



#### **CARE Act Training & Technical Assistance**





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.



[Slide Image Description: This cover slide introduces the title and category of this training. It contains the logos for the California Department of Health Care Services and Health Management Associates.]

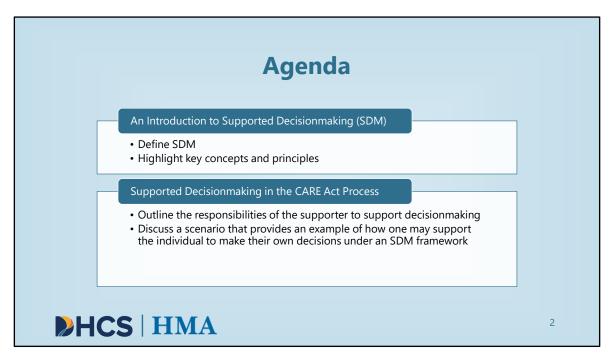
This presentation is for supported decisionmaking and the CARE Act. It is meant to orient volunteer supporters around supported decisionmaking's role in the CARE Act and the role of the supporter.

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[Slide Image Description: This slide shows the major sections of this training on a light blue background.]

#### The agenda includes:

- An Introduction to Supported Decisionmaking (SDM)
  - Define SDM
  - · Highlight key concepts and principles
- Supported Decisionmaking in the CARE Act Process
  - Outline the responsibilities of the supporter to support decisionmaking
  - Discuss a scenario that provides an example of how one may support the individual to make their own decisions under an SDM framework





## **Objectives**

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
- Understand how the supporter can help facilitate supported decisionmaking



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[Slide Image Description: This slide shows the learning objectives for this training with a light blue background.]

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[Slide Image Description: This slide includes images of the presenters of this training on a light blue background.]

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





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.

In addition to the content development by subject matter experts from Health Management Associates, this presentation material was informed by Painted Brain (peer organization based in Los Angeles), Christopher Schnieders from the Saks Institute, National Alliance for Mental Illness (NAMI) — California, and the Grave Disability Workgroup.







[Slide Image Description: This is a section divider slide to indicate a major section of this training.]

This section covers an introduction to SDM. We are going to talk about SDM as a framework generally and then look at how it's incorporated into the CARE Act.





## **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

What supports and services would enable individuals to make their own decisions?



For more information, read "The Right to Make Choices: The National Resource Center for Supported Decision-Making" and the Human Rights Brief.



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[Slide Image Description: This slide shows the definition of supported decisionmaking and an image of holding hands.]

Supported decisionmaking 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: "What supports and services would enable individuals to make their own decisions?"

So just to give some brief context, supported decision making this framework is a formalized approach to further empower people with disabilities to make their own decisions. It is a set of techniques for supporting maximizing autonomy for decision-making by 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.

In the next few slides, we are going to think about what tools we all use when we make decisions and how we can provide support to enable others to make their own decisions.

For more information, read "The Right to Make Choices: The National Resource Center for Supported Decision-Making" and the Human Rights Brief.





#### **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.





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[Slide Image Description: This slide shows the CARE Act statute language for supported decisionmaking and an image of a state capitol building.]

Th 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.







The CARE respondent may already be using or be interested in decision-supports. These supports work independently or in conjunction with SDM.















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[Slide Image Description: This slide shows decisionmaking support options in colored boxes with an image of an individual being interviewed.]

The volunteer supporter may be able to work with the person to look at different decision-supports that support self-determination.

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.

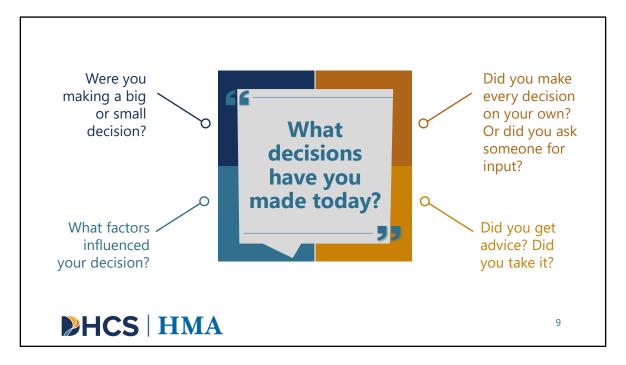
For more information, visit the 2022 California Welfare and Institutions Code -











[Slide Image Description: This slide shows the prompt question on a colorful box with additional prompt questions branching off from the colorful box.]

