SUPPORTED DECISIONMAKING & THE CARE ACT

Training Category: CARE Act Process

This presentation is for Supported Decisionmaking and the CARE Act. The training category is the CARE Act process.

Disclaimer: This session is presented by Health Management Associates. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement by, California Department of Health Care Services.
The agenda includes:

- An Introduction to Supported Decisionmaking (SDM)
  - Define SDM
  - Highlight key concepts and principles
- Supported Decisionmaking in the CARE Act Process
  - Overview of SDM and the CARE Act process
  - Review of roles in the CARE Act, including the volunteer supporter, and their relationship with the SDM framework
  - Include a scenario that provides an example of how one may support the individual to make their own decisions under an SDM framework
At the end of the session, participants will have an increased ability to:

- Explain why supported decisionmaking can be promoted for individuals who are eligible for the CARE Act
- Demonstrate familiarity with the continuum of decisionmaking supports for all parties involved in the CARE process (including the BH agency, courts/counsel)
- Apply SDM to the volunteer supporter role
DARI POGACH, JD  
Senior Consultant  
Health Management Associates

BARRY J. JACOBS, PSYD  
Principal  
Health Management Associates

The presenters Dari Pogach, JD, and Barry J. Jacobs from Health Management Associates.

Dari Pogach, from Health Management Associates, has more than 15 years of experience working with clients, communities, nonprofit organizations, policy makers, and state and national government leaders. Dari has subject matter expertise in supported decision-making as a legal theory and its practical application. She has represented clients in completing supported decision-making agreements, written scholarly articles about supported decision-making, and conducted numerous trainings for national audiences. As a senior official with the District of Columbia’s Department of Aging and Community Living, Dari led the agency’s adult protective services, case management, and nursing home transition teams. At the American Bar Association’s Commission on Law and Aging, Dari developed nationally lauded tools and programs for attorneys and other professionals, facilitated stakeholder engagement across the country, and led multimillion dollar projects dedicated to adult guardianship reform and decisionmaking supports. She has represented clients with psychiatric disabilities in a
variety of advocacy matters.

Barry J. Jacobs, from Health Management Associates, is a clinical psychologist and family therapist who has authored several books and dozens of articles on enhancing support for family caregivers. Dr. Jacobs provided more than 500 presentations about caregiving for family caregivers, community groups, and medical and mental health professionals. He is an expert in behavioral health integration, complex care management, enhancing family caregiver engagement and supports, practice transformation, team-based care, and provider wellness. He brings to HMA his knowledge and decades of clinical practice experience for individuals, couples, and families.
This section covers an introduction to SDM.
Supported Decisionmaking

Supports and services that help an adult with a disability make his or her own decisions, by using friends, family members, professionals, and other people they trust:

» to help understand the issues and choices, ask questions
» receive explanations in language they understand
» and communicate their own decisions to others


Supported decisionmaking is a paradigm shift: Instead of assuming people with disabilities lack the capacity to make decisions, SDM asks, what supports and services would enable individuals to make their own decisions? SDM means decisions aren’t made for the person, they are made by the person.

The definition was written in the context of protecting the rights of people with disabilities to make their own decisions. The process applies to all of us, including those of us whose decisionmaking authority and capacity have never been questioned.

Some of the underlying principles that underly SDM include:
• Everyone has the right to make their own decisions
• Most of us make decisions with support
• Supported decision making can empower people with disabilities to make their own decisions

Instead of approaching a situation thinking through the barriers to someone making
their own decisions (physical barriers, bad decision making skills, untreated mental illness), SDM invites us to think through: "So just to give some brief context for supported decision making this framework is a response to decades of suppression of the rights of people with disabilities to make their own decisions. It really signified a paradigm shift and the way that we think about decision-making when we talk about people with disabilities. We all have the right to make our own decisions, including people with disabilities, and we also have a right to the support and services that are truly necessary to help us make those decisions.

