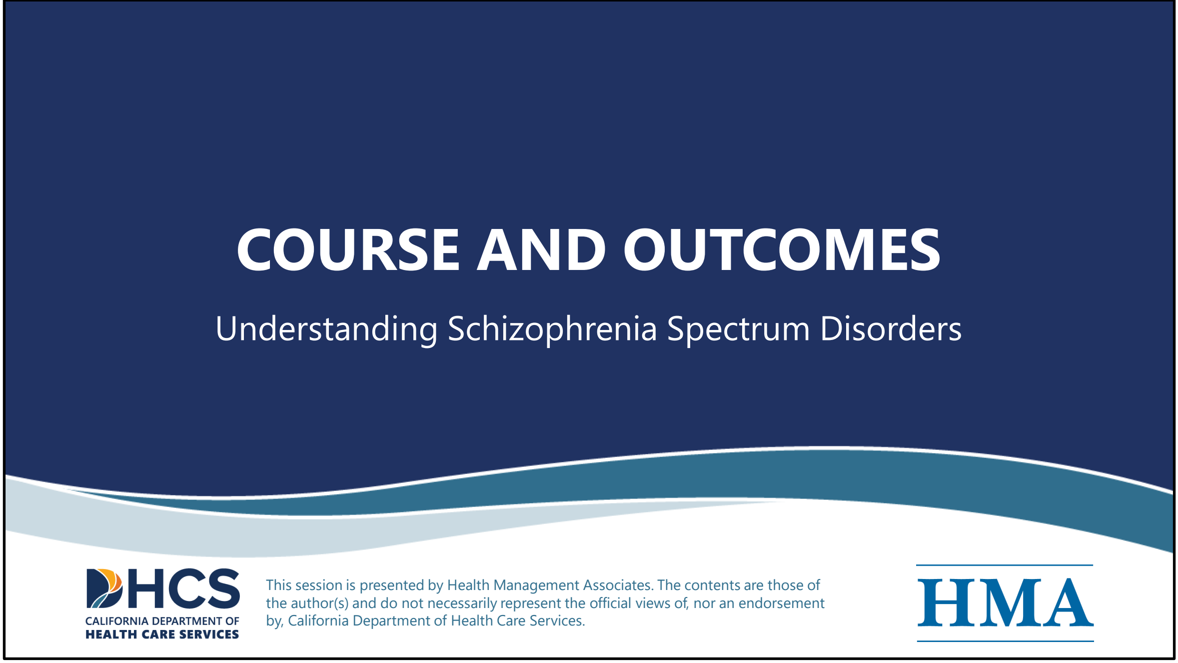
CARE Act Training & Technical Assistance



[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.]

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.

Objectives

At the end of the session, participants will have an increased ability to:

» Describe the longitudinal course of schizophrenia spectrum or other psychotic disorders and how treatment can impact that course.

» Apply elements of CARE that can contribute to positive outcomes of respondents.

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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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- Apply elements of CARE that can contribute to positive outcomes of respondents.

Agenda

Course, Risks, and Impact of Services on Long-Term Outcomes

- Orientation to the longitudinal course of schizophrenia spectrum or other psychotic disorders.
- Overview of the associated diagnoses and risks/complications.
- Introduction to the variability of outcomes.
- Implications of CARE Act.

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

In this training, we will discuss the following:

- Course, Risks, and Impact of Services on Long-Term Outcomes:
    - Orientation to the longitudinal course of schizophrenia spectrum or other psychotic disorders.
    - Overview of the associated diagnoses and risks/complications.
    - Introduction to the variability of outcomes.
    - Implications for the CARE Act.

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

Marc Avery, from Health Management Associates, is a board-certified psychiatrist and a recognized national leader in the subject of person-centered, integrated psychiatric care for high-needs and safety net patients. He has had the privilege and responsibility of providing (and overseeing) behavioral health care services to many hundreds of individuals with schizophrenia spectrum disorders and psychotic conditions including working with families, supporters, peer service providers, and other persons who assist in the care and treatment of persons with schizophrenia and related conditions.

