Building California's Comprehensive 988-Crisis System:

Community Engagement Report

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Introduction

The California Health and Human Services Agency (CalHHS), in collaboration with the Governor's Behavioral Health Task Force, released the Behavioral Health Crisis Care Continuum Plan (CCC-P) in May 2023. The plan outlines a vision for a future behavioral health crisis care system that is accessible to all Californians and encompasses a comprehensive range of essential services—from crisis prevention, to response, to stabilization.[i]

In parallel with the CCC-P's development, the Miles Hall Lifeline and Suicide Prevention Act (AB 988) was signed into law in October 2023.[ii] AB 988 took effect in September 2024 and builds on the National Suicide Designation Act of 2020, which defined 988 as the universal suicide prevention and mental health crisis hotline. AB 988 introduced pivotal provisions to increase the capacity of the existing 988 Crisis Centers, which predated passage of the National Suicide Designation Act of 2020 and AB 988 and called for coordination with related crisis service partners and programs and a reduction of unnecessary law enforcement involvement in behavioral health crises.

AB 988 also directed CalHHS to develop a Five-Year Implementation Plan for a comprehensive 988 crisis system. Central to informing this work was hearing directly from individuals and families who have personal experience with California's behavioral health crisis services and systems or who may be at greater risk of engaging with the system (e.g., individuals experiencing mental health and/or substance use challenges).

CalHHS partnered with Health Management Associates, Inc. (HMA), and Kauffman and Associates, Inc. (Kaufmann), to conduct a series of focus groups to gather feedback from people who have lived experience with the crisis system. By talking directly with a sample of respondents from impacted populations, we were able to:

- Listen to the priorities and suggestions from the intended users of the 988 crisis system
- Explore key issues relevant to the 988 crisis system
- Elevate and amplify the voices of individuals with lived experience in shaping the plan for 988 crisis system implementation

The following report offers details on the key themes and opportunities for systems improvement that emerged from these focus group discussions and further illustrates these themes with the words and perspectives of a diverse group of Californians.

Methodology

To gather feedback from individuals with lived experience with the behavioral health crisis system, CalHHS and partners HMA and Kauffman elected to facilitate a series of focus groups. To recruit focus group participants, HMA developed an electronic form for people to indicate their connections to the behavioral health crisis system and their interest in participating in a virtual focus group to share their experiences in greater detail. This electronic form was circulated widely among the agencies and organizations with representation on the 988 Crisis Policy Advisory Group (PAG) and supporting workgroups for this project. These leaders, representing different components of the crisis system, circulated the focus group opportunity among their personal and professional networks. In addition, HMA contacted subject matter experts to ensure that the sample of focus group respondents reflected a diverse set of voices and perspectives from populations of focus.

As Table 1 indicates, HMA and Kauffman conducted 13 focus groups across multiple populations. In addition to the representation of the populations of focus listed in the first column of Table 1, participants also reflected a variety of systems involvement that characterize the current and intended service users of the 988 crisis system, including people with lived experience with mental health and/or substance use challenges as well as people with lived experience with incarceration/justice system involvement and/or foster care system involvement. The systems involvement reflected in the table is based on the self-identification of focus group participants during the sessions.

Participants were not explicitly asked about their race/ethnicity, but many self-identified during the course of the discussion. Most participants were people of color, with the Black/African American, Hispanic/Latine, and Native American communities heavily represented.

Table 1. Focus Group Participants

Group/Population of Focus	System Involvement			
Group/Population	**Mental Health**	**Substance Use**	**Justice**	**Foster**
Individuals with Co-Occurring Disorders	X	X	X	-
Individuals with Co-Occurring Disorders	X	X	X	-
Individuals with Co-Occurring Disorders	X	X	X	-
Family Member Who Lost Someone to Suicide	X	X	-	-
Formerly Unhoused Individuals	X	X	X	-
LGBTQIA+ Individuals	X	X	X	X
Older Adults	X	X	X	-
Transgender Individuals	X	X	-	-
Women with Children	X	X	X	X
Young Adults	X	X	X	X
Rural/Elder Tribal Members	X	X	X	-
Youth Tribal Members	X	X	X	-
Urban Indian Tribal Members	X	X	X	-

Each of the virtual focus groups HMA conducted involved five to 10 individuals (with an overall average of eight) and lasted 60-75 minutes. HMA facilitated these sessions with a notetaker present. The focus group began with an overview of the purpose of the focus group and the 988 Five-Year Implementation Plan development process, followed by a series of open-ended prompts intended to spark discussion and the sharing of experiences with the crisis system. The content of the focus groups centered on three domains of inquiry intended to represent the crisis care continuum—preventing crisis, responding to crisis, and stabilizing crisis—followed by a discussion about desires and suggestions for systems improvement. (See the focus group protocol in the Appendix.) For their time, wisdom, and participation, each focus group participant received a $75 gift card.

