Family-Led Crisis Planning for Individuals with Serious Mental Illness and Serious Emotional Disturbance

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Certified Peer Recovery Specialist & Behavioral Health Care Manager
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Moderated by: Lynda Gargan, Ph.D.
Executive Director, National Federation of Families

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Learning Objectives

Attendees will be able to…

- Identify the signs and symptoms of serious mental illness (SMI) and serious emotional disturbance (SED) that are turning points for families whose loved ones are at risk for a mental health crisis
- Access crisis services through 988 and understand how states and community organizations collaborate to provide those services
- Create a family-led crisis plan for loved ones with SMI/SED

Presenters

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What's a Crisis?

A crisis is "any experience of stress, emotional, or behavioral symptoms; difficulties with substance use; or a traumatic event that compromises or has the ability to negatively impact a person's well-being, safety, and/or ability to function within their current family or caregiver environment, living situation, school, workplace, or community, as defined by the individual experiencing the crisis or by a parent, caregiver, guardian, or designee of the individual as appropriate."

TEXT, CALL, CHAT

988

No Judgment. Just Help.

988 SUICIDE & CRISIS LIFELINE

(SAMHSA, 2025)

CAN INCLUDE SITUATIONS WHEN:

- A person's behavior puts them at risk of hurting or being a threat to themselves or others.
- A person is unable to care for themselves or function.
- You, as the parent or caregiver, are no longer able to handle the situation and need help.
- You believe they may need emergency services, assessment, treatment, or require in-patient care.
- Intersection of co-occurring substance use and mental health leads to failure of role functioning and/or safety.

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Bringing Lived Experience to Family Support

SERIOUS MENTAL ILLNESS AND SERIOUS EMOTIONAL DISTURBANCE TURNING POINTS

BY SUSAN TERRY- BALL

TURNING POINTS

As a parent, family member, or caregiver, **learning the signs and symptoms** of serious mental illness or serious emotional disturbance in your child is an important first step.

When we begin to recognize they do exhibit those signs and symptoms, our **fears can be both immobilizing and unsettling**. Yet many parents, caregivers, and family members will tell you that led to a **turning point when they knew they were heading into a possible crisis**.

SMI AND SED

SAMHSA defines **serious mental illness (SMI)** as “someone **over 18** having (within the past year) a diagnosable **mental, behavioral, or emotional disorder** that **substantially interferes** with a person’s **life** and **ability to function**.” It’s like having an uninvited guest in your mind, one that doesn’t just pop in for a quick visit but sets up camp and starts rearranging the furniture.

SAMSHA defines **serious emotional disturbance (SED)** as “someone **under the age of 18** having (within the past year) a **diagnosable mental, behavioral, or emotional disorder** that resulted in **functional impairment** that substantially **interferes with or limits** the child’s **role or functioning in family, school, or community activities**.”

SERIOUS MENTAL ILLNESSES

Conditions that impact a person's thoughts, feelings, and actions that **frequently and substantially interfere with day-to-day functioning** are known as serious mental illness. The severity of these conditions varies, and various therapies, such as counseling, medication, or lifestyle modifications, may be necessary.

Not every person with one of the following diagnoses qualifies as someone with an SMI. Theses are examples of possible SMI diagnoses.

- **MAJOR DEPRESSIVE DISORDER WITH PSYCHOTIC EPISODES**
- **BIPOLAR DISORDER**
- **ANXIETY DISORDER**
- **SCHIZOPHRENIA**

SIGNS AND SYMPTOMS

Signs and symptoms of mental illness vary depending on the illness, but they usually affect **feelings**, **thoughts, body**, **behavior** and **connecting with people**. Behavioral signs may include **avoiding others and social activities** and **changes in sleep or food habits**. Physical symptoms may include **stomach aches, headaches,** and other aches**.** Common cognitive symptoms include **excessive worry, mood swings**, and **difficulty focusing** (SAMHSA, 2023).

Behavioral Changes

Physical Symptoms

Cognitive Symptoms

DEPRESSIVE DISORDER VS MAJOR DEPRESSIVE EPISODES WITH PSYCHOTIC EPISODES

Depressive disorders include mental illnesses with "the presence of **sad, empty**, or **irritable mood**, accompanied by **somatic** and **cognitive changes** that significantly affect the individual's **capacity to function**"

(APA, 2013)

Major Depressive Disorder with Psychotic Episodes is a type of major depressive disorder characterized by the presence of both a **major depressive episode** and **psychotic symptoms**, such as **delusions**, **hallucinations**, **disorganized thinking**, **and/or disorganized/abnormal motor behavior**.