Deborah Rose, from Health Management Associates, is a New York State licensed clinical psychologist with a history of designing and scaling new initiatives in behavioral health services. She has extensive experience working with social service agencies, behavioral health centers, care coordination, supported housing, and homeless services. Dr. Rose has broad clinical experience with a variety of underserved populations in human services and has held executive leadership positions in community-based agencies and carceral settings. Earlier in her career, Dr. Rose oversaw Kendra's Law, an assisted outpatient treatment (AOT) program in NYC. She was also

Deputy Director of Behavioral Health across the Rikers Island jail system. She has strived to improve access to and delivery of person-centered services for adults living with mental illness, substance use disorders, and co-occurring conditions.

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

This section will look at the course, risks, and impact of services on long-term outcomes.

What is George’s situation?

- 45-year-old man.
- Originally diagnosed with bipolar disorder in his early 20s; diagnosis of schizophrenia came in late 20s.
- Previously connected to treatment but stopped using medication because of side effects; then discontinued treatment all together.
- Co-occurring high blood pressure and substance use disorder.
- Currently hearing voices that others don’t hear.
- Currently unhoused.
- Enjoys nature and spending time with his friend.

How might George’s situation and health progress over the next 5 to 10 years?

Case Example: Meet George

Disclaimer: This is a hypothetical case example. Any resemblance to an actual person is purely coincidental, including race, nationality, and gender.

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

We are going to use a case example to explore the features of schizophrenia through the lens of a case example: George.

What is George’s situation?

- 45-year-old man.
- Originally diagnosed with bipolar disorder in his early 20s; diagnosis of schizophrenia came in late 20s.
- Previously connected to treatment but stopped using medication because of side effects; then discontinued treatment all together.
- Co-occurring high blood pressure and substance use disorder.
- Currently hearing voices that others don’t hear.
- Currently unhoused.

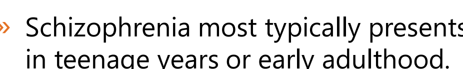
- Enjoys nature and spending time with his friend.

As we walk through this presentation, consider how George's situation and health may progress over the next 5 to 10 years.

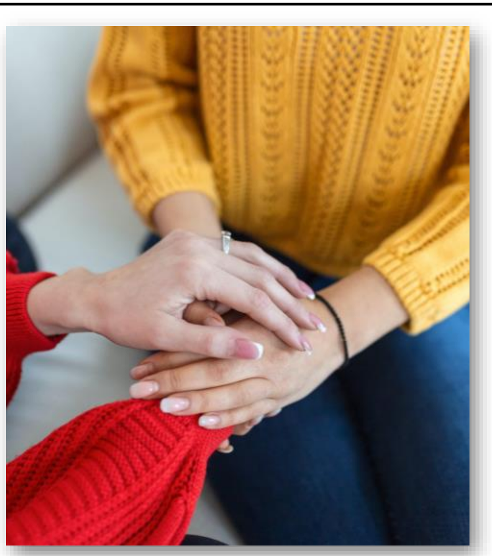
This case highlights that many people can have multiple diagnoses and/or be misdiagnosed.

Disclaimer: This is a hypothetical case example. Any resemblance to an actual person is purely coincidental, including race, nationality, and gender.

Schizophrenia Presentation



» Schizophrenia most typically presents in teenage years or early adulthood.
» Often a diagnosis is made following an episode of psychosis.
» This may follow a prolonged period of functional impairment or appear suddenly without previous symptoms or signs of illness.



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[Slide Image Description: This slide shows an image of two individuals holding hands and smiling with a description of how schizophrenia presents itself.]

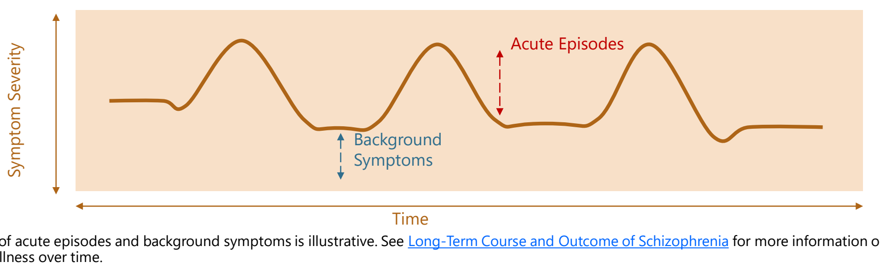
To begin our discussion of the course and outcomes of schizophrenia and related conditions, let's first mention how it starts.