The methodology for engaging Tribal communities was different because Kauffman conducted in-person focus groups in three counties: Humboldt, Sacramento, and San Diego. Specific Tribal communities hosted these in-person focus groups and collectively represented multigenerational perspectives (i.e., youth, adults, and elders) of enrolled Tribal members living in both rural and urban communities. In most cases, elected Tribal leadership (i.e., chairperson or vice chairperson) was present. A two-person Kaufmann team led the in-person focus groups, which tended to be both larger (12-20 participants) and longer in duration (approximately two hours).

Themes from the lived experience focus groups that HMA and Kauffman conducted are captured on the following pages. Feedback across focus groups was largely consistent. Direct quotes from participants are included to help capture and contextualize the findings. In some instances, readers may find the language stigmatizing (i.e., the use of words like "addict"), but it is important to present the feedback in participants' own words. It should also be noted that experiencing a behavioral health crisis can be incredibly traumatic, as reflected in the responses from participants.

Feedback from the lived experience focus groups was used to support the development of the five-year implementation plan. Themes and quotes from the focus groups are reflected throughout the implementation plan. In addition to the lived experience focus groups, a Peer Supporter Workgroup composed of individuals who are part of the peer workforce (e.g., Certified Peer Support Specialists) was engaged to provide input on the plan.

Key Themes

Cross-Cutting Themes

This section captures feedback that applies across the crisis care continuum. Subsequent sections include feedback directly related to preventing, responding to, and stabilizing crises.

Empathetic, understanding staff/volunteers are needed across the crisis care continuum.

A consistent theme across focus groups was the need for empathetic, understanding staff/volunteers. Participants mentioned caring as a need across the crisis care continuum—from 988 Crisis Centers to first responders to hospital staff. Many participants said they felt disrespected in their interactions with the crisis system—notably, in hospitals as outlined further below—and felt that these experiences only worsened their situations and reduced the likelihood that they would seek help in the future. People want to feel heard, respected, and treated with dignity. They want care without judgment, and additional training on how to guarantee a level of professionalism from all individuals working in the crisis system.

What We Heard:

- "Crisis responders and workforce need to treat every individual with empathy, dignity, and a sense of urgency.... It could be a life and death situation for the person affected."
- "I want someone who will listen to you. There should be more training for people to not be judgmental."
- "If you come in looking like trash, they treat you like trash.... I faced a lot of discrimination."
- "We need humane workers who are professionally trained."

Historical mistreatment and divestment in particular communities pose a challenge to engagement in the crisis system.

Participants framed their encounters with the crisis and overall behavioral health system in terms of a legacy of historical mistreatment and divestment in certain communities, including the African American, Native American, and LGBTQIA+ communities. This history of feeling "less than" and discriminated against made individuals less likely to engage with the system. They and their communities have had negative experiences when calling for help and seeking services. Sections below speak to pervasive stigma, fear, mistrust, and past trauma, as well as concerns about law enforcement's role in crisis response, but this overarching theme is important to acknowledge and consider when planning for the evolving crisis system.

What We Heard:

- "There's a reason so many of us are scared to reach out for help."
  – LGBTQIA+ Focus Group Participant
- "Trust is a big issue…. People need to be able to trust you. Once you've built the trust, people will start to reach out."

Individuals with lived experience should play a central role across the crisis care continuum.

Another consistent theme that emerged in every focus group is the importance of employing individuals with lived experience in the crisis system. The overarching sentiment was that people with lived experience are more empathetic and are better able to understand and support individuals going through crisis. In addition, they felt that individuals with lived experience could better address the nature of their crisis quicker than someone who might need more explanation and context to understand the nature of the need or crisis.

Participants did not specifically refer to the peer workforce (e.g., Certified Peer Support Specialists) but spoke more generally about employing individuals with lived experience as call counselors, outreach workers, first responders, mobile crisis workers, and therapists, among others. Several participants also expressed their personal desire to work in the behavioral health field and leverage their own experiences to benefit their communities.

What We Heard:

- "Some people don't know how to respond to us or respond by the book, instead of sharing their own experiences."
- "If you haven't been through what I've been through, how can you help me through?"
- "They should have counselors who have lived experience and dealt with it. Some have never touched drugs, never lost a kid, etc. It's all from a book. Another addict can understand and relate more and get people to open up."
- "I've been homeless, through the system, addicted. I've been through it all. It's nothing to brag about, but lots of us have been through the same stuff and can help."
- Comment from the Staff Member: "For me, I'll let them know that I got out of prison after 26 years. I've been clean for 14 years now. Once I tell them that, I see them pay attention a little more. I've been where they're at. For me to get out of prison and be doing what I'm doing now—I let them know that they could do it too."

Individuals would like to be connected to culturally specific service options.

Participants expressed the importance of being connected to culturally specific services. In some cases, it may be an organization or program that serves a particular population, while in others it may simply be a staff member with a similar cultural background. As with lived experience, participants felt that having someone with a shared cultural background helps them feel heard and understood. Many participants said they would be more willing to ask for help if they knew they would be speaking/connected with someone of a shared background. Participants also said that training staff to have cultural competence is good, but it cannot replace a shared experience.