Five or more of following symptoms present in 2-week period and represent change in functioning:

1. Depressed most of day
2. Markedly diminished pleasure
3. Significant weight loss or changes in appetite
4. Insomnia or hypersomnia nearly every day
5. Physical agitation or retardation
6. Excessive guilt or worthlessness
7. Decreased energy nearly every day
8. Diminished Concentration
9. Recurrent suicidal ideation

BIPOLAR DISORDER

Bipolar disorder, called manic-depressive disorder formerly, is a mental illness characterized by **emotional highs**, also known as a **manic or hypomanic episode**, and **lows**, also known as a **depressive episode**. Hypomania is less extreme than mania.

Manic episodes include **three or more** of the following, for **at least 1 week**, **most of the day nearly every day**:

1. Inflated self-esteem or grandiosity
2. Decreased need for sleep
3. More talkative
4. Racing thoughts/ideas
5. Distractibility
6. Increase in goal-directed activity or psychomotor agitation
7. Excessive involvement in activities with high potential for painful consequences

Symptoms of major depressive episodes are also present during the same period.

(APA, 2013)

ANXIETY DISORDERS

Anxiety Disorders can include symptoms such as “**excessive fear** and **anxiety** and related **behavioral disturbances.**”

They can **interfere with your daily activities**, but treatment can help.

There are many **types of anxiety disorders** that can be diagnosed by a mental health professional, including:

1. Separation Anxiety Disorder
2. Phobias
3. Social Anxiety Disorder
4. Panic Disorder
5. Panic Attack
6. Agoraphobia
7. Generalized Anxiety Disorder

(APA, 2013)

SCHIZOPHRENIA

Schizophrenia is one mental illness in the category of Schizophrenia Spectrum and Other Psychotic Disorders, all with the following key features of psychotic episodes.

Schizophrenia includes **two or more** of the following, present for a significant portion of time during a **1-month period**:

1. Delusions
2. Hallucinations
3. Disorganized speech
4. Grossly disorganized or catatonic behavior
5. Negative symptoms (i.e., diminished emotional expression)

(APA, 2013)

SERIOUS EMOTIONAL DISTURBANCES

Serious emotional disturbances can affect an individual in areas beyond the emotional. Depending on the specific mental disorder involved, a person's physical, social, or cognitive skills may also be affected to the point that it **substantially interferes with the child's functioning at home, at school, and in the community**.

Not every person with one of the following diagnoses qualifies as someone with an SED. Theses are examples of possible SED diagnoses.

- DEPRESSION
- FIRST EPISODE PSYCHOSIS
- TRAUMA & STRESS-RELATED DISORDER
- OBSESSIVE COMPULSIVE DISORDER
- OPPOSITIONAL DEFIANT DISORDER

TRAUMA & STRESS-RELATED DISORDERS

Trauma & stress-related disorders are those that **require** a **traumatic** or **stressful event** as a part of the diagnosis.

Some individuals who experience these events have **anxiety-** or fear-based symptoms and others exhibit **angry**, **aggressive**, or **dissociative symptoms**—often with some **combination** of these symptoms.

There are many **types of trauma & stress-related disorders** that can be diagnosed by a mental health professional, including:

1. Reactive Attachment Disorder
2. Disinhibited Social Engagement Disorder
3. Post-Traumatic Stress Disorder
4. Acute Stress Disorder
5. Adjustment Disorders

(APA, 2013)

OBSESSIVE COMPULSIVE DISORDER

Obsessive-compulsive disorder (OCD) includes **time-consuming obsessions**, **compulsions**, or **both** that are **not attributable** to **substance use** or a **mental health** or **physical condition**.

Obsessions are defined by both:

1. **Recurrent** and **persistent thoughts**, **urges**, or **images** experienced as **intrusive** and **unwanted**, usually causing marked **anxiety** and **distress**
2. Attempt to **ignore/suppress/neutralize** these with **another action** (compulsion)

Compulsions are defined by both:

1. **Repetitive behaviors** or **mental acts** that someone **feels driven to perform** in response to an obsession or according to rigid rules
2. These behaviors are aimed at **preventing** or **reducing anxiety**, **distress**, or a **dreaded event/situation** but are **not connected realistically** to the obsession or are **excessive**.

(APA, 2013)

OPPOSITIONAL DEFIANT DISORDER

Oppositional Defiant Disorder (ODD) includes a **disturbance in behavior** that is associated with **distress** in **self**, **others,** or **social context** and/or **negative impacts** on **social**, **educational**, **occupational**, or other **areas of functioning** and don't occur only as a part of substance use or diagnosed psychosis, depression, bipolar disorder, or mood dysregulation disorder.