- When:
  - Schizophrenia most typically presents in teenage years or early adulthood.
  - Often a diagnosis is made following a first episode of psychosis. This may appear suddenly or following a prolonged period of functional impairment (known as a prodromal period).
  - In other persons, someone may eventually be diagnosed with schizophrenia following what was thought to be another condition (e.g., bipolar disorder).

Consider our case example, George. Remember that he was first diagnosed with bipolar disorder in his early 20s, due to some significant mood swings and changes in his ability to think clearly and his judgement. Later, as the course of his symptoms continued to progress, he was diagnosed with schizophrenia in late 20s after an acute psychosis.

Course of Illness Over Time

- The experience of schizophrenia is highly variable between persons.
- Schizophrenia generally manifests as a "biphasic" illness.
- Acute episodes can occur alongside a background of longer-term symptoms and functional impairments.
- The background symptoms may exhibit progression over time.



Depiction of acute episodes and background symptoms is illustrative. See Long-Term Course and Outcome of Schizophrenia for more information on the course of illness over time.

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[Slide Image Description: This slide shows an illustrative chart depicting fluctuating acute episodes and background symptoms.]

The experience of schizophrenia is highly variable between persons.

- However, often schizophrenia follows a typical pattern of episodes of acute illness, often characterized by prominent "positive" symptoms alongside a backdrop of "negative" symptoms, which may exhibit progression over time. ("Positive" and "negative" symptoms discussed on the next slide.)
- The diagnosis of schizophrenia is typically made during one of these acute episodes, though there is often a delay, sometimes for years, between onset of symptoms and diagnosis.

George's symptoms have progressed over time, especially since he stopped treatment in his 30s. His symptom of hearing voices that others cannot hear has increased in severity, as has his social withdrawal, low motivation, and his difficulty communicating—all of this has made it difficult for him to find stable housing and maintain employment. With George, we also mentioned that he was receiving treatment at first, but he stopped taking medication because of some unaddressed side effects. He then later stopped treatment completely. We'll talk about the course of

someone's illness over time and how receiving (or not receiving) treatment can impact someone like George. First, let's take a look at those "positive" and "negative" symptoms.

Depiction of acute episodes and background symptoms is illustrative. See Long-Term Course and Outcome of Schizophrenia for more information on the course of illness over time.

Features of Schizophrenia

ACUTE EPISODE ("POSITIVE") SYMPTOMS

- Hallucinations.
- Delusions.
- Paranoia.
- Disorganized thinking.

BACKGROUND ("NEGATIVE") SYMPTOMS

- Reduced motivation.
- Impaired judgement.
- Lack of symptom recognition (anosognosia).
- Blunted emotions and affect.
- Isolative/social detachment.
- Cognitive impairment.

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[Slide Image Description: This slide shows an illustrative chart depicting acute episode ("positive") and background ("negative") symptoms.]

In the last slide we described a pattern of acute episodes of schizophrenia that are often superimposed on background symptoms. But what do we mean by these terms?

Acute episode ("positive") symptoms:

- The term "acute episode" generally refers to a rather sudden onset of symptoms
- In the case of schizophrenia, these acute episodes often feature hallucinations, delusions, paranoia, and disorganized thinking.
- These symptoms are sometimes referred to as "positive" and contrast with the "negative" symptoms that we'll discuss next. Note that the terms "positive" and "negative" are historical and don't really carry much clinical meaning anymore – for instance there is certainly little "positive" about having these symptoms. We introduce these terms as they may are still in common use, appear in the written clinical documentation.
- Sometimes the positive symptoms of hallucinations and delusions may be so vividly experienced that a person may be appearing to have an internal dialogue or be highly distracted by themself. This condition is sometimes referred to as

"responding to internal stimuli" or RIS.