CARE Act Statute

“Self-determination and civil liberties are important California values that can be advanced and protected for individuals with these untreated severe mental illnesses with the provision of legal counsel for CARE proceedings, agreements, and plans, as well as the promotion of supported decisionmaking.” CARE ACT

- The goal is to support self determination to the greatest extent possible
- SDM is a decisionmaking model for the CARE Act participant and supporter

For more information, visit the 2022 California Welfare and Institutions Code.

The state of California is emphasizing SDM. SDM is a fundamental tool for advancing California values.

“Self-determination and civil liberties are important California values that can be advanced and protected for individuals with these untreated severe mental illnesses with the provision of legal counsel for CARE proceedings, agreements, and plans, as well as the promotion of supported decisionmaking.” CARE ACT

Two things to keep in mind:
- The goal is to support self determination to the greatest extent possible
- SDM is a decisionmaking model for the CARE Act participant and supporter

Note: This is a decisionmaking framework. It is a tool that will not always work perfectly.

For more information, visit the 2022 California Welfare and Institutions Code.
Supported decisionmaking is one of several options for making decisions. Other options are included here which can be applied on their own or in conjunction with SDM.

Other options include:
- medical and financial powers of attorney
- authorized representative forms
- health care directives (including psychiatric advanced directives)
- release of information forms
- representative payees

SDM can be used as an alternative to different types of conservatorships.

For more information, visit the 2022 California Welfare and Institutions Code – 21000(g).
What decisions have you made today?

Did you make every decision on your own? Or did you ask someone for input?

Did you get advice? Did you take it?

Were you making a big or small decision?

What factors influenced your decision?

In order to better understand what SDM is and how to apply it in practice, let’s break down our own decisionmaking process to think about what are the types of decisions we make, who is in our decisionmaking network, and what are the types of influences at play when we make a decision.

For example, think about some of the decisions you’ve made today.

- Did you make every decision on your own?
- Did you ask someone for input?
- Maybe you asked your partner if your outfit looks ok? Or what you should eat for breakfast?
- Did you talk to someone about a bigger decision, such as buying a car or attending school?
- Who did you ask? Did they give you advice? Did you take it?
- Who is in your decision making network?

We all make decisions every day including big and small, and we usually use support
networks to make those decisions. We may ask for advice, but we don’t always take it, depending on how that advice aligns with our values, priorities, and preferences. And we don’t make decisions in a vacuum: there are lots of factors that impact what choices we make (which we are going to discuss on the next slide).

Individuals with disabilities and disorders are not unique in needing a support network to make decisions, not always taking other people’s advice, and having other factors that influences their choices.
What are the factors that influence decision making?

There are many factors that influence how we make decisions.

1. Race
2. Ethnicity
3. Class & education level
4. Gender
5. Culture
6. English proficiency
7. Family dynamics
8. Financial status

Supported decision making isn’t just about making a list of pros and cons. There are other factors that influence decision making. Some examples of other factors that influence decision making include:

- Race, ethnicity, class & education level, gender, culture, English proficiency, family dynamics, financial status

SDM will seem very natural to some groups. For others, SDM is a reversal of the approach to decision making. In some cultures, the majority looks to the family or community elder to make a decision.

People who meet the CARE Act requirements have likely not been respected or expected to make their own decisions, let alone a “good” decision, in many years.

Let’s consider how a few of these different factors can influence decision making:
• English proficiency: In first generation American families, a child who translates from the family’s native language to English may end up making decisions due to communication constraints.
• Family dynamics: if a volunteer supporter is a family member, there will inevitably be pre-established roles regarding decisionmaking.
• Financial status: if there aren’t enough resources, making decisions can come down to do we eat or do we have a place to sleep tonight?
What if ...

• ...the person is **threatening to harm themselves or others?**
• ...the person **doesn’t want to engage in SDM?**
• ...the person is **not communicating expressed wishes?**

How can SDM be used in various situations?

• Remember, by engaging in SDM, the supporter isn’t making the decision but is providing supports for the client to make a decision.
• SDM is a framework and a spectrum rather than a rule. It should be used to maximize the autonomy of an individual, and it will look differently in different situations.
• An individual may be untreated and unstable, but still able to accept your support in helping them make their own decisions.