ODD requires a **pattern of behaviors** lasting at least **6 months**, as evidenced by at least **4 symptoms** from any of the following categories, exhibited during interaction with at least one person who is **not a sibling**:

Angry/Irritable Mood:

1. Often loses temper
2. Often touchy/easily annoyed
3. Often angry/resentful

Argumentative/Defiant Behavior:

4. Often argues with authority figures/(for children) adults
5. Often actively defies/refuses to comply with rules/requests from authority figures
6. Often deliberately annoys others
7. Often blames others for mistakes/misbehavior

Vindictiveness:

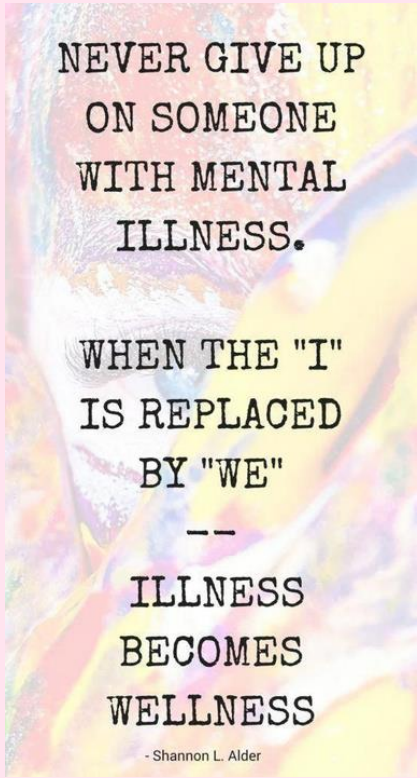
8. Has been spiteful/vindictive at least twice in past 6 months

(APA, 2013)

THANK YOU

OKLAHOMA
Mental Health & Substance Abuse

Parents Helping Parents



Lift
Community Action Agency

Coordinating with 988 to Increase Individuals with SMI/SED's Ability to Access Treatment During a Crisis

Sheamekah Williams
President
Evolution Foundation

Learning Objectives

Attendees will understand…

- The importance of a single access point to support loved ones with SMI/SED and their families in accessing immediate care.
- The difference in calls relating to a child or youth vs. adult.
- The uniqueness of a children's crisis system compared to traditional adult mobile response.
- Through shared implementation efforts, 988 and crisis staff can appropriately serve youth and adult loved ones with SMI/SED and their families.

Getting help for individuals with SMI/SED can be hard and confusing…

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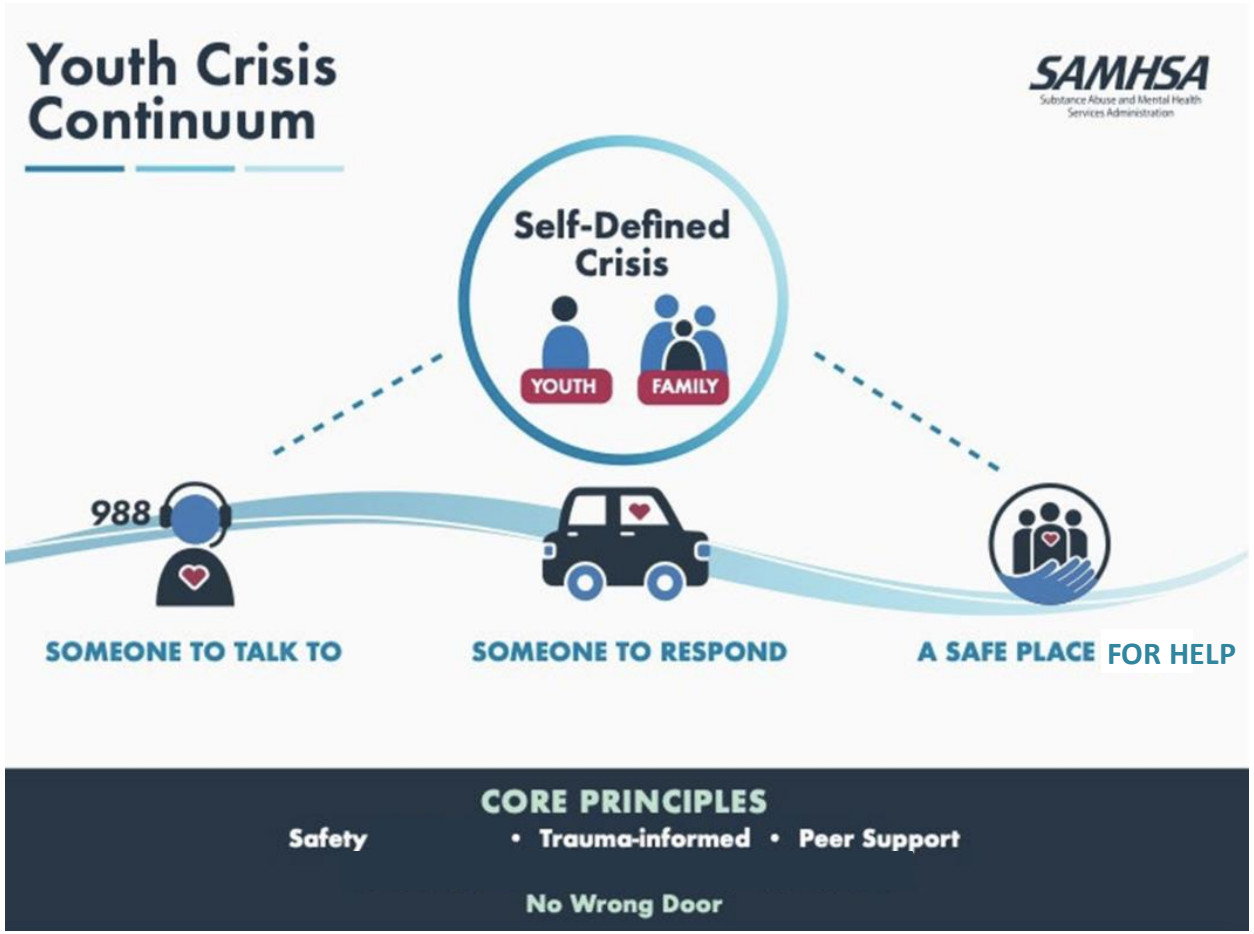


