Crisis Response Strategies for Individuals and Families with Intellectual and Developmental Disabilities with a Culturally Responsive Lens

Presenter

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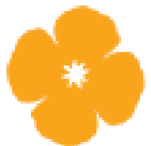

M-TAC

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Mobile Crisis Services

Mobile crisis services provide rapid response, individual assessment and community-based stabilization to Medi-Cal beneficiaries who are experiencing a behavioral health crisis. Mobile crisis services are designed to provide relief to beneficiaries experiencing a behavioral health crisis, including through de-escalation and stabilization techniques; reduce the immediate risk of danger and subsequent harm; and avoid unnecessary emergency department care, psychiatric inpatient hospitalizations and law enforcement involvement.

Behavioral Health Information Notice 23-025, p. 3

Conflict of Interest Disclosure

Dr. Kristin Dempsey has certified that she has no relevant relationships with any commercial or nonprofit organizations that represent a conflict of interest.

A New Direction for Mobile Crisis Services

- Change mobile crisis services so that the response is more resolution-focused and works to provide relief to people in crisis in the community.
- Support people in crisis where they are, while using the least restrictive means necessary.

A New Direction for Mobile Crisis Services

Mobile crisis services should be:

- Person-centered
- Trauma-informed
- Equity-driven
- Brief intervention: de-escalation and resolution focused
- Working from a lens of least restrictive interventions
- Culturally responsive, linguistically appropriate, and accessible

Welcome to Today's Session!

Today's Presenter

Kristin Dempsey, Ed.D., LMFT, LPCC

Therapist, Trainer, and Consultant

Audience Introductions

In the chat box, we invite you to share your:

- Name
- Role
- Organization
- One thing you’re hoping to learn today

Agenda

- Introductions
- Crisis and intellectual and developmental disability (I/DD)
- Symptoms and causes of I/DD and how they impact mobile crisis response
- Cultural considerations for managing I/DD
- Management of behavioral crises
- Stabilization
- Safety planning strategies
- Debriefing and follow-up check ins; peer learning coordination strategies

Learning Objectives

Participants will:

1. Define I/DD and co-occurring mental health conditions and understand the additional response considerations for this population
2. Explain warning signs and areas of risk for individuals with I/DD and use assessment questions to determine risk in each area
3. Provide practical communication strategies when working with an individual with I/DD to promote de-escalation and increased engagement
4. Offer strategies for individuals who are non-verbal or experiencing sensory or communication challenges that can promote de-escalation and increased engagement
5. Offer best practices and strategies to engage natural supports, including crisis safety planning and crisis management for people with I/DD
6. Provide strategies to seek consultation and coordination with local regional centers and individuals with I/DD expertise

Crisis and Intellectual and Developmental Disability

What is a Crisis?

A "behavioral health crisis" refers to any event or situation associated with an actual or potential disruption of stability and safety as a result of behavioral health issues or conditions. A crisis may begin the moment things begin to fall apart (e.g., running out of psychotropic medications or being overwhelmed by the urge to use a substance they are trying to avoid), and may continue until the beneficiary is stabilized and connected or re-connected to ongoing services and supports.

Behavioral Health Information Notice 23-025, p. 3 | National Council for Mental Wellbeing, "Roadmap to the Ideal Crisis System" (2021) p. 14

Individuals with Intellectual and Developmental Disability

Beneficiaries experiencing behavioral health crises may have co-occurring needs that require additional considerations in the provision of mobile crisis services. People with I/DD and co-occurring mental health conditions may experience sensory or communication challenges that may complicate the de-escalation of a behavioral health crisis. Mobile crisis teams responding to a beneficiary with I/DD shall ensure that natural supports (e.g., familial caregivers, personal attendants) are involved and consulted in the crisis response, if appropriate.[35] To the extent possible, mobile crisis teams are encouraged to include a team member with I/DD expertise or have access to an individual with I/DD expertise (e.g., a Board-Certified Behavioral Analyst) via telehealth, which includes both synchronous audio-only (e.g., telephone) and video interactions.

