is it best coming from you or a different source? Ensure that you present the "problem" in a way that is not blaming so as to avoid a negative response. If they do respond negatively, allow them time to process the information and make a plan to regroup.
- Identify how you're feeling about the situation or decision. If you're angry, sad, stressed, or feeling defensive; acknowledge that. Now may not be the best time to discuss. Can you seek another perspective from someone you trust, talk it through with a friend or therapist, etc. Consider finding a calmer time to discuss with the person.
- Listening is key; try to quiet your own thoughts about the situation or what you think the person should do and really listen to what they are saying.
- Ask questions. Become truly curious to understand their perspective. When we talk through challenges with another person, we have the opportunity to learn ourselves better, and understand what drives our desires. In asking questions of someone you're supporting, you are giving them an opportunity to think and talk through challenging situations; this may enable them to come up with the answers of some of their problems on their own.
- When possible, it may help to consult a professional who knows the person well. This person may be helpful to be part of the conversation, or they could provide their more

### OUR ABILITY TO MAKE DECISIONS DEPENDS ON A LOT OF FACTORS!

When we have patience, a calm mood, and have all our needs met—we are in a good position to make a well thought-out choice we're happy with.

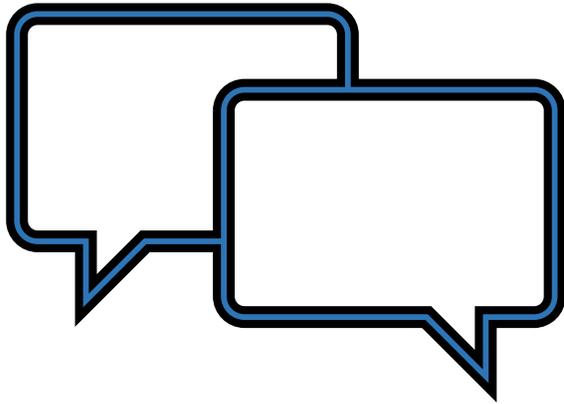
However, if we are frustrated, tired, ill, or experiencing a variety of other negative factors, we are not in the best place to make a good decision; we may not even want to have the conversation!

There is value in approaching a conversation when a person is the most well positioned to engage in hearing your opinions, and expressing their own.

objective, professional perspectives and recommendations. This might be a social worker, case manager, care manager, advocate, independent living skills (ILS) worker, chaplain, school-based supporter, or another professional who knows the person well.

- Example: *Ms. Smith, as Dad's case manager, I'd like your input. Dad and I created a cleaning schedule last month but it just doesn't seem to be working. Dad used to really enjoy having Morgan around, but now he's frequently complaining about her; do you think you and Dad can work to find a new home health aide? Or do you have other ideas? It might help for Dad to have someone consistent and hands on to do check-ins with him and work on maintaining his apartment, so he doesn't get evicted.*
- Listen to the person, while being careful to not allow your personal beliefs or preferences to impede. Before saying anything like "I think you should..." consider, explore, and discuss what is important to and for them. Ask questions that will get the person to talk through what they want and need. Frame the discussion in a way that makes sense to them. It can be helpful to lay out the pros and cons of a choice, to understand what the outcome of a 'bad' choice would be. Being able to talk through all aspects of a decision helps to gather information, and eventually enable the person to make their own decision, balancing needs and wants, weighing pros and cons, and searching for other options acceptable to them.
- Example: *Tim, I hear you saying that you want to skip work Friday to go to a concert. If you skip work you won't make any money for the day, and if you get two more unexcused absences from work you'll lose your job. You worked hard to get this job and always talk about how much you love it, since you're able to work with animals. Can we brainstorm about other ideas? Maybe there's someone you could get to cover your shift? Have you thought about talking to your supervisor? Will that band play another concert later this summer when you can ask off work? And maybe you could join your friends after work to hear about the concert?*
- Example: *Mom, I can imagine this must be hard; you've always been so independent. I understand that you don't want strangers coming into your home, and also, you've said you never want to live anywhere else but this house that you and Dad built. But with your broken hip and walker, you can't safely go downstairs to do laundry or change a fuse, and you said it really hurts to stand very long. Can we try having a helper come in a few hours on the days I have to work to help cook your meals and do the laundry? Once you're feeling better, we can stop having them. But I'm afraid you won't be able to keep living here if we don't figure out a way to help me help you.*