Background ("negative") symptoms:

- As you might imagine, the positive symptoms are often dramatic.
- Between the acute episodes, a person with schizophrenia may experience a host of symptoms sometimes referred to as "negative" symptoms. (As with the term "positive," the term "negative" is historical and doesn't convey any meaning – it certainly shouldn't be interpreted to mean anything "negative" about the person.)
- There are several 'negative symptoms – and they include reduced motivation, difficulty with decision-making, lack of symptom recognition (anosognosia), blunted emotions, social withdrawal and detachment, and cognitive impairments.
- The "negative" symptoms are often less dramatic – but are actually more strongly correlated with longer-term functional challenge, impairment, and disability. And they may progress over time.
- These background symptoms are also sometimes referred to as the "chronic" symptoms of schizophrenia. Nowadays we avoid use of the term "chronic" because of the negative stigma and connotation it conveys.
- Note that these patterns are generalizations – for instance, some persons with schizophrenia may have prominent ongoing "positive" symptoms with little or no "episodic" pattern.

One of the goals of treatment of schizophrenia is preventing and treating the occurrence of acute episodes while reducing the experience or impact of the longer-term symptoms.

Multiple or Additional Diagnoses

» Persons with schizophrenia are often at risk for developing other psychiatric diagnoses:
- Depression.
- Mood disorder.
- Post-traumatic stress disorder (PTSD).
- Substance use disorders, including tobacco.

For more on the association between schizophrenia and other disease states, see articles on the links to substance use disorders, depression, and bipolar disorders.

[Slide Image Description: This slide shows an image of George and lists diagnoses that can be associated with schizophrenia.]

It is helpful to understand that persons living with schizophrenia are, unfortunately, also at risk for developing additional psychiatric diagnoses. Like the causes of schizophrenia itself, the reason why it is associated with other diagnoses isn’t well known.

For example:
- It is common for a person with schizophrenia to experience significant depression, which may lead to a formal diagnosis of depression.
- Other persons may experience mania along with their condition leading to an additional diagnosis of bipolar disorder.
- The depression or mania may overlap with the symptoms of schizophrenia. If that overlap is significant, then the persons’ diagnosis may be changed to “schizoaffective” disorder – one of the other CARE Act-eligible diagnoses.

- Persons with schizophrenia are also at risk for exposure to trauma, and thus are at risk for symptoms of PTSD.
- Persons with schizophrenia are at high risk of developing a substance use disorder,

including tobacco use (individuals are five times more likely to use tobacco).

The presence of additional diagnoses often makes assessment of schizophrenia more complicated

For more on the association between schizophrenia and other disease states, see article on the links to substance use disorders, depression, and bipolar disorders.

Associated Risks & Complications

- » Depression.
- » Reduced self-care.
- » Self-harm or suicide.
- » Social detachment.
- » Homelessness.
- » Incarceration.
- » Risk of poorer health outcomes (including early death).

For more on the association between schizophrenia and associated diagnoses, risks, and complications, see article on the links to suicide and homelessness. For more information on the impacts of trauma (including social isolation, incarceration, and homelessness), see the Trauma-Informed Care training materials on CARE-Act.org.

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[Slide Image Description: This slide shows an image of George and lists complications that can occur.]

There are other complications that persons with schizophrenia may experience as a result of their illness. In addition to treating the symptoms mentioned earlier, treatment and support of persons with schizophrenia is often focused to help reduce the impact of various complications of the condition that persons can experience.

1. **Depression** – as noted, individuals with schizophrenia may experience significant depression – with or without a formal separate diagnosis of depression.
2. **Reduced self-care** – Individuals with schizophrenia can also begin to neglect basic elements of self-care – such as their diet, personal hygiene, and overall health.
3. **Self-harm or suicide** – Persons with schizophrenia are generally at higher risk of suicide as compared to the general population. The overall risk is about 10%, with the risk being highest in younger persons and young adults with schizophrenia.
4. **Social detachment** – Letting go of important family, friends, and other supportive persons in their lives.
5. **Homelessness** – Consider that 30% of the 582,000 unhoused individuals in the U.S. reside in California and at least 25% of those individuals are living with a

serious mental illness (National Alliance to End Homelessness).