When SDM might apply:

• Person wants to make a medical decision that is contrary to the medical team’s recommendation
• Decisions around allocation of resources
• Social or relationship decisions

Consider the following situations in which there could be limitations to how SDM can
be used.

- **The person is threatening to harm themselves or others.** If the client/respondent is threatening to harm themselves or others, the supporter should call emergency response (988 or 911).
- **The person doesn’t want to engage in SDM.** SDM can only happen if the person wants support making decisions.
- **The person is not communicating expressed wishes.** If they are not communicating currently, their previously known wishes or any legal documentation of their wishes should be considered.
What is Sean’s situation?

» Sean has a diagnosis of diabetes and opioid use disorder, and he’s currently unhoused.
» The doctor recommended he amputate his toe, which has gangrene, or he will lose his foot.
» Sean is worried he will relapse if he is medicated for surgery, and he decides to forgo the surgery.

[Slide Image Description: This slide shows a description of a hypothetical scenario for Sean and a picture of an individual pushing another individual that is in a wheelchair.]

Let’s look at a hypothetical scenario to consider how SDM works in practice.

Here’s the situation:

• Sean has a diagnosis of diabetes and opioid use disorder, and he’s currently unhoused.
• The doctor recommended he amputate his toe, which has gangrene, or he will lose his foot.
• Sean is worried he will relapse if he is medicated for surgery, and he decides to forgo the surgery.
Sean has the right to make his own decisions with the necessary services and supports. SDM can help Sean make his own decision. Sean's supporter should be able to answer some or all of the following:

» Did Sean have all the information he needed to make an informed decision?
» Did he talk to the surgeon about medication options for someone with opioid use disorder?
» Did his psychiatrist participate in the treatment plan?
» Did Sean get to tell the doctor how he felt?

What is the ideal outcome?

Let's talk about the ideal outcome of SDM. The ideal outcome is that Sean gets all the information he needs to make a decision, not that Sean makes a pre-determined choice.

Under SDM, he has the right to make his own decisions with support and all the information he needs

• Did Sean have all the information he needed to make an informed decision?
• Did he talk to the surgeon about medication options for someone with opioid use?
• Did his psychiatrist participate in the treatment plan?
• Did Sean get to tell the doctor how he felt?

In SDM, there is no “bad” decision, as long as the person was supported and informed.
In the next section, we are going to look at how SDM applies to the CARE proceedings. Consider how you would summarize SDM as a framework and make a note of questions you have about how it applies to CARE.
We’ve talked about supported decisionmaking and how it’s used broadly, and now we are going to see how this framework would apply to the CARE Act proceedings, especially through the volunteer supporter role.
Person-Centered Planning as a tool within SDM in the CARE Act

» The components of the CARE process are structured to ensure that the diverse and unique needs of each respondent are heard, recognized, and met.

» Person-Centered Planning means prioritizing the CARE respondent’s strengths, capabilities, preferences, lifestyle, and culture.

» With the help of the SDM approach, the different roles within the CARE process can use person-centered planning as a guide for supporting the CARE respondent through the process and ensuring that their priorities, choices, and decisions are heard.

For more information, access the Person-Centered Planning Training Guide.

Person-centered planning is a tool with use within SDM in the CARE Act:

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Where in the process are there opportunities to incorporate the SDM approach?

All parties in the CARE proceedings should be familiar with the concepts of SDM so that it can be a respected part of the process. We have introduced and dissected this CARE flow in prior trainings. As you look at the process now, where do you think that SDM can intentionally be incorporated throughout the CARE proceedings to ensure that the needs and preferences of a respondent are honored?

In the next slide, we are going to talk about a few points in the process that could incorporate SDM.
When should SDM be incorporated?

As SDM is really about ensuring that the client or respondent’s preferences and priorities are known, all of these components of the CARE Act should include this approach.