## Supported Decision-Making in Action: Friends Supporting Friends



**Allison:** *I read that you can get a free flu shot...should I get a flu shot?*

**Rae:** *I took some time to think about it too! I wasn't sure either, so I asked my primary care provider, and they shared why they thought it would be beneficial, and their own considerations for themselves. I also had the flu a few years ago and it was awful. If there is any way I can avoid that pain in the future, it's worth it to me. Plus, it's free to me and so easy: right*

*at my local grocery store. So, I decided to get the shot.*

**Carla:** *Same. With my son in elementary school, we try to avoid any illness we can! It was also valuable for me to remember that the flu shot also helps decrease the severity of how bad it could be. It seems like a good extra protection that doesn't cost anything because we have insurance.*

**Allison:** *Wow, those are all great points. And I didn't know I could get it so easily, without even going to the doctor. I think I'll get my flu shot too!*

Sound familiar? This conversation highlights the best aspects of supporting someone in deciding and reminds us that everyone needs some extra help from trusted others to make decisions from time to time. Allison's friends respected her question without judging why as an adult she never thought about this before; they didn't tell her what she should do but did share their opinions and considerations when she asked them to; they gave her information they thought was helpful; and they did not pressure her to make an immediate decision with the new information.

## D. Trouble Spots

### *Professionals Who Insist on Guardianship Instead of Supported Decision-Making*

Perspectives about guardianship and supported decision making are changing; however, not everyone has been exposed to these ideas and many still believe safety and risk elimination are both possible and necessary, through seeking guardianship. Supporters may find themselves in the position of having to advocate for less restrictive alternatives (LRAs) to doctors, nurses, social workers, special education professionals and even other family members.

It may be helpful for supporters to understand and be prepared to explain that Minnesota's guardianship law requires less restrictive alternatives be tried before seeking guardianship; in fact, the paperwork requesting the appointment of a guardian (called the petition) requires a description of all less restrictive alternatives that were tried and considered, for how long they were attempted, and why these LRAs won't meet the person's needs<sup>6</sup>. This also must be proven in the court hearing. The law states that the court may appoint a guardian only if it finds that the person's "identified needs cannot be met by less restrictive means, including but not limited to use of appropriate technological assistance, supported decision making, community or residential services, or appointment of a health care agent"<sup>7</sup>

*DID YOU KNOW?  
MN law states that a guardian  
cannot be appointed if a person's  
needs can be met with supported  
decision-making assistance.*

Professionals sometimes recommend guardianship as a "one size fits all," way to remedy a situation when a person's safety or decision making is a concern. While well intentioned, the professionals making the recommendation may not understand the implications of guardianship or realize there are great options to get the support needed that don't involve the courts and guardianship. Even if a professional is insisting that families seek guardianship, it's important to remember that Minnesota law does not allow for the appointment of guardians if the person's needs can be met in any other way. Further, many legal experts say that it is discrimination and a violation of the Americans with Disabilities Act to require the appointment of a guardian and removal of the person's rights instead of providing accommodations for the person's disabilities.

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<sup>6</sup> [Minnesota Statute 524.5-303\(b\)\(9\)](#)

<sup>7</sup> [Minnesota Statute 524.5-310\(a\)\(2\)](#)

### *Professionals Who Don't Believe the Person's Ability to Make Decisions*

Most health care and social service professionals were trained that people need to be capable of giving informed consent (or refusal) for those services, treatments, or residential options. In this way of thinking, if a person does not fully understand the complexities of a decision or is diagnosed with conditions related to dementia or intellectual or developmental disabilities, it is often thought that they are incapacitated (or incompetent) and need to have a guardian appointed to make informed decisions for them. *But that is not correct*, according to Minnesota's guardianship law. To have a guardian appointed, the law says that it has to be proven that the person is incapacitated, meaning that the person "is impaired to the extent of lacking sufficient understanding or capacity to make personal decisions, and who is unable to meet personal needs for medical care, nutrition, clothing, shelter, or safety, even with appropriate technological and supported decision making assistance."<sup>8</sup> Minnesota law defines supported decision making as "assistance from one or more persons of an individual's choosing in understanding the nature and consequences of potential personal and financial decisions which enables the individual to make the decisions and, when consistent with the individuals wishes, in communicating a decision once made."<sup>9</sup>

Regardless of the person's diagnosis, or how much help they might need to arrange for care and services, as long as those needs can be met with help from others, the person is not "incapacitated" under Minnesota law and therefore not eligible for the appointment of a guardian. People, when supported by trusted others, are often much more capable of making decisions than professionals think they are.