Figure 9: Unifying Principles to Achieve Accessible and Effective Crisis and Mental Health Services

 (SAMHSA, 2022, 2024, 2025)

Customization Matters!

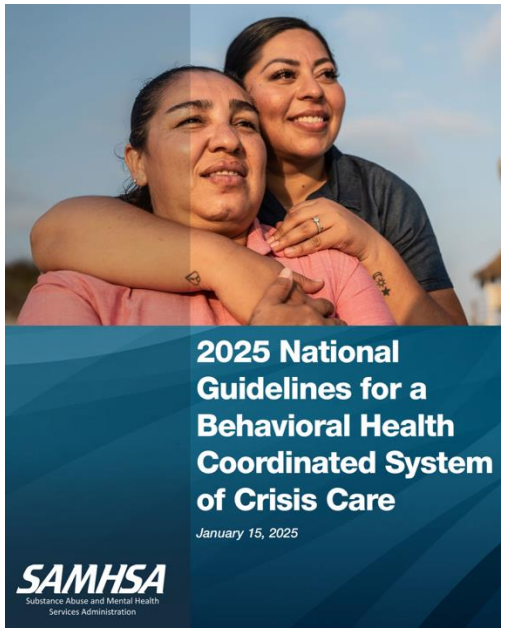
Pathways to Care

(Planning-Messaging-Marketing)

- Communities (Rural, Urban, Tribal)
- Schools
- Custody Youth
- All Child Serving Agencies
- Emergency Responders & Departments
- ID & DD families
- Early Childhood
- Transition Age Youth
- Adults

Make it as easy as 123!

Mobile Response & Stabilization Services - MRSS



- **Upstream Intervention** – available for families in pre-crisis
  - Administrative Structure, Oversight, and Policy
- **Single point of access 24/7/365**
  - Someone to Contact: 988 Lifeline and Other Behavioral Health Lines
- Recognizes a **family's sense of urgency**
  - Someone to Respond: Mobile Crisis and Outreach Services
- Focuses on the **shifting care pathways from high intensity services**
  - A Safe Place for Help: Emergency and Crisis Stabilization Services
- Recognizes **natural intervention points**
  - Role of Crisis Services within Broader Behavioral Health Ecosystem
- Recognizes and supports the **natural support system**
  - In-Home Stabilization Services
- Recognizes the **healing potential within communities**
  - Communications and Community Engagement
- Recognizes that the exposure to **higher intensity services can be trauma inducing**
  - MRSS + Systems of Care as an alternative

(SAMHSA, 2025)

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Recommendations

State leadership to integrate and align 988 and Mobile Crisis Team (MCT)/MRSS implementation efforts including training and technical assistance for 988 providers around MCT/MRSS best practice:

- Build on SAMHSA's vision of 988 as a hub for behavioral health needs and direct linkage to the greater crisis and behavioral health service array.

- Include customized, training, practices, and workflows that:
  - Acknowledge the various needs of unique populations and behavioral health needs.
  - Account for the service array available in the caller's (texter's) community.