We are calling out activities in bold that definitely should incorporate the SDM approach:

- Psychiatric Advanced Directive (PAD): We will address this in detail in our PAD training.
- Voluntary engagement: although all aspects of the CARE proceedings are voluntary for the respondent, voluntary engagement can happen early on in which the respondent agrees to engage in services before the court process begins in earnest. At this point, the respondent’s needs and preferences should be reflected in the way that they engage in services.
- CARE plan/agreement: a CARE plan/agreement will formalize services that the respondent will have access to and that the BH agency will agree to provide. All parties—including the respondent and the supporter—should collaborate on the
plan/agreement, and the end product should reflects needs and preferences of the respondent in the different sections outlined by statute, including: behavioral health services, medically necessary stabilization medications, housing services, social services (including services)

• Graduation plan: the graduation plan should also consider the needs and preferences of the respondent, to help them transition out of the CARE court process in a way that maximizes their stability

To complete each of these activities effectively, engaging with the client/respondent with regards to their preferences, priorities and overall goals is critical.
Let’s use another case example to look at how SDM can be applied in the CARE proceedings.

What is Ray’s situation?

• Diagnoses of schizophrenia, alcohol use disorder, type II diabetes
• Not engaged with a mental health provider
• History of inconsistent use of antipsychotics
• Recent emergency room visits related to his neuropathic pain
• Currently unhoused
• Referred for CARE Act proceedings by a Homeless Outreach worker who checks in with him regularly
• Ray elects his older sister as his volunteer supporter

Disclaimer: This is a hypothetical case example. Any resemblance to an actual person is purely coincidental
[Slide Image Description: This slide shows an image of an individual representing Ray and a description of where Ray is in the CARE Act and some of Ray’s preferences.]

Where is Ray in the CARE process?

- Ray has progressed to the point of creating a CARE agreement
- The BH agency has made initial recommendations:
  - Complete a medication evaluation and follow the provider’s recommendations
  - Pursue substance use disorder (SUD) treatment options
  - Engage with a PCP for his medical conditions

What are some of Ray’s preferences?

- Willing to see a psychiatrist for an evaluation
- Does not want to commit to medications
- Not interested in SUD treatment or seeing a PCP
- Interested in financial support and housing

Disclaimer: This is a hypothetical case example. Any resemblance to an actual person is purely coincidental.
• He is not interested in pursuing SUD treatment or seeing a PCP
• Ray wants to focus on getting additional financial support and housing

Disclaimer: This is a hypothetical case example. Any resemblance to an actual person is purely coincidental
With Ray’s consent:

» Talk to the BH agency’s case manager and other associated providers about why they are making these recommendations

» Ensure that Ray’ case manager is aware of Ray’ preferences and priorities

» Talk through options with Ray so he can make his own decisions about which treatment and services he would like to have included in his CARE agreement

How can Ray’s sister help him understand his options to make decisions related to his CARE agreement?

Let’s consider how Ray’s sister (as his voluntary supporter) can help Ray understand his options to make decisions related to his CARE agreement.

• Sister engages in activities at Ray’s request to help him make an informed decision about his CARE agreement.

• Again, with Ray’s consent, she may reach out to the BH case manager to understand why team has made each specific recommendation

• The sister emphasizes Ray’s priorities and preferences to the BH case manager

• She talks through various options and their potential consequences with Ray to help him decide which services he would like
There is a brief on the supporter role in the CARE Act available on CARE-Act.org. The brief covers the following:

- What does the supporter role entail?
- Who is the supporter?
- What are the key operating principles of the supporter’s role?
- How is the supporter selected?
- Can a supporter change throughout the CARE proceedings?
- What are considerations that should guide the supporter role?
- What can a supporter participate in?
- What trainings are available to supporters?
- Statute Language & Citation
The Supporter Role and SDM - Training

Training on the roles and principles of supporters and provides a deeper look at how they can incorporate SDM into their role.

In addition to that brief, there is also a training specific to the role of the volunteer supporter. It covers the roles and principles of supporters and provides a deeper look at how they can incorporate SDM into their role.
Helping Respondent Anticipate Consequences

While anticipating consequences is important to making informed decisions, the volunteer supporter should not lecture the respondent about potential consequences.