What We Heard:

- "Lots of therapists have cultural competency, but it's not the same as looking at someone of your own race and culture and understanding them."
- "There's generational trauma, and you need someone who understands what we've been through. You need to understand the condition and experience to heal it."
- "Lots of people are less willing to talk to people who don't look like them. More would reach out if they knew they really understood and cared and were not just going through the motions."
- "They don't know how to help us…. They really don't understand." (Participant talking about their experience as an LGBTQIA+ individual seeking support)
- "We need more traditional healers involved in stabilization." – Native American participant
- "[We need] an all-Native PERT (psychiatric emergency response team) made up of people in recovery and walking the Red Road."

Ongoing engagement with individuals engaged in crisis services should be considered to inform quality improvement.

Participants were eager to engage and share their stories. They sincerely appreciated being asked about their experiences. Many focus groups ended with the participants thanking the facilitators for giving them the opportunity to share. Though participants did not directly ask for ongoing engagement with individuals receiving crisis services to inform and improve the system, it aligns with their collective feedback about prioritizing lived experience and their willingness to share their stories. Engaging with individuals with lived experience from impacted populations at periodic intervals as the five-year plan is implemented could demonstrate an ongoing commitment to listen and adjust state direction based on the intended users of the crisis system.

Preventing Crisis

Awareness of the 988 Suicide and Crisis Lifeline is limited.

A consistent theme across focus groups was that most participants were unaware of the 988 Suicide and Crisis Lifeline. Most were unaware of the hotline entirely or were only vaguely familiar with its purpose. Several participants had called the lifeline and shared mixed experiences. Participants were very interested in learning more about 988 and raised questions about its purpose, what happens when you call, who you get connected to, what the outcomes might be, and so on. Numerous participants shared that the crisis line would have been beneficial to them when they were in crisis and felt like they had no place to turn.

What We Heard:

- "I needed a number. I needed help before I relapsed, but I had no one to reach or reach out to."
- "I have a cousin who is dealing with [mental health] issues. It would be nice to have somewhere to call that's more focused on mental health, not just drugs and alcohol. She ended up running from the hospital because we couldn't find a place to go."
- "If I get into a fight with someone and get so hot-headed, instead of calling someone to use drugs, can I call 988 and ask them to talk to me so I'm not having a mental breakdown? I wish I could have called them and say I'm freaking out and don't want to use."
- "If I had seen 988 posted I would have called them instead of calling 911 every time I couldn't get myself together. I was pregnant and deprived and throwing up and needed to call 911. I would go to the hospital, and they would say nothing is wrong and set me free."
- "I wasn't diagnosed as a kid, but I knew something was wrong and I knew I went through trauma. If at that point someone gave me a number…that would have been great."
- "I called 988 for myself and spoke to someone. It calmed me down and kept me from going and getting 5150[1]-ed. It helped me sort out my thoughts."

Many participants lacked awareness of available prevention services.

Participants also described a lack of awareness and/or access to prevention services. They spoke to being unfamiliar with nearby services and the options that might be available to them. Many participants said they had not engaged in prevention services but thought that they might have been helpful prior to experiencing crisis. Several shared stories about events and interactions that were leading up to crisis and served as "missed opportunities" for early identification and/or prevention.

What We Heard:

- "Like, I have anxiety. I should get assessed and go get help, but I never seen people out asking if you wanted to get assessed and get help."
- "A lot of people with mental health issues don't want to get checked up, but if there's a place or a person that could help someone like that, it would make a life worth it."
- "In the African-American community, there's nowhere to go to. You need to go by bus to get help, and some aren't willing or able."

Broad communication is required to build awareness of the 988 Suicide and Crisis Lifeline, as well as to support destigmatization of behavioral health challenges.

When asked for suggestions to build awareness of the 988 Suicide and Crisis Lifeline, participants described a need for broad communication strategies, such as commercials, billboards, and social media ads. Focus group members felt that these kinds of broad-based strategies would raise general awareness of the existence of the lifeline and where to call when they or a loved one is in crisis. Participants also agreed that communication and outreach would reinforce and support behavioral health destigmatization within the communities.

What We Heard:

- "We need an education campaign launch focused on the spirit of love and deserving of care, like the COVID period of masking campaigns like, 'Wear your mask to protect your grandma.'"
- "Lots of resources go to people experiencing the conditions, but I don't think there's much going to the others to help with destigmatization."
- "[We need] Education for our people on how to reach out for support."
- "People simply do not know what to do [in a crisis]."
- "Cell phones are young people's lives." – Participants describing the need for social media ads.

Storytelling and testimonials should be core components of broad communication strategies.

When asked about what types of messaging and outreach would be most effective, participants suggested testimonials from a diverse array of individuals with lived experience, including people who have direct experience with the crisis system. They felt that these stories would resonate with individuals who have experienced crises and build empathy and understanding in the community. Participants wanted to see people like themselves in these public service videos and advertisements. They thought this kind of representation would add credibility and help people understand what the 988 Lifeline could offer them in terms of both immediate help and connectivity to longer-term care.