Instead of stating that the person can't or doesn't understand a decision, supporters and providers should be exploring how they can help the person understand the decision they face.

### *Supporter Doesn't Agree with Person's Decisions*

If the person makes, or intends to make, a decision that seems unsafe or worrisome, talk to them! Really listen and understand their reasons behind the decision: talking through the potential outcomes of a decision can be extremely helpful.

Find out more about person's decisions: what are they thinking about the decision? Seek clarification of their thought process, what's important to them about this, what other ways might meet their wishes, that are safer?

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<sup>8</sup> [Minnesota Statute 524.5-102, Subd.6](#)

<sup>9</sup> [Minnesota Statute 524.5-102, Subd.16a](#)

Don't presume to know the person's rationale. Keep asking questions to get to the root of what is important to the person. Questions like, "What made you choose that option?" or "tell me more about why this is important to you" is more supportive and engaging than "Why did you decide that?" Phrase questions to genuinely seek more information so the person feels heard, rather than feeling they need to defend their choice.

Supporters should challenge themselves to confront their own tolerance for risk. Remember, we all make choices that others might think are too risky, but which give us pleasure. Think about finding ways to reduce serious harm, rather than trying to completely eliminate any risky outcome. What is reasonable? Is there an acceptable level of risk? Consider options that will help the person be as safe as necessary, rather than focusing only on as safe as possible.

Even with all this conversation, the person may still choose to make a call that supporters disagree with. They could choose to go to the concert, and skip their shift that day, or decline home care services that have been arranged. Supporters should remember they've still done their job as a supporter! This support is exactly what the person wanted, to help in processing through what their options were. The supporter's job was to help them understand the repercussions of this choice, and they still chose the option that the supporter does not agree with. *This does not mean the supporter has failed, and it does not mean the person cannot make their own decisions.* It means they are human and have their own set of priorities and standards in how their needs balance with their wants. In helping someone to process through decisions, supporters are creating a framework for them to work through other choices and challenges in the future. And this does not have to be the final word: re-approach the conversation at a different time.

### *Supporting the Supporter*

It is so often fun and rewarding to support people, watching them thrive with outcomes based on their own choices. And it can also be exhausting: the supporter may be burdened by feeling personal responsibility for ensuring the person's happiness and safety; it can be painful and provoke anxiety when the person does not accept the supporter's help or coaching; and others, such as neighbors, professionals, and even other family members may be pressuring the supporter to "solve" a problem.

It's important for the supporter to also have support. Supporters sometimes need to vent to someone they trust, to feel they can safely and without judgement, express their own frustrations and worry. Supporters may feel stuck when they don't know what to do next, or how to be an effective supporter. Supporters may find themselves anxious and worried that they are putting too much emphasis on safety or too much emphasis on supporting what the person wants at the cost of safety. These are all normal reactions!

Just like the people being supported, supporters need help too. Supporters should turn to their own networks of personal friends, family, and community for emotional support and brainstorming. It may be helpful to seek out professionals to connect supporters and the person to formal resources, to help identify if there should be a shift in focus from self-determination to safety. Sometimes friends, family, community members or professionals may be another voice that the person may be more inclined to listen to, in seeking the sometimes-delicate balance of arranging for what is important for the person (health, basic needs, safety) and what is important to the person, such as their hobbies, relationships, and other personal choices.

Minnesota has numerous advocacy and support services available throughout the state that can be excellent resources for supporters and the people they are supporting. Contact the [Guardianship Information Line](#) for in-depth consultation, information, and resources.

## BOUNDARIES

Setting boundaries is ok...and necessary!

Boundaries will look different in every situation.

Being a supporter doesn't mean doing *everything* for a person.

It's ok to say no sometimes, or remind the person of things they are capable of doing themselves.