Supporters may help respondents think through the potential consequences of their options in order to make the most informed decision possible. Though the supporter may help the respondent accomplish this by framing questions, the supporter should not lecture the respondent about the possible pros and cons of each choice.

**Recommended approach:**
- Ask the respondent whether they would like to think through the potential consequences of choosing one option vs. another
  - If the respondent agrees, then the supporter can help them list pros and cons of each choice to make a more informed decision
  - If the respondent doesn’t agree, then the volunteer supporter should not insist on telling them what may occur (unless it will cause imminent harm). With the respondent’s permission, the supporter may share their concerns with the respondent’s BH therapist and/or support team.
How can Ray be supported by these CARE Act roles using SDM to make informed decisions and meet his needs and wishes?

We’ll be calling out these 4 roles within the CARE Process who we recommend participation in, utilization of, and awareness of, the SDM approach:

1. Client/respondent
2. Volunteer Supporter
3. the County BH Agency
4. CARE Court

In the next few slides we are going to talk about how SDM can be used a tool by each of these roles.
How can Ray use SDM as a tool to express his needs and wishes?

» Communicate with the supporter & BH provider
  • Express preferences, choices, priorities
  • To ultimately inform the CARE agreement/plan

» Use decisionmaking support network

» Make a list of pros and cons

» Participate in the development of a Psychiatric Advance Directive

» Ask for the supporter (if preferred) to join visits that would be helpful, with:
  • the BH Provider
  • Respondent’s counsel

Ray (as the respondent going through the CARE process) can use SDM to express his needs and wishes by:

• Communicating with the supporter & BH provider expressing preferences, choices, priorities that will ultimately inform the CARE agreement/plan.
• Using a decisionmaking support network
• Making a list of pros and cons
• Participating in the development of a Psychiatric Advance Directive
• Asking for the supporter (if preferred) to join visits that would be helpful, with:
  • the BH Provider
  • Respondent’s counsel
How can Ray’s sister use SDM as a tool for her supporter role?

- Listen to Ray’s concerns and ask him what are his preferences and goals
- Help Ray organize his thoughts
  - Take notes
  - Make lists or a diagram
  - Repeat his statements back to him
  - Have the conversation at different times
- Attend Ray’s BH appointments (if Ray requests)
- Listen to Ray and respond to his concerns/requests
- Remind Ray that this is his decision
- Talk to Ray about potential consequences

We have talked about how Ray’s sister (as his supporter) can help him understand his options to make decisions throughout the CARE process. Now let’s consider some tools that supporters can use to help ensure principles of self-determination throughout.

Some things that Ray’s sister can do:
- Listen to Ray’s concerns and ask him what are his preferences and goals
- Help Ray organize his thoughts
  - Take notes
  - Make lists or a diagram
  - Repeat his statements back to him
  - Have the conversation at different times
- Attend Ray’s BH appointments (if Ray so requests)
- Listen to Ray and respond to his concerns/requests
- Remind Ray that this is his decision
- Talk to Ray about potential consequences
The BH agency can use SDM as a tool by:

- Listening to Ray’s concerns
- Respecting the role of Ray’s supporter as someone who is supporting Ray to make his own decision
- Meeting with Ray, his supporter (if Ray requests), and additional professionals who may be able to help Ray make his own decision
- Speaking with Ray about how you can work together to provide services that address Ray’s priorities
- Applying a multidisciplinary approach that includes a psychiatrist to problem-solve Ray’s concerns about medication
- Giving Ray as much information as possible to assist him with his decisionmaking

[Slide Image Description: This slide shows an image of an individual representing the BH agency and gives a description of how the BH agency can use SDM.]
How can the CARE Court Roles respect SDM as a tool?

» Confirm that Ray has chosen his sister as his supporter (or request that a supporter be appointed)
» Confirm that there is no irresolvable conflict between Ray and his sister as his supporter
» Respect the role of Ray’s supporter as someone who is supporting Ray to make his own decision
» For counsel: if Ray requests, include his sister in meetings/conversations

[Slide Image Description: This slide shows an image of a gavel and gives a description of how the CARE Court can use SDM.]