Behavioral Health Information Notice 23-025, p. 24

Definition of Intellectual and Developmental Disability

- An intellectual disability is when limitations in your mental abilities affect intelligence, learning, and everyday life skills.
- The effects of this can vary widely. Some people may experience minor effects but still live independent lives. Others may have severe effects and need lifelong assistance and support.
- A common misconception is that intellectual disability is just a limitation on intelligence assessed by a simple IQ test. An IQ test is only one piece of information.
  - Some people have an average or above average IQ but have trouble with other abilities necessary for everyday life.
  - Other people have lower than average IQs but also have skills and abilities that are strong enough that they don't meet the criteria for intellectual disability, or they meet criteria for a milder form of intellectual disability than an IQ test indicates.

Cleveland Clinic, 2023

Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition-Text (DSM-5-TR) Criteria

- The DSM-5-TR defines intellectual disabilities as neurodevelopmental disorders that begin in childhood and are characterized by intellectual difficulties as well as difficulties in conceptual, social, and practical areas of living.
- The DSM-5-TR diagnosis of I/DD requires the satisfaction of three criteria:
  - Deficits in intellectual functioning
  - Deficits in adaptive functioning that significantly hamper conforming to developmental and sociocultural standards for the individual's independence and ability to meet their social responsibility
  - The onset of these deficits during childhood
- Classification of severity is also determined upon diagnosis
  - Mild to Moderate I/DD
  - Severe I/DD
  - Profound I/DD

Diagnostic and Statistical Manual of Mental Disorders-fifth edition-text revision (DMS-5-TR)

Mobile Crisis Services and Individuals with Intellectual and Developmental Disability

Mobile Crisis Services should always be person-centered and trauma-informed.

Person-centered care aims to shift thinking about an individual with I/DD from their deficits and needs within a system to focusing on their strengths, capabilities, and potential to contribute to their community. Person-centered care aims to develop collaborative supports with individuals with I/DD focused on community presence and participation, positive relationships, respect, and competence.

National Association of State and Mental Health Program Directors, 2017

Prevalence of Intellectual and Developmental Disability

- I/DD is uncommon but widespread. Worldwide, it affects 1% to 3% of children. It's slightly more common in men and people assigned male at birth than in women and people assigned female at birth.
- In the current DSM-5-TR, the formal name is Intellectual Developmental Disorder (Intellectual Disability).
- We do not always know the cause of I/DD. Common causes include differences in brain development, genetic disorders, and brain damage from illness or injury, that occurs before 18 years of age.

Cleveland Clinic, 2023 | Diagnostic and Statistical Manual of Mental Disorders-fifth edition-text revision (DMS-5-TR)

Individuals in Crisis and Intellectual and Developmental Disability

- Crisis experiences are subjective and may stem from both external and internal factors.
- For individuals with I/DD in crisis, the cause is often developmental in nature.
- Intellectual and developmental disabilities are often a significant part of crisis presentation.

Symptoms and Causes of Intellectual and Developmental Disability and How they Relate to Mobile Crisis Services and Teams

Symptoms of Intellectual and Developmental Disability and the Mobile Crisis Teams

» Without understanding I/DD, mobile crisis teams may misunderstand the symptoms of crisis during their response. Understanding the symptoms and causes of I/DD is vital for effective assessment. The symptoms of intellectual disability include deficits in academic skills, social skills, and domestic skills.

» Intelligence related symptoms:
- Delayed or slowed learning of any kind (such as in school or from real-life experiences)
- Slowed reading speed
- Difficulties with reasoning and logic
- Problems with judgment and critical thinking
- Trouble using problem-solving and planning abilities
- Distractibility and difficulty focusing

https://iddtoolkit.vkcsites.org/mental-and-behavioral-health/initial-management-of-behavioral-crises/

Symptoms of Intellectual and Developmental Disability and the Mobile Crisis Teams

Adaptive behaviors revolve around abilities and learned skills needed to live independently. Symptoms of adaptive behavior-related limitations can be any of the following:

- Slower learning of toilet training and self-care activities (bathing, dressing, etc.)
- Slower social development
- Little or no fear or apprehension of new people (lack of "stranger danger" behaviors)
- Needing help from parental figures or other caregivers with basic daily activities (bathing, using the bathroom, etc.) past the expected age
- Difficulty learning how to do chores or other common tasks
- Trouble understanding concepts like time management or money
- Needing help managing healthcare appointments or medications
- Trouble understanding social boundaries
- Difficulty with or limited understanding of social interactions, including friendships and romantic relationships

https://iddtoolkit.vkcsites.org/mental-and-behavioral-health/initial-management-of-behavioral-crises/

Discussion

You respond to a mobile crisis call at a home with a frustrated parent reporting that their 24-year-old son, Jacob, became enraged and broke some dishes when told he needed to complete his chores before family members arrived for a visit. The parents are noticeably upset and angry, stating that he should know better. His mother tells you that he had testing to determine learning and other disabilities in elementary school, and the family was told at that time that he had "borderline intellectual functioning".

Given what you know already, what might you be wondering about Jacob and his potential needs? What strategies would you use to support Jacob in de-escalating and experiencing relief?

Poll Question

In addition to intellectual developmental disability, what other developmental disabilities might you find co-occurring with I/DD?

a) Autism spectrum disorder

b) Substance use disorders

c) Attention deficit hyperactivity disorder

d) All of the above

Co-Occurring Disorder and Crisis

Co-occurring disorders (COD) occur along with I/DD. COD needs to be considered as the expectation and not the exception. Consider the co-occurring nature, how might the disorders interact with each other?

- Attention Deficit Hyperactivity Disorder (ADHD) might increase distractibility
- Substance Use Disorder (SUD) might increase impulse control disorder
- Autism Spectrum Disorder (ASD) might impact an individual's ability to be flexible and communicate verbally
- Other disorders that often co-occur with I/DD include mood and anxiety disorders and movement disorders

Cultural Considerations for Managing Intellectual and Developmental Disability

Cultural Considerations for Adults with Intellectual and Developmental Disability

» Individuals with I/DD in crisis might be considered disabled, or the family/community might see their emotional status as a symptom of something else.

» Individuals with I/DD are impacted by the larger culture in which they live.

» How any culture views developmental disability will greatly impact internalized messages and external supports that in turn can exacerbate or mitigate crisis situations.

» Culture influences an individual's relationship to disability, including:

- Understanding of a disability and its etiology
- Whether to seek help
- Treatment options
- Relationships with health professionals

https://kidsnewtocanada.ca/mental-health/developmental-disability

Cultural Considerations for Individuals with Intellectual and Developmental Disability

- In many cultures, social interdependence and an individual's role within the larger family and community are highly valued, while independence and autonomy are valued less than in Western cultures, which can affect how disability is perceived.
- Many cultures seek out spiritual healers and traditional alternative medicines.
- In many cultures, attitudes toward a disability may include religious acceptance.
- People may believe that a disability is caused by factors such as the influence of past lives, mystical intervention, or the past actions of a parent.
- Health practitioners should acknowledge and consider the culture of the individual.
- Providers should avoid assumptions about a family's cultural practices and beliefs.

Cultural Considerations for Adults with Intellectual and Developmental Disability

Providers should work with the cultural and social framework of the family:

- Observe the family's interaction style – notice who speaks first, whether the family is collaborative or authoritative; when in doubt, defer to elders
- Honor the space and eye contact practices of the culture
- Observe carefully and find ways to be humble and respectful to family
- Listen for common phrases and ways of speaking; determine if you need to bring in a translator
- Prepare in advance by learning about the cultural practice of families in your community
- Humility and curiosity should be your guiding attitudes for approaching all families, as each system has its characteristics and practices

https://kidsnewtocanada.ca/mental-health/developmental-disability

Discussion

Given your experiences with disability in your own culture or those cultures with which you have had contact, what are some additional examples of how a community's shared and lived beliefs impact treatment of people with I/DD?

Management of Behavioral Crisis

Behavioral Management of Crisis

Crisis behavior is a **symptom** and not a **disorder**. Behavioral change is often the only way people with I/DD can express that something is wrong and communicate a need.