This is an important way to take care of yourself, as a supporter.

Setting boundaries is not a luxury: your emotional health is important too!

Remember: you can't control the person's choices, actions, or reactions; you can only control how you respond to them.

## IV. Frequently Asked Questions

### *What Are Some Examples of Supported Decision-Making?*

Supported Decision-Making can take so many shapes; it may be helpful to think of the options falling into two categories: formal and informal.

#### **Formal**

Utilizing formal tools such as:

- *Supported Decision-Making Agreement*: the person chooses specific supporters to help with particular decision-making tasks, formalized in a written document.
- *Health Care Directive*: a person, called the principal, can specify medical treatment preferences and/or appoint a Health Care Agent to make decisions for the person if they are unable to participate in health care decision-making.
- *Power of Attorney*: a person, called a principal, appoints a trusted other, called an attorney-in-fact, to manage the person's finances on their behalf.
- *Representative Payee*: an individual or organization appointed by the Social Security Administration to manage a person's Social Security benefits. The person can nominate their preferred representative payee.
- *Release of Information Forms*: the person can grant trusted others permission to talk to their health care providers, social service professionals, special education professionals, residential and other service providers to assist in decision-making and arranging for needed care and services.

#### **Informal**

Practices, approaches, and creative ways to support the person without a formal tool. Examples include ensuring the person has access to materials presented in plain language; alternative formats such as visual or pictorial or audio format; allowing extra time to discuss choices; creating lists of pros and cons of various choices; role playing activities to help the person understand choices or feel more confident communicating their choices; attending meetings or appointments with the person to help take notes and ask clarifying questions; or simply being a person they can simply call to vent, explore options, express fears, or whatever else is helpful to the person to enable them to understand the choices they face and make decisions regarding those choices.

There is no one way to do Supported decision-making. Options and opportunities for supporting a person are as varied as are the people being supported. Remember, the approach depends on what makes sense for the person, and for their supporters.

### *Can Professionals Be Supporters?*

Absolutely! Many people don't have any family or trusted friends to support them, either by choice or circumstance. Professionals can play a powerful role in supporting a person in decision-making: just as family or friend supporters would, professionals can help an individual understand a decision, sort through potential options, and weigh pros and cons. We all want people in our life we can trust and turn to. For many, these people are a paid support, for others, it's family or friends or a combination of both. Supported Decision-Making looks different for everyone. The specifics of how formal or informal supports may look is entirely dependent on the person, what decision-making help they're seeking, and who the trusted people in their lives are. TIP: for those who do utilize professionals as their supporters, it's important to have back-up plans, or teams of supporters, so there are no gaps if the professionals move on to other jobs and are no longer available to the person.

### *Is a Written Supported Decision-Making Agreement Required?*

Minnesota does not require a written form for a person to receive support in making decisions or arranging for care and services. Depending on the person's situation, they may want to write down their chosen supporters, areas of life they wish to have help from those supporters, or anything else they want to specify: this is called a Supported Decision-Making Agreement (SDMA). The benefits of a written SDMA include clarifying areas of support and formally informing providers that the person has thought about this and made deliberate choices about who will assist them. A downside of writing an SDMA, could be providers not honoring it because they don't believe it is a legitimate form, or not knowing how to interpret the document because it is a new concept to them. Or, providers could lean too heavily on it, talking only to supporters and not to the person. Remember, people always have the right to decide who they want to help them, or talk to providers on their behalf, or attend meetings with them.

Minnesota law does not currently describe or require a written supported decision-making agreement form, so some providers are reluctant recognize the appointment of supporters. One approach to overcome the lack of familiarity is adding an SDMA to one's Health Care Directive as an addendum. Attaching it to this legal document and sharing it with providers is one way increasing its legitimacy with providers as they are very familiar with Health Care Directives. Completing a Health Care Directive with an attached Supported Decision-Making

#### *FUN FACT*

*Minnesota's Health Care Directive is very adaptable: it can stand alone as a decision-making guide for a person's care team if they're not able to communicate health care preferences. Or, it can be used to appoint an agent to make decisions for (and with) the person, regardless of their ability to understand complex medical choices. And, it can do both!*

Agreement is a great opportunity to discuss what is important to the person in terms of health and medical care and who they trust to make decisions with them now as well as in the future, should they be completely unable to make any health care decisions.