6. **Incarceration** – Individuals with schizophrenia are also at risk for incarceration and justice involvement.
7. **Risk of poorer health outcomes (including early death)** – One final concern is the long-term risk of health conditions in persons with serious mental illnesses including schizophrenia – who often experience dramatically reduced life expectancy due to complications of medical conditions that are often treatable, including diabetes, weight gain, high cholesterol, and cardiovascular illness.

Let's look at George. The complications he's facing are social detachment, homelessness, and reduced self-care. As George participates in the CARE process, it's helpful to understand the full context of George's diagnosis and additional complications. Understanding these complications can help all members of the CARE team—including courts and counsel—identify and eliminate biases that might be triggered by these associated diagnoses, risks, and complications.

For more on the association between schizophrenia and associated diagnoses, risks, and complications, see article on the links to suicide and homelessness. For more information on the impacts of trauma (including social isolation, incarceration, and homelessness), see the Trauma-Informed Care training materials on CARE-Act.org.

Variable Outcomes

Schizophrenia outcomes are highly variable. A recent systematic review of studies on people with schizophrenia over a 20-year period showed:

- ~ 60% had moderate or better outcomes.
  - ~ 25% had substantially recovered.
  - ~ 35% had good or better outcomes.
- This leaves about 40% with ongoing serious symptoms and need for ongoing support services.
- Many experience long-term medical outcomes such as:
  - Cardiovascular illness.
  - Diabetes.
  - Shorter life expectancy.

For more information on possible outcomes, see The Prognosis of Schizophrenia: A Systematic Review and Meta-analysis with Meta-regression of 20-Year Follow-up Studies and Life Expectancy and Cardiovascular Mortality in Persons with Schizophrenia.

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[Slide Image Description: This slide shows an image of George and lists different variables relating the outcomes of the course of schizophrenia.]

So what is the long-term outlook (or prognosis) for someone who is diagnosed with schizophrenia or a related condition?

- The general public often has a skewed impression of the overall outcome of schizophrenia.
- Though it's a serious diagnosis, the overall outcomes are not as dismal for everyone as is often believed.
- For instance, in a recent systematic review (looking at many studies), the investigators found that after 20 years or more (likely both in and out of treatment), almost 25% of persons with schizophrenia had substantially recovered (nearly normal social functioning, independent life, and no psychotic symptoms over an extended time period).
- About one-third had a good or better outcome (mild symptoms, no more than some functional limitations).
- In total, almost 60% had a moderate or better outcome (no more than moderate symptoms and impairments).
- This unfortunately does leave about 40% with poorer outcomes (e.g., serious

symptoms, need for ongoing supervision) - and persons who are eligible for CARE Act likely fall into this category.

For more information on possible outcomes, see The Prognosis of Schizophrenia: A Systematic Review and Meta-analysis with Meta-regression of 20-Year Follow-up Studies and Life Expectancy and Cardiovascular Mortality in Persons with Schizophrenia.

Medication Treatment Impacts Outcomes

» Duration of untreated psychosis is associated with poorer outcomes.

» Non-adherence over time is also associated with poorer outcomes.

» Fewer deaths occur in persons taking antipsychotic medication.

For more information on possible outcomes and treatments, see Long-Term Course and Outcome of Schizophrenia; Course, Prognosis, and Outcomes of Schizophrenia; Long-Term Outcome of Patients with Schizophrenia; Duration of Untreated Psychosis and Outcomes; Mortality; Why are the Outcomes in Patients with Schizophrenia So Poor?; The Prognosis of Schizophrenia: A Systematic Review and Meta-Analysis; Association Between Duration of Untreated Psychosis and Outcome; Associations Between Relapses and Psychosocial Outcomes; and Life Expectancy and Cardiovascular Mortality in Persons with Schizophrenia.

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[Slide Image Description: This slide shows three icons: a healthcare provider, an arrow, and medications.]