What We Heard:

- "It should feel like a [Narcotics Anonymous] meeting. [Speakers could say], 'I have 30 days clean. I feel like myself again,' and then talk about their background and situation. I had no one to turn to, but there is hope." – A participant describing what they thought would be an effective ad.
- "We need more people describing how it works for people like us [LGBTQIA+ individuals]."
- "Feeling the support from others, staff, counselors, people in recovery—it really helps to hear other people's stories."

Though participants recommended broad communication strategies, they felt that it is important to meet people where they are.

Though participants said broad communication strategies were important, they spent much more time describing more on the ground and lower-tech strategies. Participants shared that most of what they know about services comes from word of mouth, flyers/posters, and information shared through grassroots service providers. They felt that information needed to be available and visually evident "where people who need the service are," such as treatment centers, hospitals, homeless shelters, and the local offices of key public agencies, as well as more ordinary community settings like libraries and grocery stores. Participants also noted that overt "street" outreach involving teams of people who canvas a neighborhood or area with printed materials is the best way to engage individuals who are experiencing homelessness and/or currently in crisis.

What We Heard:

- "Messengers need to 'come down' to the community level to have these conversations."
- "Put information in DCFS [Department of Children and Family Services] offices, WIC [Special Supplemental Nutrition Program for Women, Infants, and Children], and welfare offices. Places where people go—libraries, grocery stores, hospitals."
- "At [a treatment facility] everyone needs to check in with the monitor to sign in and out, so flyers work well. Make them big and bold."
- "Word of mouth is the best Indian advertising!"
- "Do y'all have any flyers or cards to share for us that we can give out to help make a difference and promote?"
- "You need to go into the community with brochures and information: 'Here's where to call, here's where to go.'"
- "When people are going through crisis, they're not looking up [at billboards]; they're looking down at the ground because they've been down for so long. Advertisement is good, but you need 1:1 outreach. You need someone to ask you how you're doing, offer you a sack lunch or something, and show you that they really care."
- "Word of mouth is good. Get the people who use it [988 and prevention services] to spread the word. Get the people who use it involved."

Trusted messengers should be leveraged to share key messages.

As noted above, many focus group participants recommended word of mouth and more localized communication strategies. They also described the need to engage trusted messengers to implement these strategies, including individuals with lived/living experience who can share information about the 988 Lifeline, as well as promotion by trusted community leaders. Typically, focus group participants identified these messengers as people who work for treatment providers, high schools, and other health-oriented local community-based

organizations (CBOs). Participants felt that this would be an effective way to build awareness of and, importantly, trust in the 988 Lifeline as a viable option before or during a crisis.

What We Heard:

- "It's important that the people who need the help know—and more importantly, believe—that the help being offered is real. It can't just be words or empty promises."
- "We need to go into schools and build awareness of what's available."
- "California Indian Country thinks differently, such as the need to educate family members who are head of their clans [the people that family members go to in distress]. If the clan head person is toxic, people go to their Tribal government."
- "Our schools should be able to teach more about it."
- "Staff lets us know about jobs, programs, upcoming things. Even this focus group."
- "Addicts helping addicts….People going out to help other addicts and spread the word."

The creation of a Tribal-specific 988 Lifeline may help to build trust and improve quality in Native American communities.

Participants in the Native American focus groups expressed a desire for a Tribal-specific 988 Lifeline. They felt that Indigenous individuals would be more likely to call this line and that they would be better served by call counselors from their community. This belief aligns with feedback shared in other focus groups (reflected above) about a desire for culturally specific services that leverage a workforce that is more diverse and representative.

What We Heard:

- "Training the 12 call centers is not enough, it's only checking the box."
- "There is too much staff turnover to do quality training on Tribes due to staff changes."
- "A non-Native person might not understand, and we would want to talk to someone with experience."

Linkage to services and long-term treatment are crucial to breaking the cycle of crisis.

Participants also described the need for follow-up services and connections to long-term care as critical for preventing future crises. For example, many noted the "revolving door" or vicious cycle of repeated behavioral health crises followed by arrest and/or hospitalization and then release back into the same conditions and living situations that precipitated the incident. These topics are discussed further in the Responding to Crisis and Stabilizing Crisis sections.

Responding to Crisis

Stigma, fear, mistrust, and past trauma may prevent people from calling for help during a crisis, especially individuals from historically marginalized communities.

One of the most consistent themes across focus groups was that stigma, fear, mistrust, and past (including intergenerational) trauma make individuals less likely to call for help, especially people from historically marginalized communities. While participants expressed interest in the 988 Lifeline, they also described concerns about privacy, confidentiality, and potential downsides of calling.