### *What If the Person Won't Let Others Help?*

Sometimes it feels as if something bad needs to happen before we can step in to help to a person who cannot understand or recognize that they need assistance. There are significant worries about the person's vulnerability and safety, yet they won't let anyone help. This is a tough and stressful space to be in! But even though it's true that the requirements for involuntary or court intervention are very high, it doesn't have to mean that the only option is to wait for something bad to happen.

This is a time for careful reflection by the people concerned about the individual. Consider whether the resistance is related to how supporters are approaching the person. Or maybe the resistance is about how the person is feeling about help: Does the person feel shamed and judged? Are they afraid of losing their sense of autonomy and independence? Do they think that accepting help makes them weak? Are they afraid if they need help, it means they will have to move to a care setting?

It can also help for supporters to take a moment to step back and reflect. What are you most worried about and what is the reality of that fear coming true? Are there ways the risks can be reduced? If the person feels that you are truly on their side and want them to have what they want, alongside concerns for safety, they may be more willing to receive your help.

You may find it helps to talk it through with someone slightly removed from the situation; a slightly more distanced perspective may help calm your worries. Consider what other supports the person has and with whom you can discuss the concern, such as a doctor, social worker, independent living skills worker, or others. Consider whether there are other services you can suggest to support the person now, and maybe avoid the negative outcome later. It's ok to take things a day or two at a time, re-evaluating what is changing in the person's life, and whether that same worry still exists. It may be helpful to think about balancing risk and happiness by considering the idea of setting things up to be as safe as necessary, which is quite different than as safe as possible.

Ultimately, if the person is unable to participate in supported decision-making and truly unable to get their needs for food, clothing, shelter, medical care, and safety met in any other way, involuntary intervention, such as guardianship may be necessary.

### *Can a Guardian Utilize Supported Decision-Making?*

There are times where a court ordered guardianship is the only option. In these instances, a guardian is tasked with making decisions for an individual that will not only ensure their health and safety, but also their quality of life. Making decisions that are centered on the person and their preferences is part of the job of a guardian. In every decision, a guardian should encourage the individual to be involved to the greatest extent possible, seeking the person's opinion and input, including currently and previously expressed wishes and preferences.

While these practices are person centered, ethical and moral, they are not supported decision-making. They are informed by supported decision-making, but they are not supported decision-making. Supported decision-making means the person makes the final call. While great decision-making support and growth can happen for an individual within guardianship, ultimately, the guardian has the power and responsibility to make decisions for the person. True *supported* decision-making can only happen outside of the power imbalance of a guardianship relationship.

***[Supported Decision-Making] is a paradigm, it is not a process, it is not a program. It means working with a person to identify where help is needed and finding a way to provide that help so that person can make their own decisions... the key question is, what will it take? What Will It Take?***

**Holly Ceasar**

## V. Supported Decision-Making in Real Life

Below are three examples of supported decision-making in action demonstrating successful approaches supporters have engaged to help address what's important to and what's important for the person.

### **Example 1: Chuck**

*Tonya's grandfather Chuck was recently diagnosed with moderate dementia. He's been very closed off and won't talk to any of the kids or grandkids. All Chuck will say is "I am NOT leaving my house!" Tonya is worried Chuck might wander off or fall one day. Chuck confuses days/time and Tonya isn't sure if Chuck is getting proper nutrition or remembering to take his medications. Chuck's other family members are pressuring Tonya to "make him move to Assisted Living."*

*As his supporter Tonya calls Chuck's favorite nurse, Nick, at his primary care clinic to discuss the situation and what he thinks she should do. Fortunately, Chuck had previously signed a Release of Information Form, allowing the nurse to talk to Tonya.*

*Nick calls Chuck and talks to him about needing to have a little bit of help ("Doctor's Orders!"), at least to try it for a few weeks, and says he knows and trusts some really nice people at a home care agency who can help with cooking and laundry.*

*Chuck (although somewhat begrudgingly) agrees with Nick's suggestion; Nick then gets the doctor to write an order for home care. Nick coordinates with the home care agency to get the services started. When the agency calls Chuck to set up the appointment, he tells them "No Way!". Tonya and Nick talk to Chuck again, asking him to try it for a few weeks, as a favor to Tonya, and reminded him that the doctor ordered the services. Tonya meets the home care nurse at Chuck's house, and he agrees to talk with her.*