So how can we have an impact on the natural course of schizophrenia and related conditions to help persons with those conditions to lead more comfortable, meaningful lives? Though this is not a presentation on treatment per se, it is important to emphasize that there are many evidence-based treatments that are available and that have been shown to impact the lives of persons with these conditions. Additional information about treatments that are available for persons with schizophrenia is provided in previous CARE trainings on the resource website.

Treatment has been shown to have a beneficial effect on long-term outcomes. Persons who are offered and adherent to treatments generally have much better outcomes. In contrast, longer durations (greater than nine months) of untreated psychosis are generally associated with poorer overall outcomes. It is also shown that fewer deaths occur in persons taking antipsychotic medication. (Association Between Duration of Untreated Psychosis and Outcome in Cohorts of First-Episode Patients: A Systematic Review | Psychiatry and Behavioral Health | JAMA Psychiatry | JAMA Network)

As mentioned earlier, one of the two main strategies of treatment is to reduce, delay or prevent the experience of acute episodes of schizophrenia. One of the many reasons for this is because the experience of more, or more severe, acute episodes of schizophrenia are associated with poorer long-term outcomes. (Associations Between Relapses and Psychosocial Outcomes in Patients With Schizophrenia in Real-World Settings in the United States - PMC (nih.gov))

On the next slide, we'll discuss how CARE could help to impact these outcomes.

For more information on outcomes and treatments, see Long-Term Course and Outcome of Schizophrenia; Course, Prognosis, and Outcomes of Schizophrenia; Long-Term Outcome of Patients with Schizophrenia; Duration of Untreated Psychosis and Outcomes; Mortality; Why are the Outcomes in Patients with Schizophrenia So Poor?; The Prognosis of Schizophrenia: A Systematic Review and Meta-Analysis; Association Between Duration of Untreated Psychosis and Outcome; Associations Between Relapses and Psychosocial Outcomes; and Life Expectancy and Cardiovascular Mortality in Persons with Schizophrenia.

[Slide Image Description: This slide shows 10 boxes that depict ways the CARE model can help.]

The CARE Act process aims to serve as an upstream intervention and support for individuals with schizophrenia spectrum or other psychotic disorders, that may assist in preventing hospitalizations, incarcerations, and LPS conservatorships.

Leveraging the state's investments in behavioral health and homelessness prevention, CARE ensures access to comprehensive and wraparound treatment, housing, and other services and supports to promote stabilization and recovery. CARE adds another option in the continuum of care, with the goal of helping individuals stabilize, move toward recovery, and thrive in community-based settings.

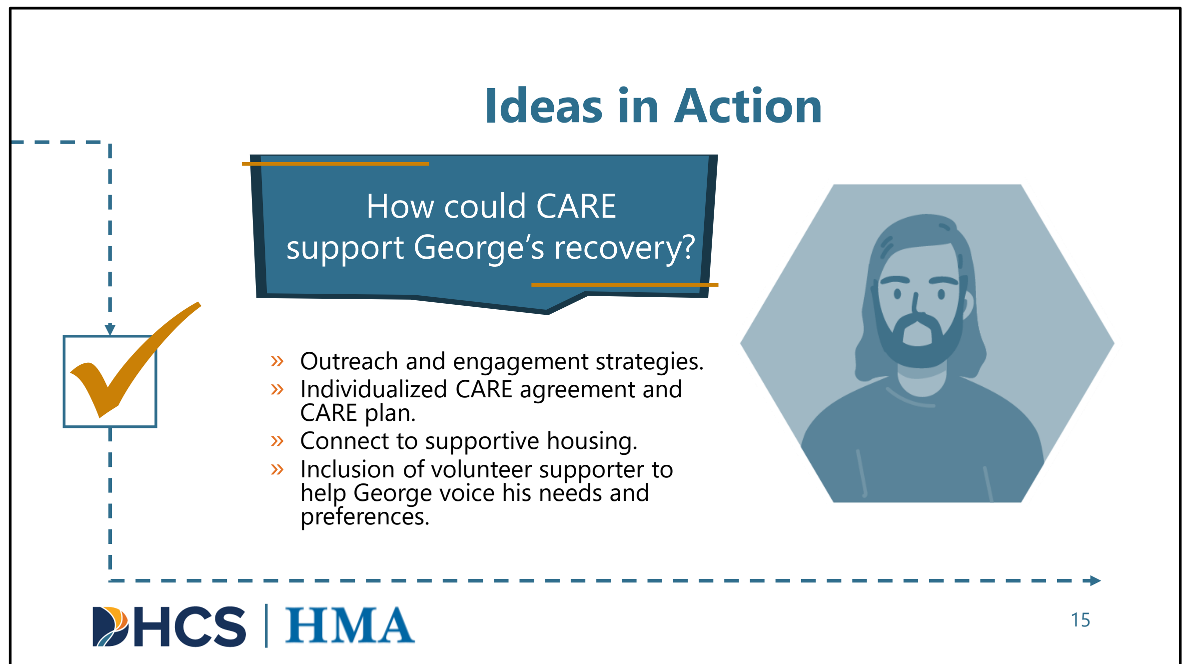
CARE includes the following approaches to support the success of eligible respondents:

- Trauma-informed outreach and engagement – behavioral health teams are being strategic and creative in locating and engaging respondents into their services, meeting the client “where they are at,” and often starting with providing resources and meeting immediate needs to build rapport and trust.
- Wraparound services and coordination, multidisciplinary model of care – teams are

typically considering the Assertive Community Treatment (ACT) or Full Service Partnership (FSP) model of care.

  - Linkage to other services, including CalAIM programs such as Enhanced Care Management (ECM) and Community Supports.

- Housing that ideally includes additional supports, which may include behavioral health services, case management, substance use disorder services, and peer support.
- Medications as a part of the comprehensive behavioral health services.
- Peer Recovery Supports may be an important part of an individual's recovery, with mutuality, mentorship and coaching. In addition, many CARE teams are incorporating peer support into both their behavioral health teams and homeless outreach teams, which have been found to contribute to engagement efforts.
- Overall, the CARE Act uplifts the tenets of the Recovery Model, in that:
  - All components of the CARE agreement and CARE plan must be individualized to the respondent's needs and preferences.
  - CARE speaks to the development of psychiatric advanced directive that outlines the respondent's treatment and personal preferences. These can be utilized in moments of crisis and also inform ongoing treatment planning.
  - CARE speaks to the volunteer supporter role – a person who is approved by the respondent to support the respondent in expressing their preferences, choices and decisions.
- Please note that the CARE Act adds an element of county accountability to provide the services outlined in the CARE agreement and plan.
- Legal representation – a CARE respondent is provided legal representation.



[Slide Image Description: This is an Ideas in Action slide that provides an opportunity for participants to practice using the information. It contains a checkbox and an arrow.]

How could CARE support George?

- Outreach and engagement: teams are using a trauma-informed approach for outreach and engagement and informing the court on their efforts, progress and timing.
- The county behavioral health (BH) team will work with George to develop an individualized CARE agreement and/or CARE plan that address George's preferences and treatment/medication options.
- The county BH team will make recommendations regarding housing and supports that they may be able to prioritize for George.
- George may identify and approve a volunteer supporter that can assist with George's navigation of the CARE process and ensure his needs and preferences are voiced.

Objectives

At the end of the session, participants will have an increased ability to:

» Describe the longitudinal course of schizophrenia spectrum or other psychotic disorders and how treatment can impact that course.

» Apply elements of CARE that can contribute to positive outcomes of respondents.

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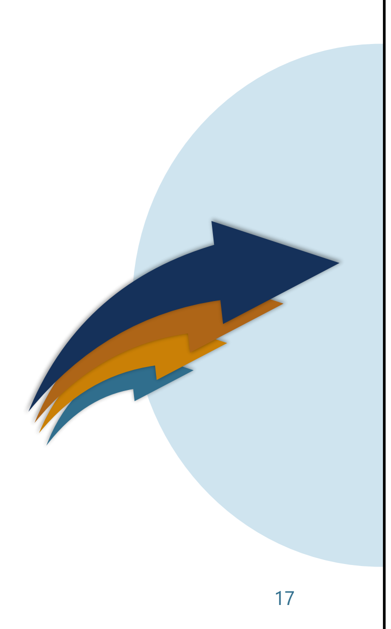
[Slide Image Description: This slide shows the learning objectives for this training with a light blue background.]