For example, youth participants spoke to concerns about their parents finding out they called, whereas women with children were concerned that a call to a crisis line might result in their children being taken away. Closely tied to anxieties about calling were concerns about who might show up if they did. As noted previously, most of the participants had neither heard of

nor called the 988 Lifeline. The crisis responses they had experienced mostly involved law enforcement and other first responders, with many describing negative and sometimes traumatic experiences.

What We Heard:

- "I know a lot of people feeling suicidal wouldn't want their parents to know, and they could be judged or get in trouble for reaching out for help."
- "They want to know where you're at before they give you help. People on drugs might be sketchy and not want to give their information."
- "Law enforcement or CPS [Child Protective Services] might take [your] kids because they're having a bad day or want to relapse….That's another thing that stopped me from calling 211 [a health and human services hotline]. They're mandated reporters and will call 911."
- "You want to be honest and spill your guts out, but you need to watch how you say things." – Participant expressing fears about being reported to CPS when seeking help
- "For me, asking for help has always been a problem. As a drug addict, I think I can do it by myself. It feels like people won't listen because they haven't for a while."
- "Electronics can get searched and parents will know."

Participants expressed substantial concern about law enforcement's response to 988 crisis calls.

As noted above, many participants expressed concerns about law enforcement's potential involvement in the crisis system. Many focus group participants relayed negative personal experiences, as well as stories about discriminatory treatment and traumatic incidents involving friends, family members, and other people in their communities.

Some felt that law enforcement should never be involved in crisis response, whereas others felt that they should only be included if there is a safety concern and should then defer to crisis experts once the situation is secure. For example, one participant described law enforcement conducting a pat down to check for weapons followed by law enforcement

ceding the space to a crisis counselor to engage with the individual in crisis. Participants were worried both about the outcome of law enforcement involvement, such as being arrested or put on a 5150 involuntary hold, and about police presence potentially escalating the crisis and making a bad situation worse because of historically poor interactions.

What We Heard:

- "If someone walked up with a shirt and glasses, not a uniform, the person would be more likely to listen and work with you. When an officer comes, it can get out of hand."
- "Some people are afraid of the police. It heightens things. People need someone with an easy voice to keep them calm and explain the process."
- "I needed more of a compassionate ear, without the fear of cops showing up."
- "A lot of us don't want to call the cops, ever." – Young adult participant
- "You already know something's wrong with them. By arresting or pointing your gun, you're just provoking their anxiety more."
- "The police are not in a position to assist in mental/behavioral health emergencies."
- "I would be concerned about my safety because the police are not well equipped to deal with mental health issues. I worried about [them] being undertrained in mental health and de-escalation training."

Individuals with specialized training and/or lived experience are best positioned to respond to someone in crisis.

When asked who should respond to a crisis if not law enforcement, participants suggested sending individuals or mobile crisis teams with specialized training and/or lived experience. Some professional job classifications mentioned included therapists, counselors, social workers, etc. Focus group members said these types of individuals, along with peer specialists, would be better able to understand and alleviate the situation, de-escalating the crisis and responding with greater empathy and supportive guidance. Participants felt that

this type of response would lead to better outcomes and increase the likelihood of connecting them to the next stage of care.

What We Heard:

- "[Crisis response] reminds me of a hostage situation where they'll send out a negotiator specially trained to deal with that type of situation, not just police or an ambulance. Have a mental health crisis expert come out first to address the situation without it escalating further."
- "Find a way to send only qualified individuals instead of police. Crisis teams instead of police intervention."
- "It's expensive to have fire, ambulance, and police come out every time. If it's a specialist, that would help to save resources."
- "Once they knew I wasn't a threat, we talked through my plan, what I needed, what I wanted." –A participant talking about a positive crisis experience in another state where the police deferred to a crisis expert.
- "There should be crisis teams of trained people."
- "The best solution would be not to put this on the police. They're already dealing with a lot and are on edge."

Consideration should be paid to technology and cell phone services, especially in rural and Tribal communities. Directing in-person responses (when necessary) also is uniquely challenging in these communities.

Several participants—most notably participants in rural and Tribal communities—described technology access and cell phone service as barriers to crisis response services. Although several noted that 988 text/chat is often still available in so-called "dead zones," the inability to call during a crisis is limiting. Tribal groups also described challenges with routing in-person responses when necessary. In Tribal lands and rural areas, homes and businesses often share addresses (some in different locations). Furthermore, GPS systems do not recognize some addresses, with locals relying on landmarks to provide direction.

Stabilizing Crisis

Crisis services need to be timely and more accessible.

Participants who experienced crisis services consistently noted a need for timelier and easier access to stabilization services, both immediate and longer-term. Several individuals noted delays in receiving services and felt that faster responses and connections to care would instill trust in the system and showcase its commitment to responsiveness. Many participants spoke to difficulties in accessing crisis services, such as detox facilities, sobering centers, and crisis stabilization units, and of being turned away because of eligibility requirements or limited capacity. Participants described the adverse psychological impacts and negative consequences of being turned away at key moments when they needed help. We also heard about the additional barriers facing people with young children who feared family separation and other consequences of seeking help at a crisis facility.