- Explore ways to engage caregivers and natural supports as appropriate for background and collateral information.
- When onsite, greet everyone involved and ask the individual in crisis who they would like to participate (voice and choice).
- For non-verbal individuals, use alternative communication strategies.

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Behavioral Management of Crisis

- Very frequently, the “something wrong” is not a psychiatric problem. It may signal that the person has a physical health problem causing pain or discomfort or that their environment is not meeting their needs.

- During all stages of interacting with individuals in crisis, reflect on their experiences, acknowledge strengths, and provide choice.
  - Active listening often brings calm to individuals; it is often the most effective remedy in a crisis
  - Highlighting strengths helps to build motivation by increasing self-efficacy
  - Praise self-regulation and engagement through soothing techniques ("I like the way you are taking deep breaths; that seems to be helping you right now")
  - Ask the individual in crisis what they might need in the moment (glass of water, a snack, a comforting and safe object)

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Behavioral Management of Crisis

Assess and **manage** the behavioral crisis by working with the individual, caregivers, and available support resources:

- Engage caregivers in conversations at the scene and bring them into separate spaces to have conversations with caregivers about the history of symptoms, current stressors, and their understanding and/or beliefs regarding the cause of issues
- Avoid being over-directive with the individual or caregivers
- Try to give a menu of options and emphasize autonomy whenever possible; voice and choice are key
- Clarify the cause of the crisis, and assess and manage sequentially any discernible contributing factors, such as medical issues, supports and expectations, emotional issues, and psychiatric disorders

https://iddtoolkit.vkcsites.org/mental-and-behavioral-health/initial-management-of-behavioral-crises/

Behavioral Management of a Crisis

Non-Verbal Individuals

When someone cannot or will not talk with us, try other non-verbal ways of communication (e.g., experiment with writing, pictures, hand motions, eye contact, and facial expressions) and use best judgment on what seems and feels appropriate in the moment.

Guidelines:

- Introduce yourself and be inclusive – do not assume someone cannot hear or understand because they will not speak
- Watch your tone – if you are talking with an adult, speak as if you are talking with an adult and not a child
- Reduce distractions

Adapted from: https://www.vha.ca/blog/communicating-with-someone-who-is-non-verbal/

Behavioral Management of a Crisis

Non-Verbal Individuals

Consult with caregivers to determine how the individual typically communicates

Consider:

- » Communication boards
- » Music and reading
- » Using pictures, objects, or writing
- » Using close-ended questions to obtain basic information and engage in some aspects of communication

Adapted from: https://www.vha.ca/blog/communicating-with-someone-who-is-non-verbal/

Risk Management

- Risk Assessment: Assess risk to the individuals and others
  - **Harm to self:** Assess risk to self and caregiver/environmental supports in place
  - **Victimization or exploitation:** Assess risk to individual and others as well as caregiver and environmental supports
  - **Harm to others:** Assess risk to others as well as caregiver and environmental supports
- Consider referring individuals and families to appropriate agencies that can help them develop a Wellness Recovery Action Plan

https://iddtoolkit.vkcsites.org/mental-and-behavioral-health/initial-management-of-behavioral-crises/

Additional Available Toolkits and Resources for Mobile Crisis Teams

Available tools and resources for providers to expand knowledge, and skill set when working with individuals with I/DD in crisis are below.

- Risk Assessment Toolkit for Behavioral Crisis from Health Care for Adults with Intellectual and Developmental Disabilities: Toolkit for Primary Care Providers
- Behavioral/Emotional Concerns Caregiver Checklist
- Psychiatric Symptoms and Behaviors Checklist

https://iddtoolkit.vkcsites.org/mental-and-behavioral-health/initial-management-of-behavioral-crises/

Discussion

Sarah is a 37-year-old woman living with her aunt in public housing. She recently returned home after being away for about three weeks, providing no explanation for her absence. Sarah has visibly lost around 20 pounds and her affect is very flat (unemotional).

Sarah's aunt called for mobile crisis services due to Sarah making vague references to "ending it all." The aunt is alarmed by marks on Sarah's arms, uncertain if marks are needle tracks or if Sarah has been cutting again. She has been Sarah's primary caregiver since Sarah was removed from her mother's care at age 14.