The CARE Court can utilize SDM by:

• Confirming that Ray has chosen his sister as his supporter (or request that a supporter be appointed)
• Confirming that there is no irresolvable conflict between Ray and his sister as his supporter
• Respecting the role of Ray’s supporter as someone who is supporting Ray to make his own decision

For counsel: if Ray requests, include his sister in meetings/conversations
In this scenario, Supported decisionmaking can help ensure that...

- Ray has the information he needs to make his own decisions
- Ray can talk through the pros and cons of his decisions
- Ray understands possible outcomes and consequences of his decisions
- Ray’s Volunteer Supporter (and others in his supported decisionmaking network) have been part of the process
- Ray feels respected and heard
- Ray makes self-directed decisions to the greatest extent possible

The ideal outcome of SDM is not a predetermined, “good” decision. It’s that Ray makes his own decisions to the greatest extent possible.
Sample Tools for Supported Decisionmaking

- National Resource Center for Supported Decision-Making: [Supported Decision-Making Model Agreements](#)

SDM is an emerging approach, but there are great resources about how to apply it in practice. We will share more resources with you in the appendix.

Visit the National Resource Center for Supported Decision-Making for sample [Supported Decision-Making Model Agreements](#).
What are the biggest challenges to implementing principles of SDM during CARE proceedings?

- **One potential barrier is the acuity of illness.** If there are people that are not ready to engage in the process, then SDM may not be the right tool. Other options should be sought after at that point. We hope that we find the right time to approach individuals when in the course of their disease, when they are not suffering with severe symptoms and are willing and able to engage in the process and benefit from the framework. To help them make the best decision possible and feel respected and heard which will allow them to fully participate in treatment to find a real benefit to themselves and their families. The court and behavioral health agency should check in at weeks three, four, and eight to see if a person may be at a good point for engagement. This is corollary to the volunteer supporter role, if the respondent does not what a volunteer supporter in the beginning it does not mean they cannot have one later in the process. This is the person-centered approach to understand where a person is at in their behavioral health journey.
• **Another challenge is setting up a support decisionmaking network.** We are talking about individuals who are likely disenfranchised and isolated. Counties face challenges in implementation and identifying supporters. One option is to look at the local community to organizations; however, there may be a logistical challenge identifying the appropriate supporter. Trust is an important word and is the whole point of SDM. Basic trust for someone with severe mental illness is important for engagement and getting a respondent through the whole CARE Act process.
At the end of the session, participants will have an increased ability to:

• Explain why SDM is a fundamental principle of the CARE Act
• Demonstrate familiarity with the continuum of decisionmaking supports for all parties involved in the CARE process (including the BH agency, courts/counsel), including SDM
• Apply supported decisionmaking as a decisionmaking model to the volunteer supporter role
Next Steps

» Visit CARE-Act.org for resources (including recordings of past trainings) and to submit questions/TA requests.

» Receive notifications of trainings, TA, and other engagement opportunities by completing the form to join the communication listserv.

Next steps include:
• Take the evaluation after this training.
• Visit CARE-Act.org for resources (including recordings of past trainings) and to submit questions/TA requests.
• Receive notifications of trainings, TA, and other engagement opportunities by completing the form to join the communication listserv.
Questions?

CARE-Act.org | info@CARE-Act.org

We are here to support you and provide you with those opportunities to connect and hear about implementing the CARE Act. The website is CARE-Act.org, and our email address is info@CARE-Act.org.

[Slide Image Description: This slide shows the CARE-act website and the email address.]
Resources

» CPR: About Supported Decision-Making
» National Resource Center for Supported Decision-Making
» ACLU: Supported Decision-Making: Frequently Asked Questions
» Person-Centered Planning Training Guide

[Slide Image Description: This slide shows the SDM resources.]

- CPR: About Supported Decision-Making
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