What We Heard:

- "Faster response time would build confidence in the system."
- "You're asking for help, but then they say they can't help with that. It makes you feel minimized like you're not worth their time. I'm looking for help and I get turned down. Mentally, you're like, 'Why am I even trying to get better?'"
- "It's unfair that family can't go together. Couples and families on the street don't have somewhere to go together. Family separation is a barrier—makes it hard to get help—especially with kids."
- "I used to use meth, but when I got to rehab they wanted me to do detox but nowhere did it for meth. It's hard to be pregnant on the street and have to detox on your own. Lots of things can happen to a woman."
- "There should be places where we can take our children. We're all our children have at times."

Crisis stabilization services are viewed as too short in duration.

A consistent theme across focus groups was that crisis stabilization services are too short in duration. The groups described the significant physical and psychological impacts of experiencing a crisis and noted that it takes more than a few days to stabilize. In addition, several described not having a place to go after their short-term stay and spoke about returning to the same environment that preceded their crisis resulting in a vicious cycle or revolving door of crisis episodes. Throughout, it was clear that participant experience with short-term crisis services was influenced by what did or did not happen next. Most were unable to be linked to additional support after their stint at a crisis stabilization facility.

What We Heard:

- "It's a cycle of input and output....People in crisis need stabilization and they need more than three to five days. They need to be connected somewhere to get them into services that will break the cycle."
- "I was self-medicating previously—was on skid row with a mix of addiction and mental health. I would go to the hospital, get out, and then go right back to the street."
- "I liked it [crisis facility], but on the other hand, they made me leave. You should be able to stay as long as you need to. I didn't like that part."
- "Sometimes when we call for help, someone comes but the services provided aren't long enough to actually get the help we need."
- "Stabilization is a revolving door."

Participants described negative experiences at hospitals while in crisis and expressed a need for alternate destinations.

One of the most consistent themes across focus groups was that participants had negative experiences at hospitals while in crisis. As the quotes below indicate, participants felt disrespected in these settings and felt they received neither the treatment nor they care they needed. Many participants had been held on 5150 holds, with most describing an experience of being held for days without getting any real help, only to be released and cycle back into crisis.

Several participants, however, believed that a 5150 hold was preferable to being arrested, even if it was more "embarrassing" in the short term. Because of these experiences, many participants described a fear of going back to the hospital while in crisis, with several saying that this concern was a barrier to reaching out for help. Several participants also explicitly asked for alternate, nonhospital settings to go to while in crisis.

What We Heard:

- "I was often on 5150s and in psych facilities, but all they wanted to do was drug me….It was dehumanizing, but I couldn't process it or communicate at the time. You're asking for help, but they don't want to help."
- "I think some people don't call because they don't want to go to the hospital."
- "A 5150 is more embarrassing in the short term, but it's better in the long run. You're not being locked up or charged."
- "I was in psychosis and was begging to be transferred to a psych facility. I didn't know what was happening and they made me sit in a hall on a gurney for three days. My things were stolen, they kept my ID. All the steps were punitive. I didn't get anything out of that experience. I didn't learn anything."
- "Big problem when there is crisis-crisis….They go to the hospital and get left in a hallway on a gurney with a watcher—sometimes as much as eight days."

Improved linkages to long-term care are required to prevent future crises.

As noted above, participants generally described negative experiences when accessing crisis services. In many cases, however, participants were expressing frustration that they were not connected to the services that they needed post-crisis. They described being released without a next place to go, with many returning to the streets where they continued to experience crises. On the other hand, some participants described their successful journey from crisis to long-term recovery and stabilization. These respondents described going from immediate crisis stabilization to longer-term crisis services and ultimately to residential programs, housing, and outpatient treatment. These individuals credited the provider organizations for supporting their transitions of care, but also noted that they needed to work hard to stay engaged and connected to services. Several focus groups participants also described the importance of simultaneously addressing mental health and substance use challenges, as well as the benefits of detox programs that are co-located with longer-term service offerings.

What We Heard:

- "At the age of 40, I went in and out of mental hospitals, jails, other facilities, but once I got connected with [a dual diagnosis program], that all changed."
- "I've seen lots of people get forced out with no place to go. People have a set time, but not everyone gets connected to what they need in that time period. You can't kick people back to the street because then you start the cycle again."
- "It was a cot to sleep on and a few meals. We were kicked out at 9 am. Basically, it's an overnight [crisis] facility, which is good. But there was no bridge or introduction to sobriety."
- "It didn't seem like people in the system are aware or interested in providing assistance beyond the immediate."
- "I had to make calls, do interviews, have a good attitude about taking meds, abide by rules, or else I wouldn't be accepted. It worked out for me, but it doesn't for everyone."
- "We need more long-term care. Ninety days is not enough, sometimes up to two years is needed."
- "Inside the prison walls people are mentally ill and then they just let them out….We need to get them into the mental health system, and then you might have a chance."