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



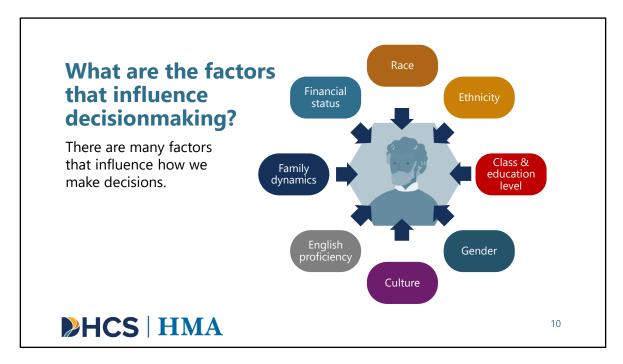


networks to make those decisions. We may ask for advice, but we don't always take it, depending on how that advice aligns with our values, priorities, and preferences. And we don't make decisions in a vacuum: there are lots of factors that impact what choices we make (which we are going to discuss on 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.







[Slide Image Description: This slide shows various factors that influence decisionmaking in colorful circles that all point to an image of an individual representing Ray, the case study individual for this presentation.]

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

• 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?



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[Slide Image Description: This slide shows a list of scenarios when SDM does and does not apply.]

How can SDM be used in various situations?

- Remember, by engaging in SDM, the supporter isn't making the decision but is providing support to assist the client in making 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 be applied differently in different situations.
- For example, a person with schizophrenia who may be untreated and unstable, may still be able to accept your support in helping them voice their preferences and choices towards making their own decisions.
  - In some circumstances, this may be using skills such as reflective listening, weighing pros and cons, and reminding the client of past wishes/preferences.
  - In other circumstances, however, it could be referring to Psychiatric Advance
    Directives (PADs) or Advance Health Directives to determine what
    preferences they have outlined in the past. Problem-solving with the





individual in the moment may not always be possible with the CARE Act participant, and instead, referencing documents such as the PADs to understand their documented preferences and choices that were made when they were better able to express these, will be an important approach.

- When considering working with persons in CARE Act who may have untreated schizophrenia and impaired insight into their illness, there may be situations when using an SDM approach may not always be appropriate or effective. As we mentioned, SDM is not a light switch either on or off. Rather, it is a tool that can be tailored to maximize autonomy of an individual. There are likely moments (which we will discuss in a moment) where you should continue to respect and listen to the individual, but you won't be able to engage them in SDM. In these instances, it's best to rely on the advice and guidance of professional care providers for alternative approaches.
- Providing this kind of support to an individual with serious mental illness—such as the CARE participant—requires a trauma-informed approach that includes patience, empathy, remaining neutral, and withholding judgement. Relevant trainings include:
  - A series of trainings on schizophrenia (parts  $\underline{1}$ ,  $\underline{2}$ ,  $\underline{3}$ ) which include both education about schizophrenia and its symptoms, but also communication strategies to use with individuals living with schizophrenia.
  - Trauma-informed care (parts <u>1</u>, <u>2</u>, and <u>3</u>), which includes approaches that that acknowledge how their traumatic experiences may influence an individual's behaviors, reactions, and communication.
  - Maintaining neutrality as a supporter (link <u>here</u>), which includes strategies for how to remain neutral in the supporter role
- Overview of the supporter role (link <u>here</u>), which includes roles and responsibilities
  of a supporter in using SDM

#### 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 examples 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.



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[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 forego the surgery.





### **SDM** in Action



#### What is the ideal outcome?

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?



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[Slide Image Description: This slide is in continuation to the previous slide, it shows the same picture and gives more description of Sean's hypothetical scenario.]

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.

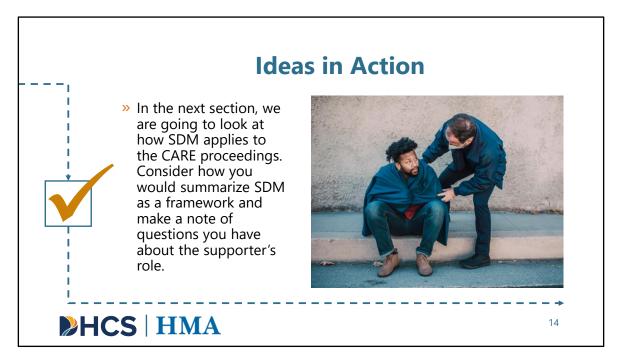
Under SDM, he has the right to make his own decisions with support and all the information he needs

- 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.