*Once Chuck gets to know the homecare staff he enjoys "having someone to visit with, since you kids are just so busy," and the primary homemaker builds a trusting relationship with him. Although he can't remember the homemaker's name from visit to visit, Chuck looks forward to "that nice girl coming to make me lunch and visit."*

*Chuck is now able to continue living at home safely, and with support from Tonya and Nick, made the decision to accept home care so he could keep living safely at home.*

## **Example 2: Jose**

*Maria's son Jose is 20 and has been in a school-based transition program as part of his Individualized Education Plan. Lately he has been skipping class, riding the city bus around town, and is getting in trouble by missing required program activities. He refuses to talk to Maria and just stomps off when she brings it up. Maria is fed up and considering guardianship so that she can ensure he goes to school and isn't putting himself at risk riding the bus all over town.*

*Maria decides to call Jose's older cousin Miguel to ask his advice. She also places a call to the school social worker.*

*Miguel calls Jose to talk about what's going on at school.*

*The social worker suggests a team meeting, but Maria is not sure that will help Jose make better decisions because he often gets very quiet in large groups. The social worker suggests that the three of them meet in her office since Jose is generally relaxed in that space and may be more willing to talk.*

*During the meeting Jose opens up about how he wants to try a different education program because this one is too basic and doesn't feel like a good fit. Jose explains that he wanted to tell Maria but she was "so mad, that I didn't think you'd listen."*

*Jose, Maria, and the social worker spend a long time talking about what Jose wants for his life. The social worker shows curiosity and genuine concern, while asking open ended questions that really allow Jose to express himself in his own time.*

*The social worker is able to lay out pros and cons of staying in his current program (closer to home, friends there, loves the pool) versus going to an alternative program (more challenging courses, college credit, doesn't know anyone, an extra ½ hour bus ride) and Maria offers her opinion too.*

*Ultimately Jose, after looping in Maria and Miguel, takes the information the social worker provided him and decides to enroll in the other program.*

*Jose asks Maria to help him understand the application process and organize paperwork, so he doesn't miss any steps.*

### **Example 3: Harriet**

*Harriet, who has moderate Alzheimer's Disease, tells her daughter Gladys during a visit that she has to go to Target and get some gift cards for \$500 each, but cannot say what they are for or why she needs them. During a visit, the phone rings and Gladys answers it: it is immediately obvious that Harriet is being targeted by scammers as the caller immediately asks if Harriet has gone to the store and obtained the gift cards and attempts to bully Gladys into speaking with Harriet*

*Gladys and Harriet explore her vulnerability to phone scams and overall phone use. Is the phone needed to have caregivers gain access to her apartment? Gladys coaches Harriet about how to screen calls using caller ID and voice mail, and not to answer any calls whose number she does not recognize, reminding her that legitimate callers will leave a message. Gladys and Harriet explore whether it makes sense to change phone numbers to stop the scammers from calling. Though Harriet is reluctant to do so, Gladys reminds Harriet how it feels to have the phone constantly ringing, and her desire to answer the calls, many of whom are scammers who can successfully prey on very smart people. Gladys writes reminders on a tablet near the phone to help remind Harriet.*

*Harriet's other daughter Sammy is her Attorney-in-Fact and Health Care Agent. Sammy and Gladys talk about additional protective ways to prevent Harriet from being taken advantage of: Sammy and Harriet go to the bank to review previous transactions to determine if they are legitimate transactions or if she has already been exploited. When they find out she has, they file a report with MN Adult Abuse Reporting Center (1-844-880-1574) and contact the police. They also work with the bank to set up flags for unusual activity, set new limits for cash withdrawals or transactions. Harriet agrees to give her bank cards and check book to Sammy for safe keeping in exchange for having petty cash available for personal needs.*

*Now that Harriet understands that bad people are trying to steal from her, she agrees to have ongoing conversations with Sammy and Gladys to continue to monitor the calls and requests for money that she receives. Monitoring will include tweaking the plan as needed. For example, next action steps might include changing her phone number, getting a simple cell phone so her daughters can easily track callers, and even having Sammy moving funds to another bank if the scammers convince Harriet to get more money because they already know where she banks, and reporting new instances of exploitation.*