Sarah has a history of bipolar disorder, diagnosed during her teenage years, and received treatment for opioid use disorders last year. She has a male partner who occasionally comes into her life, and the aunt is concerned she has been with him recently as, "he doesn't treat her right."

What are your concerns and what resources are available for Sarah? How would you best approach and engage Sarah and her aunt? What do you want to know that is not written here? Why?

Stabilization and
Safety Planning Strategies

Crisis Management: Stabilizing in the Short Term

- Create a plan with the individual and caregivers for how to re-stabilize the situation and manage the behavior. These strategies must reflect the individual's specific condition, their triggers and coping strategies, any helpful environmental changes and modifications, and available caregiver resources.

- Take the following into consideration:
  - Establish what has been helpful or not for this individual in the past
  - Use de-escalation strategies (e.g., ask the individual if it would help to go to a quiet, safe place; use existing safety response plans when appropriate)
  - Discuss increasing environmental supports and/or decreasing environmental stressors (e.g., additional family/agency/staff supports, change in expectations- can be short or long-term)

https://iddtoolkit.vkcsites.org/mental-and-behavioral-health/initial-management-of-behavioral-crises/

Crisis Management: Stabilizing in the Short Term

- Seek consultation when an individual is unable or unwilling to participate in any conversation or safety planning and provides indication that they are gravely disabled and at risk of harming themselves or others
- **Check on medications**: ask caregivers to provide medication history and permission to check with the prescriber
- What to do if symptoms worsen or caregivers are unable to manage:
  - Send to higher levels of care if indicated as necessary for safety: sending to the emergency room or inpatient hospitalization should be the last option unless required to maintain the safety of the individual in crisis or the safety of others from the individual in crisis
  - Conversations about voluntary treatment for higher levels of needs/care should be at the forefront of conversations and engagement when it is determined an individual cannot maintain safety in the community

https://iddtoolkit.vkcsites.org/mental-and-behavioral-health/initial-management-of-behavioral-crises/

Best Practice Strategies for Safety Planning with Individuals Living with Intellectual and Developmental Disability

- Building rapport is key
- More options created in collaboration with the individual, caregivers, and natural supports aid in problem solving
  - Useful questions to start the conversation: "what has worked in the past?"
- Identify trusted clinical supports, people, and safe places when appropriate
  - Be as specific as possible
- Check that everyone included in the plan is comfortable with their role and is able to provide the support identified
- Modify plan as needed-it should be individualized to each person's abilities, resources, and what feels best and safe for them
- Take your time and be patient
- Encourage the individual in crisis and caregivers to update and refine the plan: the goal is for them to use the safety plan and adapt as needed

Debriefing and Follow-up Check-ins and
Peer Learning Coordination Strategies

Debriefing and Follow-up Check-ins

Debriefing

- Review crisis strategies, actions taken, and what was effective or ineffective
- Make recommendations for the management and prevention of future behavioral crises
- With caregivers and available resources, develop a comprehensive and proactive crisis safety plan as appropriate to meet the individuals' needs and enhance their quality of life
- For individuals who visit the emergency department frequently for behavioral causes, it may be helpful to develop a dialogue with local emergency department staff and caregivers about alternative resources
- **Review medications:** Include over-the-counter medications and any possible recreational drugs used; review any new medications prescribed during behavioral crises

https://iddtoolkit.vkcsites.org/mental-and-behavioral-health/initial-management-of-behavioral-crises/

Debriefing and Follow-up Check-ins

Follow-up Check-ins

» Mobile crisis teams are required to follow up and check in with beneficiaries within 72 hours of the initial mobile crisis response (BHIN 23-025, section IV, f, pg. 16).