At the end of the session, participants will have an increased ability to:

- Describe the longitudinal course of schizophrenia spectrum or other psychotic disorders and how treatment can impact that course.
- Apply elements of CARE that can contribute to positive outcomes of respondents.

Next Steps

- Visit CARE-Act.org for resources (including recordings of past trainings) and to submit questions/TA requests.
- View the other trainings in this series.
  - Institutionalization and Criminalization of Persons with Schizophrenia Spectrum Disorders
  - Guidelines for Treatment
  - Clinical Features and Diagnosis



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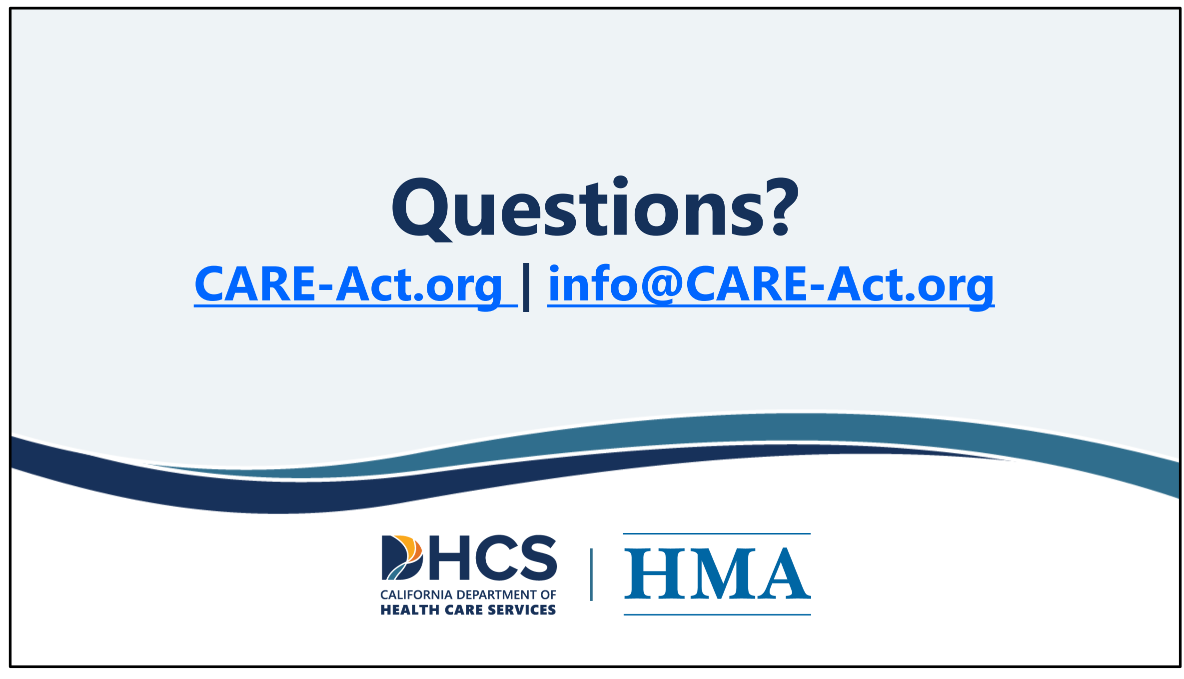
[Slide Image Description: This slide shows bullets with next steps. It contains decorative arrows.]

Please let us know how we can best support your teams. Contact info@CARE-Act.org with questions, join the communications listserv, and submit requests and feedback for CARE Act TTA. Please also visit the CARE Act Resource Center website for training decks and recordings, which will be added two weeks after each training.



[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 **CARE-Act.org** and our email address is **info@CARE-Act.org.**