[Slide Image Description: This slide shows an ideas in action prompt with a picture of an individual placing a blanket on another individual.]

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 the supporter's role.







[Slide Image Description: This is a section divider slide to indicate a major section of this training.]

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.



The SDM approach helps the different roles within the CARE process in using personcentered planning in supporting the respondent and ensuring their priorities, choices, and decisions are heard.

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



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[Slide Image Description: This slide shows an image of an individual representing Ray and components of person-centered planning.]

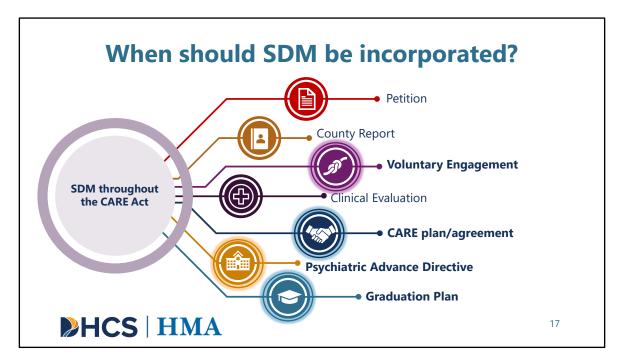
Person-centered planning is a tool with use within SDM in the CARE Act:

- 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.







[Slide Image Description: This slide shows inflection points in the CARE Act processes and highlights which processes can incorporate SDM.]

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. The supporter can help ensure that SDM is used throughout.

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

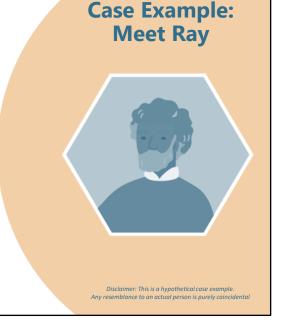
To complete each of these activities effectively, engaging with the client/respondent with regards to their preferences, priorities and overall goals is critical.





#### What is Ray's situation?

- » Diagnoses of schizophrenia, alcohol use disorder, type II diabetes
- » Not engaged with a mental health provider
- » Consistently declines antipsychotic and diabetic medications
- » Recent emergency room visits and complaints of 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





[Slide Image Description: This slide shows an image of an individual representing Ray and a description of Ray's situation.]

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
- Consistently declines antipsychotic and diabetic medications
- Recent emergency room visits and complaints of his neuropathic pain; recent involuntary transports to emergency rooms due to agitated behavior. The last ER admission was noted to have poor self-care, complaints of neuropathic pain, and multiple past involuntary acute psychiatric hospitalizations under WIC 5250
- Currently unhoused and living in alley ways, having left or been removed from numerous temporary shelters immediately after admission.
- Referred for CARE Act proceedings by a Homeless Outreach worker who checks in with him regularly, who notes that Ray remains agitated and suspicious and believes





that his food is poisoned and that the devil is speaking to him through family members.

• Ray expresses some initial hesitancy about his sister being his supporter related to his paranoid beliefs. However, he ultimately decides to approve her in this role.

Disclaimer: This is a hypothetical case example. Any resemblance to an actual person is purely coincidental





#### 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 medications
- » Not interested in SUD treatment or seeing a PCP
- » Interested in financial support and non-congregate housing



# Ray in the CARE Process



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?

- The CARE process regarding Ray has progressed to the point of creating a CARE agreement
  - Ray outlines his preferences with the help of his sister
- The BH Agency also makes initial recommendations for the CARE agreement content, including
  - complete a medication evaluation and follow the provider's recommendations
  - Pursue SUD treatment options
  - Engage with a PCP for his medical condition

Whare some of Ray's preferences?

 Ray tells his sister that he'll see a psychiatrist for an evaluation but will not commit to taking medications





- He is not interested in pursuing SUD treatment or seeing a PCP
- Ray wants to focus on getting additional financial support and non-congregate 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



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[Slide Image Description: This slide shows an image of an individual representing Ray's sister and a description of how Ray's sister is involved in the CARE Act process.]

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

We've been talking about ideas specifically related to the CARE agreement. Ray's sister can use principles of SDM throughout the CARE process to help ensure principles of self-determination throughout.