(SAMHSA, 2025)

Recommendations (Cont'd)

Develop policies and procedures for 988 that acknowledge unique needs across the lifespan of individuals with SMI/SED offering developmentally informed approaches:

- **Children/young people & Families**
  - Align with Systems of Care values and principles
  - MRSS with MCT members trained in child development, family systems, and other relevant topics and with knowledge of relevant services
  - Youth and Family Peers
- **Adults**
  - Cross-agency and community-based organization collaborations
  - Adult peers
- **Older Adults**
  - Cross-agency collaborations and community-based organization collaborations (agencies/organizations specializing in older adults)
  - Train 988 staff on considerations unique to older adults such as dementia, elder abuse/neglect, isolation, and caregiving relationships
  - Older Adult Peers

(SAMHSA, 2025, 2022; E4, 2024)

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Recommendations (Cont'd)

Prioritize rapid, face-to-face, developmentally appropriate assessment and response for children and families:

- Explicitly allow for 988 providers to collect demographic information—which is not a requirement to receive services—early in the call, including the age and location of the caller or person in crisis.
- Prioritize in-person MRSS (non-police) responses over phone resolution for the child population by implementing GPS-enabled technology to dispatch care more efficiently.
- Support connections between 988, mobile crisis teams, and crisis facilities, including warm-handoffs to home- and community-based programs and/or coordinated transportation to facilities.
- Use whole family approach that avoids unnecessary and inappropriate involvement of the child welfare system.
- Gather data on call volume, response time, user satisfaction, and outcomes to inform continuous quality improvement.

(SAMHSA, 2025, 2022)

EVOLUTION FOUNDATION

Recommendations (Cont'd)

Allow young people/loved ones with SMI/SED and their caregivers/families to define the crisis:

- Do not screen out based on acuity levels or presenting problems.
- Allow access regardless of insurance status or ability to pay.
- Promote early intervention and identification.
- Recognize that parenting challenges and relational concerns are tied to, not separate from, child/family behavioral health outcomes.

(SAMHSA, 2025, 2022)

EVOLUTION FOUNDATION

Recommendations (Cont'd)

Educate providers, young people, loved ones, and their families on the goals of MRSS and normalize face-to-face responses:

- MRSS dispatches a mobile crisis team rather than law enforcement, except in rare and specific circumstances (for example, suicide or homicide attempt in progress).
- MRSS believes that most people with SMI/SED can be kept safe in natural environments (homes and communities), even those with heightened level of risk. MRSS works to keep people out of hospitals and residential settings.
- MRSS is available to respond, regardless of acuity, because face-to-face responses include outcomes for young people and their family preventing more restrictive or harmful interventions later.

(SAMHSA, 2025, 2022)

EVOLUTION FOUNDATION

Recommendations (Cont'd)

Provide support around infrastructure and technology:

- To connect 988 and MRSS, allowing for seamless communication and dispatches, as demonstrated in New Jersey.

- Acknowledge that sophisticated systems are needed, and such technical expertise is not always present in social service organizations/is costly.
  - Caller ID
  - GPS-enabled technology
  - Text, chat, video
  - Real-time regional bed registry

(SAMHSA, 2025, 2022)

EVOLUTION FOUNDATION

FAMILY LED CRISIS PLANNING

Making It Work For You

Melinda Brummett
Statewide Family Support Specialist Trainer
and Peer Coach
With Oregon Family Support Network

CRISIS STABILIZATION VS CRISIS PLANNING

Crisis planning and building of strategies starts at outreach and engagement for:

- Early identification
- Prevention
- Early-stage crisis intervention
- Safety-plan creation

So that families, and their supports can work to disrupt the crisis cycle.

(AFSP et. al, 2021)

Reactive

Identified Symptomatic Behavior Reduction

Increases Immediate Safety

Reactive plans generally focus on the behavior of one person with SMI/SED and seek to provide immediate increased safety in that moment. This is important in many cases, but does not look at long term skill building, awareness, self-efficacy, or change needed for the family. It can also unintentionally send a message that other members of the family are not needed in the process or have no role to play.

Proactive

Whole Family

Identifies Activations, Signs, Symptoms

Uses/Builds Protective Factors as a Strategy for Response to Crisis

Crisis planning, in contrast, is a supportive mindfulness process that addresses the unique strengths and needs of each loved one with SMI/SED and the family. The goal is a proactive disruption of the crisis cycle in times of distress so that crisis stabilization needs can be reduced.