» Support continued resolution of the crisis as appropriate, checking for updates and adherence to:

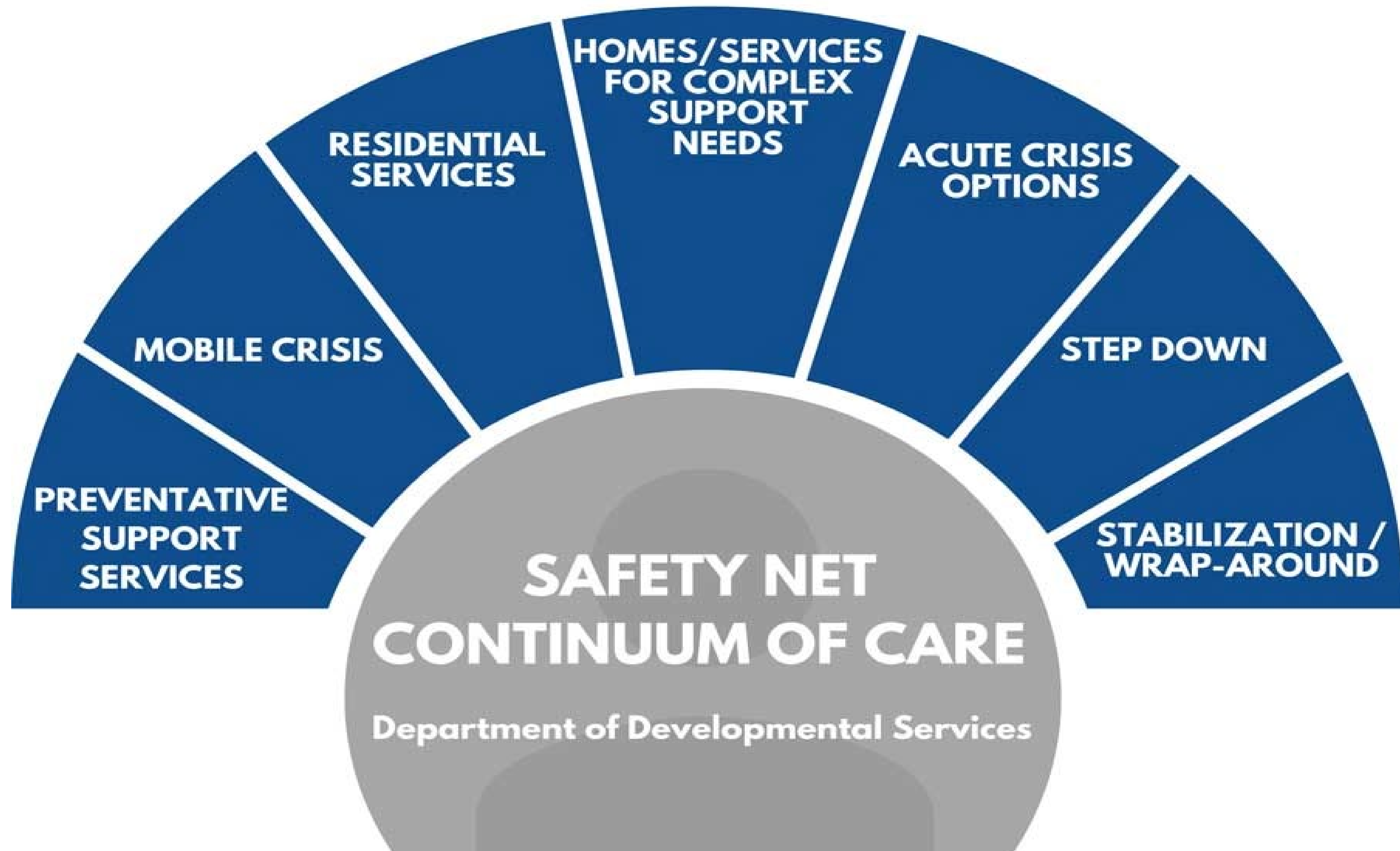
- The crisis safety plan when appropriate
- Referrals to ongoing supports as needed, check on the status of appointments, and provide continued support for linkage
- If a case manager or other needed resource (e.g., a behavior analyst) are not in place, work to provide referrals to ongoing supports by accessing local/regional resources (California Resources)

https://iddtoolkit.vkcsites.org/mental-and-behavioral-health/initial-management-of-behavioral-crises/