Some things that Ray's sister can do:

· Listen to Ray' concerns and ask him what are his preferences and goals

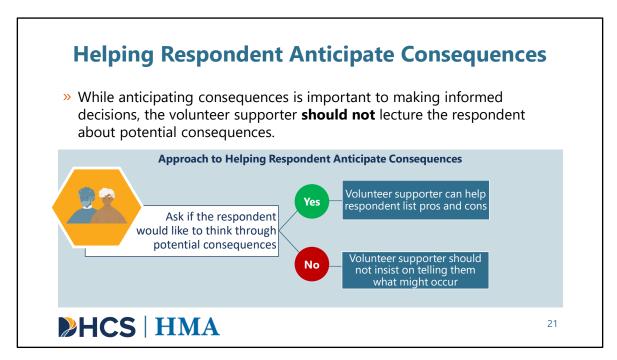




- Help Ray organize his thoughts
  - Take notes
  - · Make lists or a diagram
  - Repeat his statements back to him
  - Have the conversation at different times
- Attend Ray's BH appointments (if Ray so requests)
- Listen to Ray and respond to his concerns/requests
- Remind Ray that this is his decision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







[Slide Image Description: This slide shows an image two individuals representing Ray and his sister. There is a flowchart that shows outcomes of Ray saying yes or no to anticipating 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





# Supported decisionmaking in CARE can help ensure...

- » 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





[Slide Image Description: This slide shows an image of an individual representing Ray and a description of what SDM can help to ensure.]

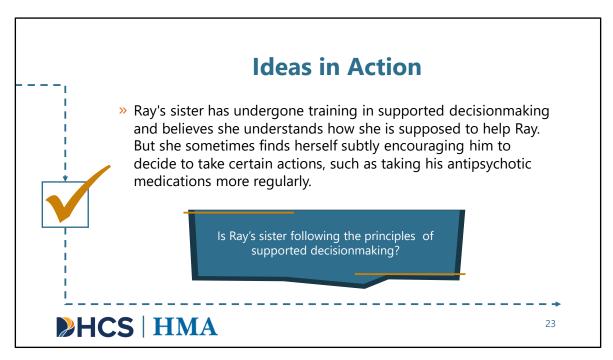
In this scenario, supported decisionmaking can help ensure that...

- 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 the final decision

The ideal outcome of SDM is not a predetermined, "good" decision. It's that Ray makes his own decisions to the greatest extend possible.







[Slide Image Description: This slide shows an ideas in action prompt with a hypothetical scenario related to SDM.]

As we move into the section on how volunteer supporters can eliminate person bias, let's consider a realistic scenario that Ray's sister might face in her role as a supporter.

- Scenario:
  - Ray's sister has undergone training in supported decisionmaking and believes she understands how she is supposed to help Ray. But she sometimes finds herself subtly encouraging him to decide to take certain actions, such as taking his antipsychotic medications more regularly.
- Question:
- Possible Answer:
  - Ray's sister's reaction is normal and expectable for a caring family member, but it is not SDM. When utilizing SDM, the sister is expected to encourage Ray to make informed decision reflecting his priorities and preferences. It is important for her to review information on VS role and attempt again to take non-directive stance.





# **Objectives**

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
- Understand how the supporter can help facilitate supported decisionmaking



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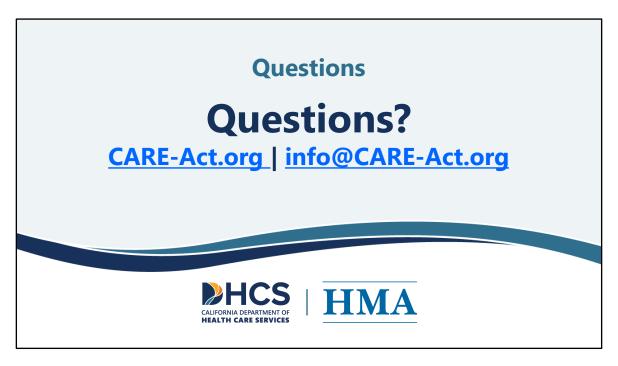
[Slide Image Description: This slide shows the learning objectives for this training with a light blue background.]

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
- Understand how the supporter can help facilitate supported decisionmaking







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

We are here to support you and provide you with those opportunities to connect and hear about implementing the CARE Act. The website is <a href="mailto:CARE-Act.org">CARE-Act.org</a> and our email address is <a href="mailto:info@CARE-Act.org">info@CARE-Act.org</a>.





#### 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



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[Slide Image Description: This slide shows the SDM 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