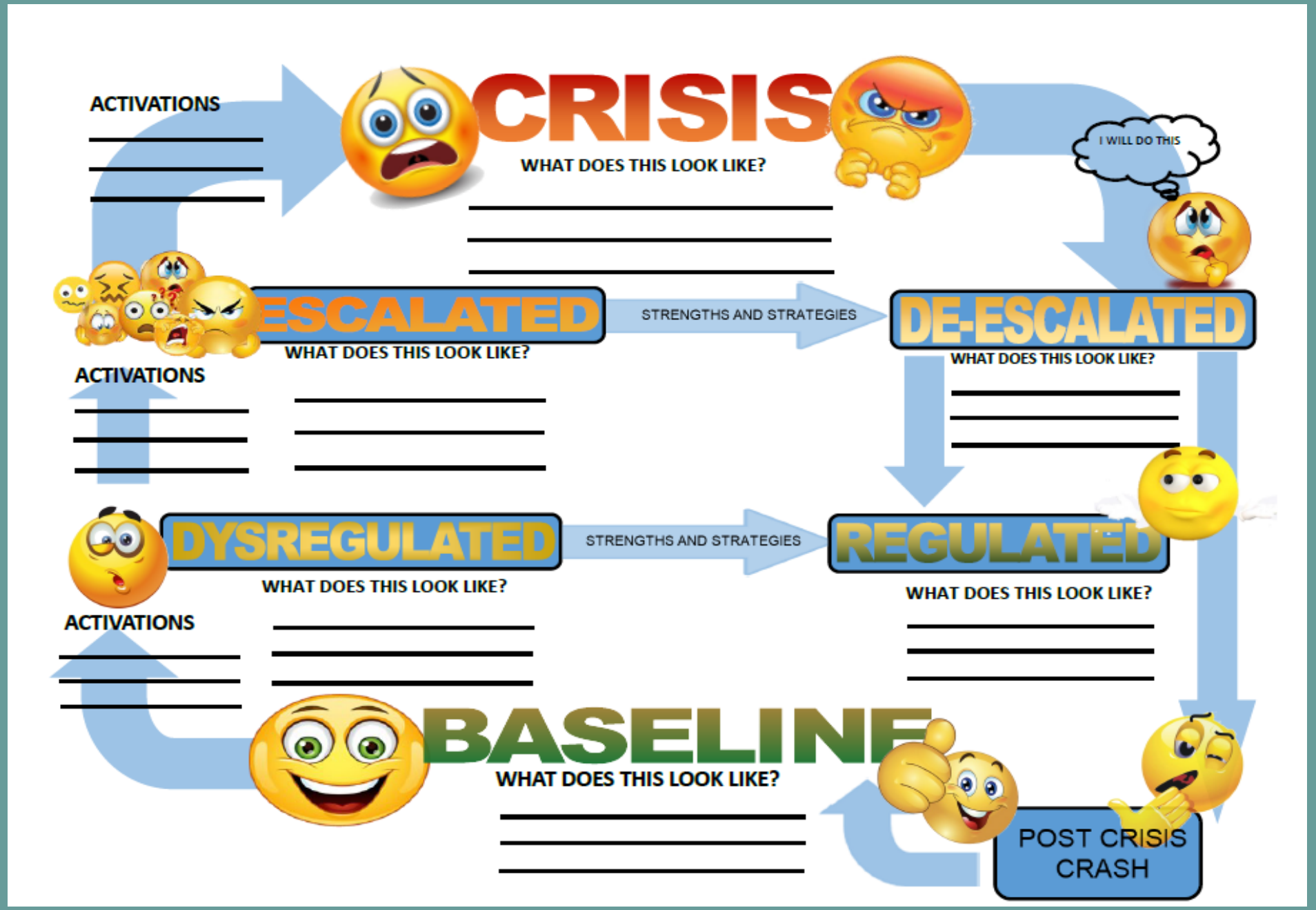
In addition to family peer support, families in crisis can connect with mental health providers for mental health diagnoses and supports within the context of a proactive crisis planning process.

Reactive Plan

Proactive Plan

Family-led crisis planning promotes a tipping of the scales in a holistic, family-centered way.

Family-led crisis plans end up as authentic, meaningful, usable, and family OWNED. It helps to strengthen bridges between the person with SMI/SED, family, the informal network, and the formal provider network. It can increase self-management skills over time and evolve as a living document.


ACTIVATIONS
CRISIS
WHAT DOES THIS LOOK LIKE?
I WILL DO THIS
ESCALATED
WHAT DOES THIS LOOK LIKE?
STRENGTHS AND STRATEGIES
DE-ESCALATED
WHAT DOES THIS LOOK LIKE?
ACTIVATIONS
DYSREGULATED
WHAT DOES THIS LOOK LIKE?
STRENGTHS AND STRATEGIES
REGULATED
WHAT DOES THIS LOOK LIKE?
ACTIVATIONS
BASELINE
WHAT DOES THIS LOOK LIKE?
POST CRISIS CRASH

FAMILY PEER SUPPORT IN CRISIS PLANNING

A Family Peer's involvement in family-led crisis planning brings a unique, lived-experience perspective that supports empowerment, trust, and collaboration.

HERE'S WHY FAMILY PEER INVOLVEMENT MATTERS:

- Lived Experience = Authentic Connection
- They Help Keep It *Family-Led*
- Bridge Between Systems and Families
- Normalize the Stress of Crisis
- Support Long-Term Stability
- Model Hope and Resilience

IDENTIFY WHO WOULD LIKE TO BE ACTIVE IN THE CRISIS PLANNING PROCESS

- Participation is a choice
- Avoid power struggles
- Be mindful of future opportunities
- Some may be ready to do more then others
- Even young children can contribute
- Change your lens around resistance

IDENTIFYING STRATEGIES

Looking at our past can help us to plan more efficiently:

What has worked?
What has not worked?
Who helps me?
Who is sometimes not helpful?
What makes me feel better?
What makes me feel worse?
Is there an environment that activates me?
Has a service helped? Hurt?
What have I never tried but wanted to?