## Conclusion

Supported decision-making is a “series of relationships, practices, arrangements and agreements, of more or less formality and intensity...designed to assist an individual with a disability to make and communicate to others decisions about the individual’s life.”<sup>10</sup>

Supported decision-making is simply making decisions with the person, not for the person, to ensure they are safe, happy, and living their best life. It’s about being creative in helping people achieve what they want while ensuring their health, safety and basic needs are met. It’s about finding the balance between quality of life, or the dignity of risk, and safety.

Supported decision-making approaches ensure a person’s voice is heard, that their wants and desires are honored, and that their basic human rights are preserved. Their life can be lived in the way that is best for them, and your support is making that a reality.

Sometimes being a supporter can feel like a heavy burden, especially when you’re worried about the person. Remember, you have support too!

These *Best Practices in Supported Decision-Making* are provided for you: there are so many ways to support people. The specific needs, desires, and personality of the person you’re supporting guide your approach to make supporting the person work. Everyone needs something different: you will find your unique and special way of supporting the person, unlike anyone else. That’s what makes it so valuable, effective, and even fun! You and the person you are supporting know best what works in your relationship. We encourage you to use this document as your guidepost as you forge your own way forward. We’d love to hear how it’s going for you and if you have tips to share with others.



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<sup>10</sup> Institute on Community Integration, Frontline Initiative 2017, Vol. 14 (2), *Supported decision-making as alternative to guardianship*, Robert Dinerstein

## SUPPORTED DECISION-MAKING CHECKLIST

- ✓ Supporters are chosen by the person: identification of who will help in what areas of decision-making (family; friend; coworker; professionals such as case manager, job coach, ILS worker, other)
- ✓ Person drives the conversation, unless they want others to do so
- ✓ Person and Supporters have identified areas where the person needs or wants support
- ✓ Supporters are educated to role: supporting, guiding, not making decision, keeping own biases out, okay to illuminate natural consequences, and “if you do this, then that”
- ✓ Supporters understand how the person envisions them supporting
- ✓ Supporters make decisions *with* the person not *for* the person (unless the person asks them to)

## VI. APPENDIX

- A. Quality Trust Explainer Graphic
- B. Supported Decision-Making Health Care Directive Addendum
- C. Explainer Videos Links



# Supported Decision-Making (SDM)

## Quality Trust for Individuals with Disabilities

### 1 What is SDM?

A process in which people who need assistance with decision-making receive the help they need and want to make life decisions for themselves

A way to preserve rights and build on existing capacity with real life experience and learning

An essential element for achieving self-determination and meaningful inclusion in community

An empowering, skill building and transformative approach to assisting people

### 2 What happens now?

Little to no emphasis on "teaching" decision-making skills

Low expectations for children or adults with disabilities to be involved in decision-making in meaningful ways

Superficial use of "preferences" in structured programming

Bias toward use of **substituted** decision making methods (e.g., guardianship) as a primary support



### 3 Rethinking Support

How do all people become good decision-makers?

What role and responsibility do professional "helpers" have to support individual decision-making?

What about the role of families?

What could support look like? (one size will not work for all)



### 5 What can you do?

Acknowledge decision-making as a basic human right and natural part of the human experience

Expect that all children with disabilities will develop as decision-makers and ensure involvement in decision-making throughout the lifespan

Help people develop relationships and support systems necessary for accessing support in decision-making when needed (e.g. Friends, family, trusted professionals and generic service providers, etc.)

Learn to evaluate the need for intervention by weighing the risk of harm or failure with the risk of loss of dignity, self-direction and overall quality of life.

Educate people and families on the options available.