Coordination with Local Regional Centers and Individuals with I/DD Expertise

- There are 21 Regional Centers in CA that are community-based agencies
  - Regional Centers provide assessments, determine eligibility for services, and offer case management services
- In addition to providing the individual with I/DD lifespan services, Regional Centers provide services and resources to caregivers
  - Respite care
  - In-home support services
  - Transportation services

Regional Centers Continuum of Care



https://www.dds.ca.gov/services/crisis-safety-net-services/

Peer Learning Coordination Strategies

- » What are some ways your county is currently partnering with Regional Centers and other experts in I/DD? Are there MOUs? Is there direct collaboration between providers and mobile crisis teams?
- » Does your county outreach to your local Regional Centers for support when working with individuals with I/DD in crisis?
- » What are strategies you have used in the field when providing mobile crisis services to an individual in crisis with I/DD needing linkage and referral for ongoing supports and services?
- » Are you utilizing telehealth to access team members or external individuals with I/DD expertise?

National, State, and Local Resources

- CA Department of Developmental Services
- State of California Department of Justice - Advocacy Resources
- Disability Rights California-Advocacy Resources
- CA Department of Developmental Services - Regional Centers
- National Inclusion Project
- Changing Perspectives - Disability Awareness
- National Institute of Child Health and Human Development
- SAMHSA Substance Use Disorder for People with Physical and Cognitive Disabilities
- NAMI

- Individuals with I/DD have intellectual and adaptive challenges that need to be understood by mobile crisis teams to support successful interactions and work toward relief and crisis resolution.
- Understanding behavioral symptoms and working to understand what an individual might need to reduce stress is an important step in helping to manage crises among individuals with I/DD.

- Mobile crisis teams can address warning signs and risk factors to help reduce stress and assess individuals with I/DD needs.
- Being aware of the cultural needs of individuals and families will help build trust and support engagement and problem-solving.
- Collaborating with caregivers and creating safety plans are important steps in managing a crisis.
- Debriefing follow-up check-ins from mobile crisis teams after a crisis is an essential step in reducing harm through building ongoing resilience and coping strategies.

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- California State Council on Developmental Disabilities. Disability Thrive Initiative Resource Library: https://scdd.ca.gov/IDDThrive/
- Cleveland Clinic. What is intellectual disability? Retrieved at https://my.clevelandclinic.org/health/diseases/25015-intellectual-disability-id#:~:text=An%20intellectual%20disability%20is%20when,need%20lifelong%20assistance%20and%20support.

Resources

- Committee to Evaluate the Supplemental Security Income Disability Program for Children with Mental Disorders; Board on the Health of Select Populations; Board on Children, Youth, and Families; Institute of Medicine; Division of Behavioral and Social Sciences and Education; The National Academies of Sciences, Engineering, and Medicine; Boat TF, Wu JT, editors. Mental Disorders and Disabilities Among Low-Income Children. Washington (DC): National Academies Press (US); 2015 Oct 28. 9, Clinical Characteristics of Intellectual Disabilities. https://www.ncbi.nlm.nih.gov/books/NBK332877

- National Association of State Mental Health Program Directors. (2021). The Vital Role of Specialized Approaches: Persons with Intellectual and Developmental Disabilities in the Mental Health System.

- National Council for Mental Wellbeing. (2021). Roadmap to the Ideal Crisis System: Essential Elements, Measurable Standards and Best Practices for Behavioral Health Crisis.

- Risk Assessment Toolkit for Behavioral Crisis from Health Care for Adults with Intellectual and Developmental Disabilities: Toolkit for Primacy Care Providers

- Psychiatric Symptoms and Behaviors Checklist

Questions

Closing and Thank You

Your feedback is important to us!

Post-Survey, attendees must opt into the 90-day survey so we can collect your emails to send out the Certificates of Completion.

The completion of this survey is vital to our quality control and to the future funding of this project, as it allows us to provide you with training and technical assistance at no cost. In addition, it allows us to continually improve our services and provide the information and resources you need in the field.

Please take a few minutes to complete the survey!
Your time and feedback are greatly appreciated and valued!

Appreciation!

thank you

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