WHAT IT LOOKS LIKE….

- Families don’t feel judged or blamed because of their loved one's behavior.
- Families can ask for the services and supports they need and maintain a sense of dignity and respect.
- Families feel valued and validated.
- Families express challenges, ideas, or plans without fear of alienation or retribution.

THE WHY….

Families know what works for them.

Families know what their limitations are.

Families can keep track of services and change.

Family and youth comfort and buy-in are necessary for success.

Family experience is holistic.

Families face the challenges all day and every day.

Families have credibility.

CRISIS IS... WHEN LIAM'S SPACE IS NOT SAFE

LIAM DOES NOT LIKE TRANSITION OR CHANGE.

- HAVING A SUBSTITUTE TEACHER
- CHANGING WHAT WE'RE DOING
- STOPPING WORK BEFORE WE'RE DONE
- SCHOOL DRILLS • FIELD TRIPS
- ASSEMBLIES • ROOM VISITORS
- SPECIAL PARTIES

SMILE

- SPENDING TIME WITH TEACHER'S AIDE
- USING RESOURCE ROOM
- ADVANCE WARNING FOR DRILLS AND EVENTS • USING A COUNTDOWN TIMER
- Ms. JOHNSON, MR. VALADEZ, MS. REED
- SNACK AND STRESS FIDGETS

THANKS

- CHANGING WHAT WE'RE DOING - LIKE T.V., GAMES, EATING, PLAYING TOYS, RIDING MY BIKE.
- TAKING TURNS / SHARING • BEDTIME
- WAKING UP • GETTING READY FOR SCHOOL
- SOMEBODY BEING SICK • VACATIONS.
- VISITORS IN MY HOUSE

LOL

- COLLABORATIVE PROBLEM SOLVING
- TIMERS • SNACKS • SCHEDULE
- FAVORITE BREAKFAST FOOD
- WARM BUBBLE BATH BEFORE BED
- GOING TO LIAM'S SPECIAL SPACE
- WEEKLY REWARDS • GRANDMA, TYLER, SOPHIA, DAD

STORE

- NOT GETTING WHAT I WANT
- TAKING TOO LONG
- BORING
- TOO LOUD
- TOO MANY PEOPLE
- HURTS MY EYES
- KEEPING MY HANDS TO MYSELF

- PICKING MY TREAT AHEAD OF TIME
- HOLDING / CHECKING OFF THE LIST
- MAKE IT A GAME
- EAT A SNACK ON THE WAY
- HEADPHONES
- MOM, STOP & GO HOME

PARK

- TOO MANY PEOPLE
- KIDS WON'T PLAY WITH ME
- I DON'T WANT TO GET OFF THE SWING
- WHEN I GET HURT
- SOMETHING IS ROPED OFF.
- WHEN I HAVE TO LEAVE

- BRING MY OWN THINGS - BIKE, FRISBEE
- TAKING A FRIEND WITH ME
- MOM NOT BEING ON HER PHONE
- MOM BRING A FRIEND
- TIME WARNINGS
- GRANDMA, TYLER, SARA, MARGARET

QUESTIONS

- ARE YOU TIRED?
- ARE YOU HUNGRY?
- DID YOU TAKE YOUR MEDICINE?
- WHO CAN HELP?
- DID SOMETHING HAPPEN TODAY?

TOOL BOX

HEADPHONES • TIMER
WEIGHTED STUFFED ANIMAL
SUGAR FREE SNACKS
PILLOWS • "SPECIAL SPACE"
STICKERS • BREAKS
PLAY DOH • BUBBLES
FRIENDS & FAMILY
SKILLS TRAINER • BOARD GAMES