### 4 Providing Support



Take direction from the person and his or her will and preferences

Customize actions to and with the person

Find new tools for your toolbox

- Communication
- Peer Support
- Practical Experiences
- Life Coaching

Be flexible and try multiple ways

### Reference

Quality Trust for Individuals with Disabilities: The Council on Quality Leadership, and Burton Blatt Institute. "Supported Decision Making: An Agenda for Action"-February 2014

 **Quality Trust**

[www.dcqualitytrust.org](http://www.dcqualitytrust.org)  
[www.supporteddecisionmaking.org](http://www.supporteddecisionmaking.org)

SUPPORTED DECISION-MAKING ADDENDUM  
TO THE HEALTH CARE DIRECTIVE OF

\_\_\_\_\_  
(name)

1. **Purposes of this Addendum.** I, \_\_\_\_\_, (name)  
\_\_\_\_\_, (address)  
\_\_\_\_\_, \_\_\_\_\_ (city, state, zip)  
DOB: \_\_\_\_/\_\_\_\_/\_\_\_\_,

declare the following:

- 1.1 **Supported Decision Making:** My Supporter does not make decisions for me. This supported decision-making agreement is to support and accommodate me to make life decisions. These decisions include, but are not limited to: where I want to live, the services, supports, and medical care I want to receive, whom the I want to live with, and where I want to work, without impeding my self-determination. This document gives immediate power to my appointed supporter.
- 1.2 **Release of Information:** This supported decision-making agreement also serves as a release of information, allowing my supporters to receive confidential information. I only authorize the release of my confidential information to my supporter so that my supporter can help me obtain a copy of the confidential information, help me understand the information contained in this confidential information and help me communicate my decisions based on this confidential information. My supporter shall ensure that my confidential information is kept privileged and confidential and is not subject to unauthorized access, use or disclosure. My supporter may only release my confidential information to any other person, provider or organization with my permission. I also retain the right to obtain my confidential information on my own without the help of my supporter.

2. **Appointment of Supporter(s).**

Primary: I appoint as primary supporter to make decisions with me:

my _____ (relationship),	my _____
_____ (name)	_____ (name)
_____ (address)	_____ (address)
_____	_____, _____
_____	(city, state, zip)
_____, _____	Telephone: (____) _____ - _____,
(city, state, zip)	

Telephone: (\_\_\_\_) \_\_\_\_\_ - \_\_\_\_\_ .

Successor: If for any reason my primary supporter named above is not reasonably able to serve, I appoint as successor supporter:

**3. Powers of Supporter.**

3.1 Upon my request, my Supporter may help me with life decisions in areas including, but not limited to, the following:

- 3.1.1 Obtaining food, clothing and a place to live;
- 3.1.2 My physical health;
- 3.1.3 My mental health;
- 3.1.4 Getting an education or other training;
- 3.1.5 Choosing and maintaining my services and supports;
- 3.1.6 Finding a job; and,
- 3.1.7 Additional life decisions as I request in the future.

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

- 3.2.1 Help me get the information I need to make medical, psychological, financial, or educational decisions;
- 3.2.2 Help me understand my choices so I can make the best decision for me;
- 3.2.3 Help me communicate my decision to the right people; or,
- 3.2.4 Provide other support as I request in the future.

**4. I authorize the following information to be released:**

- 4.1 Health Information: All health information, including, but not limited to, HIV/AIDS Test Results/Treatment, and Drug, Alcohol, or Substance Abuse Records;
- 4.2 Mental Health Information: All mental health information, including, but not limited to Mental Health Treatment, Intrusive Mental Health Treatment, Test Results and Psychotherapy Notes;
- 4.3 Case-Related Information: My entire case file/records;
- 4.4 Education/Special Education Information: All education/special education records;
- 4.5 Employment Information: All employment records;
- 4.6 Financial/Property Information: All financial/property records;
- 4.7 Housing Information: All housing information; and,
- 4.8 Supports and Services: All records related to any supports and services provided to me.
- 4.9 Subject to the following limitations (if any): \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**5. HIPAA Release:** Unless otherwise limited above, my Supporter has the same right as I would have to receive, review, and obtain copies of my medical records and to consent to disclosure of those records. For the purposes of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), I hereby designate any of the above Supporters named in this document as my Personal Representative as defined in the above-mentioned Act. Unless otherwise limited above, these Supporters have the authority that I have, pursuant to HIPAA to receive, review, and obtain copies of my past and present medical records, including records regarding my



Appendix C  
CESDM White-Board Animation  
Explainer Videos



[Understanding Guardianship](#)

[How to Do Supported Decision Making](#)



[Supported Decision Making in Practice](#)