Culturally specific services are important to meet the needs of impacted communities.

Several groups—including ones that focused on LGBTQIA+, youth and young adults, and Native American individuals—described the need for population-specific/culturally informed crisis services. They described feeling unsafe or unaccepted in settings for the general population and that they would be better served by a place/program designed for them. This sentiment aligns with the cross-cutting theme of culturally specific services but is called out here because it may have implications for facility development—not just personnel or program design.

What We Heard:

- "We [LGBTQIA+ individuals] don't often feel confident going into many places….I don't feel safe. I've been judged and laughed at. It makes you want to give up."
- "We need our own Tribal residential stabilization facility."

Participants felt that peer-run crisis stabilization and treatment services are empowering and impactful.

Several participants also talked about their positive experiences at peer-run crisis centers. They described feeling understood and accepted in a way that they did not by other players in the crisis system, such as treatment providers and first responders. They also described feeling more empowered in programs where peers are the decision makers.

What We Heard:

- "For me, I had been running for so long until I got into a psycho-social program where members had 'say so' about the program. I was finally in this environment where I had nothing to push against, no reason to run, so I had to surrender. And after that, I began to heal."
- "They had art classes, groups, and it was run by peers. Police weren't there or therapists who didn't know why people were acting the way they do. It felt like a comfortable place to go."

Housing and employment are foundational to long-term stabilization.

Another consistent theme across groups was the importance of housing and employment in supporting long-term stabilization. They described housing and employment as both foundational and motivational (i.e., factors that compel people to continue to focus on their treatment and recovery). Many participants talked about the challenges of finding housing after being in a residential treatment setting, despite their best efforts and those of their treatment teams. The lack of affordable, safe, and clean housing was consistently cited as a barrier to long-term recovery. Even if housing could be secured, many felt that the poor condition of units designated for low-income, formerly unhoused individuals contributed to the cycle of crisis.

What We Heard:

- “Housing is what’s needed. Some guys get lucky and get it right away. Some will be here waiting for six months, won’t get it, and then won’t have anywhere to go.”
- “Housing and jobs keep people motivated.”
- “Most of the time the client is barely getting their feet on the ground and don’t know where to go. They don’t have [post-treatment] housing always, so we’re just putting them back on the street. Most people will go back to their comfort zone, which is addiction. I’ve seen clients like a revolving door. Cycling in and out because there are no long-term resources.” – Staff member comment
- “We hope people get into a place where they’re motivated, but most end up in places that are depressing, which doesn’t support healing and improvement. They might as well go back on the street.” - Staff member comment

Opportunities for Systems Improvement

Below is an overview of several opportunities emerging from the lived experience focus groups for consideration in the development of the Five-Year Implementation Plan and in other behavioral health transformation efforts.

Opportunities for Systems Improvement
Cross-Cutting Factors: • Support the hiring of individuals with lived experience across the crisis continuum • Trauma crisis workers on cultural competency and trauma-informed care • Expand access to culturally specific and peer-run services and facilities • Continue to engage individuals with lived experience to inform service design and quality improvement
Preventing Crisis: • Leverage trusted messengers, storytelling, and testimonials to build 988 Lifeline awareness • Ensure that communication strategies consider and support on the ground and word of mouth sharing of information
Responding to Crisis: • Acknowledge and work to address concerns and questions related to privacy and mistrust that may serve as a barrier to calling 988, particularly in historically marginalized communities • Explore the creation of a Tribal-specific 988 Lifeline to better serve native communities • Reduce unnecessary engagement with law enforcement during crisis response • Ensure that crisis responders have specialized training in crisis response
Stabilizing Crisis: • Reduce unnecessary hospitalizations and 5150 holds • Expand availability of and access to alternate destinations and crisis stabilization facilities • Improve linkages to longer-term and supports post-crisis stabilization

Conclusion and Thank You

HMA and Kauffman and Associates, Inc. would like to thank the focus group participants as well as the individuals and organizations that helped to convene these groups. Participants were incredibly open and candid about their experiences with the crisis care continuum. Their input will inform the development of the Five-Year Implementation Plan.

As noted above, we would recommend engaging individuals with lived experience from impacted populations at periodic intervals *as the 988 plan is implemented* to demonstrate an ongoing commitment to listen and adjust state direction based on the intended service users of the crisis system.

Appendix

Building California's Comprehensive 988-Crisis System
Focus Group Guide for Individuals with Lived Experience

Overview

Through AB 988, the California State Legislature directed the California Department of Health and Human Services (CalHHS) to develop a five-year plan for implementing the statewide mental health crisis and emergency response system. CalHHS has engaged Health Management Associates, Inc. (HMA), to support this effort. Central to this work is hearing directly from individuals who have encountered the crisis system or who may be at greater risk of engaging with the system (e.g., individuals with mental health and/or substance use disorders). The purpose of this focus group is to capture thoughts and perspectives on the Behavioral Health (BH) Crisis System in California.