SAFETY CHECKLIST

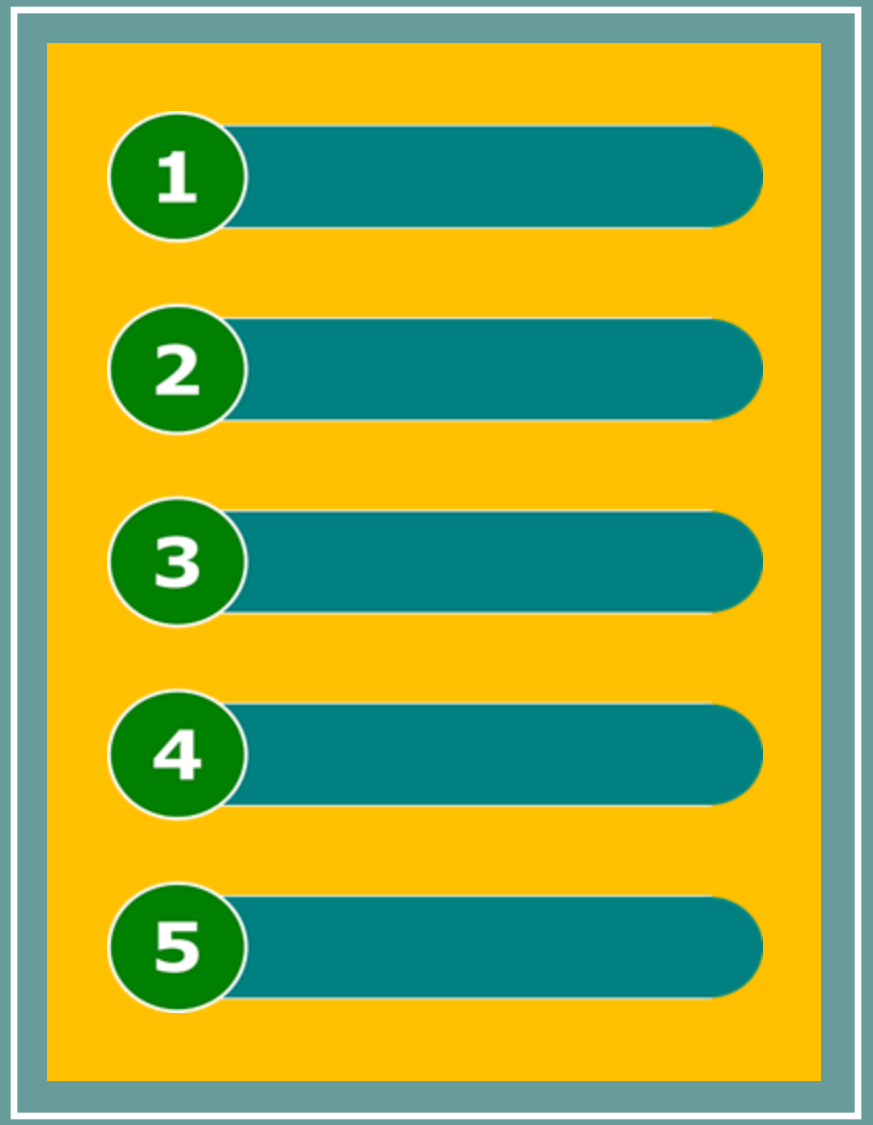
CAR CHILD SAFETY LOCK
"SHARPS" PUT AWAY
GIVING POLICE HEADS UP
SIBLINGS GOING TO NEIGHBORS
PETS OUTSIDE
CALLED CRISIS LINE

ONE'S INDIVIDUAL EXPERIENCE (LIFEWAY) MATTERS

A family's lifeway, strengths, barriers, language, and experiences will all be on stage in the event of a crisis and must be utilized when helping a family design their individualized plan. Every family has a unique lifeway. This lifeway will determine how they react, who will be involved, if it's a private or public matter, what resources are utilized, etc.

Understanding components such as whether this is a patriarchy/matriarchy, who makes decisions, who is with the loved one more, are they a private family, are there spiritual considerations to know, what is their communication style, are some behaviors acceptable that other families see as not…. And so on. A plan that goes against one's lifeway/daily norms is a plan that will sit on a shelf.

IDENTIFY WHAT IS MOST IMPORTANT TO YOUR FAMILY



Thank you!

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Bringing Lived Experience to Family Support

www.ffcmh.org

Lift Community Action Agency

www.liftca.org

EVOLUTION FOUNDATION

www.evolution-foundation.org

Oregon Family Support Network

www.ofsn.org

SAMHSA Sponsored Webinar Series:

Family-Driven Support for People with Serious Mental Illness (SMI) and Serious Emotional Disturbance (SED)

JUNE 17 — 1:30 - 3:00 pm ET

Collective Impact: Working Together to Support Individuals with SMI and SED and Their Families

Presenter: Paul Schmitz

WATCH RECORDING

JUNE 23 — 2:.30 - 4:00 pm ET

Emotional CPR: An Evidence-Based Support for Individuals with SMI and SED and Their Families

Presenter: Kimberly Ewing

WATCH RECORDING

JUNE 30 — 1:30 - 3:00 pm ET

Family-Led Crisis Planning for Individuals with SMI and SED

Presenters: Susan Terry-Ball, Sheamekah Williams, and Melinda Brummet

RECORDING COMING

AUGUST 6 — 2:00 - 3:30 pm ET

Crisis Intervention Teams: Partnering with Families of Loved Ones with SMI and SED

Presenters: Muriel Jones Banks, Lieutenant Steven Thomas, and Madonna Greer

REGISTER HERE

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