During this focus group, we are going to ask several open-ended questions that are intended to spark a conversation. There are no right or wrong answers to these questions. We simply want to hear your honest opinions and encourage you to provide suggestions that point toward solutions that improve how we prevent, respond to, and stabilize crisis. You can also simply tell your story to help us better understand your experience. Your comments, suggestions, and stories will be used to identify where we can do a better job. Your input will help redesign the BH crisis system in California. Everything that is said here we treat confidentially. That means we will not identify any individual person or link what you say back to you.

Before we begin our conversation, are there any questions about what we are doing or why we are conducting this focus group?

Experiences During Crisis Response—Equitable Access

California wants all people to be able to locate and ask for help during a BH crisis. The state is committed to designing a system where access or use of crisis services is safe, timely, and available to all the diverse populations that live in our state. We sometimes describe this goal as "equitable access." In this part of the conversation, we want to hear about your experiences accessing or using crisis response services and supports in your local community. We sometimes hear people talking about crisis response as a Place to Call or Someone to Respond. Most often, these include crisis lines, like 988 and or other suicide or mental health crisis hotlines, as well as mobile crisis response teams, law enforcement, or other first responders.

- Think about the last time you accessed a part of the BH crisis system, what sort of response were you expecting and what response did you actually get?
    - Did you call for help or did you physically go somewhere?
    - If you called….
        - Who did you call for help? Was it a 988 Lifeline? Someone else?
        - Was the situation resolved on the phone or was there a response?
    - If a response….
        - Who showed up?
        - How did it go?
        - Where were you taken?
        - What could have improved the experience?

- From your perspective, do you think most people are getting the same quality and access to the crisis system? If not, why not?
    - Probe: What is most challenging or needs improvement?
    - Probe: Which groups or special populations are least likely to get access crisis response services in your local community?
        - Who is most likely to "fall through the cracks" in the current system?
- What would you like to see changed to make crisis response more accessible, safe, timely, and equitable?
    - What do you wish the crisis system understood about your needs and experiences as a person in crisis?
    - Is there something missing that needs to be added or significantly modified to respond to crisis effectively in your community?
    - What would demonstrate to you that your community is improving its response to BH crisis?

Experiences as Part of Crisis Stabilization

Stabilizing crisis is about making sure that individuals who have experienced a crisis have a place to go after a crisis where they receive care. In the short term (24 hours or less), these may include crisis stabilization units (CSUs) as well as newer models like crisis respite and sobering centers. In the medium term (up to 60 days), stabilization often places individuals in residential services that provide partial hospitalization and ongoing treatment. Longer-term (>60 days) stabilization would include placement into psychiatric services for extended care. For this part of the conversation, we'd like to hear about your experiences with obtaining post-crisis care in your local community.

- Think about your experience after a BH crisis. What sort of stabilization or post-crisis care were you expecting and what services and support did you actually get?
    - Where were you taken?
    - How long did you stay?
    - Did you go to more than one kind of facility?
    - How was your crisis transition or "step-down" handled?
    - How would you describe the care you received?

- From your perspective, do you think most people are getting the same quality and access to stabilization or post-crisis services? If not, why not?
    - Probe: What are the main challenges you or your peers experience in getting care after a crisis?
    - Probe: Which groups or special populations are <u>least likely</u> to be able to get stabilization services in your local community? *For example, insufficient stabilization services for youth compared to adults.*
        - Who is most likely to "fall through the cracks" in the current system?

- What would you like to see changed to make crisis stabilization more accessible, safe, timely, and equitable?
    - What do you wish the crisis system understood about your needs and experiences as a person trying to adjust to life after a BH crisis?
    - Is there something missing that needs to be added or significantly modified to crisis stabilization to help people in your community?

Prevention—Public Awareness and Messaging

Thank you for telling us about your experiences with the BH crisis system. Of course, it is critical to provide preventative care. We must make sure that people know how to get help for themselves or others before a crisis happens. In this part of the conversation, we want to hear about crisis prevention, especially how people in your community are informed and educated about BH in your local community.

- How much do people in your community know about crisis prevention services and resources?
    - Probe: peer warm lines that allow someone to talk with someone with lived experience
    - Probe: online or digital self-help tools to get information about BH
    - Probe: harm reduction services like medication for addiction treatment (MAT)
- In your local community, what's been most successful in communicating the importance of preventing crisis?
    - What kinds of messaging would you like to see about BH and BH crisis?
        - Who is a credible messenger for you?
    - Which platforms or media are best for communicating to people like you?
        - Probe: Social media, billboards, TV advertising, etc.
- What resources or support would have helped you avoid needing to access crisis services in the first place?
    - What would demonstrate to you that your community is committed to preventing BH crisis?

Endnotes

[i] California Health and Human Services Agency. Behavioral Health Crisis Care Continuum Plan. May 2023. Accessed May 10, 2024.
[ii] Office of the Governor. Letter to Members of California State Assembly. September 29, 2022. Accessed May 10, 2024.