NAMI
National Alliance on Mental Illness

# CRISIS SERVICES

## Focus Group Study Report

## 2022

# About NAMI

The National Alliance on Mental Illness (NAMI) is the nation's largest grassroots mental health organization dedicated to building better lives for the millions of Americans affected by mental illness. What started as a small group of families gathered around a kitchen table in 1979 has grown into the nation's leading voice on mental health. Today, we are an association of thousands that includes state organizations, local affiliates and volunteers who raise awareness and provide advocacy, education, and support in communities across the United States.


## Importance of 988

988 is the new three-digit dialing code connecting people to the 988 Suicide and Crisis Lifeline (formerly the National Suicide Prevention Lifeline) where compassionate, accessible care and support is available for anyone experiencing or supporting a loved one in mental health-related distress — whether that is thoughts of suicide, mental health or substance use crisis, or any other kind of emotional distress.

The goal of the 988 Suicide and Crisis Lifeline is to provide immediate crisis intervention and support. When someone calls 988, a trained crisis counselor will answer the phone, listen to the caller, understand how their problem is affecting them, provide support and share resources, as needed. Crisis counselors are trained to help in a variety of crisis situations, and no caller is required to disclose any personal information.

NAMI is committed to advancing efforts to reimagine crisis response in our country. A poll conducted by NAMI in partnership with Ipsos in May 2022 found that 9 in 10 people believe those in a mental health or suicide crisis should receive a mental health response, not a police response and over three-quarters of Americans want mental health professionals to be the primary first responders. NAMI believes that every person in crisis, and their families, should receive a humane response that treats them with dignity and connects them to appropriate and timely care. NAMI is calling for a standard of care for crisis services in every community that includes 24/7 call centers that answer 988 calls locally, mobile crisis teams and crisis stabilization programs. This network of services can help end the cycle of emergency department visits, arrests, incarceration, and homelessness.

## Acknowledgements

This research was conducted by The Hannon Group, a market research firm that specializes in outreach to multicultural audiences, on behalf of NAMI and is based on the findings of 24 focus groups conducted between February-March 2022. Participant screening and discussion guides were prepared with input from NAMI staff and an advisory team of field volunteers. Final report was prepared by Nina Richtman, Director of Justice Diversion Task Force and was reviewed by Elizabeth Stafford, Director of Research, Jill Shumann, National Director of Strategy and Impact and Jessica Walthall, Senior Manager, Research. Additional thanks to Jessica Tornabene, Senior Manager, Justice Diversion Task Force, for her insights, edits and inputs throughout the project. This project was possible in part due to generous support from lululemon.

**NAMI**

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NAMI HelpLine: 800-950-NAMI (6264)

Text "NAMI" to 741741 to reach the Crisis Text Line

Facebook: www.facebook.com/NAMI/

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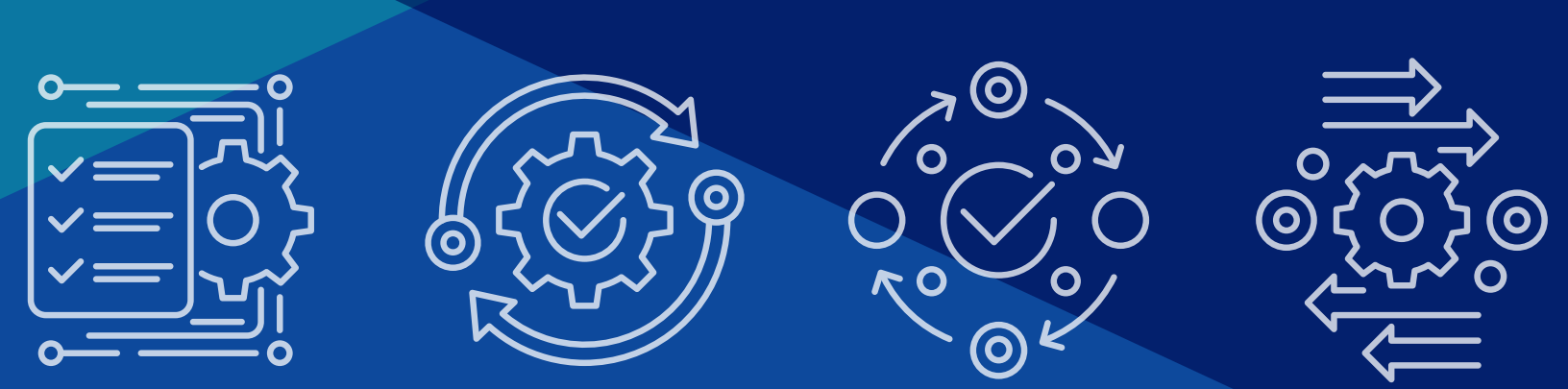

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# METHODOLOGY

The study design consisted of 24 90-minute mental health crisis services focus groups that were conducted virtually. The focus groups were conducted between February 1, 2022, and March 10, 2022. All participants were 18 years of age or older who have personally experienced a mental health crisis or (most notably in the case of parents and family members) those who supported a loved one or family member through such a crisis. Individuals self-identified around the following demographic criteria, and two focus groups, with 8-10 participants per group, were conducted for each of the 12 demographic groups.

1. **African American–** Identifies as Black or African American
2. **Asian American/Pacific Islander–** Identifies as being of Asian, Native Hawaiian or other Pacific Islander descent
3. **Blind/Low Vision–** Identifies as blind or having low vision which was defined as a vision loss that cannot be corrected with glasses, contacts or surgery
4. **Deaf/Hard of Hearing–** Identifies as deaf or hard of hearing
5. **Family members–** Identifies as an adult who supported an adult family member, who is not one of their children, through a mental health crisis
6. **Hispanic–** Identifies as being of Hispanic, Latino or Spanish origin
7. **LGBTQIA2s+–** As defined by answers to screening questions related to gender and sexual identity
8. **Mobility Disability–** Identifies as having a disability that affects motor skills such as walking or manipulating objects by hand
9. **Native American–** Identifies as American Indian (Native American) or an Alaska Native
10. **Parents–** Identifies as a parent that has supported one or more of their children under 18 years of age through a mental health crisis
11. **Veterans–** Identifies as someone who served on active duty in the U.S. Armed Forces, military Reserves, or National Guard
12. **Young Adults–** Someone 18 to 25 years of age who has personally experienced a mental health crisis

Beyond the previously identified 12 cohorts, The Hannon Group recruited a mix of participants based on several other demographic variables, including: gender identity, sexual identity, age, race/ethnicity, community type (urban, suburban, small town, rural), household income, education level, and geography (all U.S. residents).

Due to the qualitative design of the study, the data shared in this report represents insights from individuals who participated but is not representative for all who identify as part of a specific demographic.

# EXECUTIVE SUMMARY

This research project was designed to gain insight into the experiences of people seeking help during a mental health crisis. NAMI engaged individuals who had experienced a mental health crisis or loved ones who supported someone in such a crisis from 12 demographic groups. Focus group discussions concentrated on understanding barriers to crisis services, as well as perceptions and expectations related to the then-upcoming availability of 988. By improving our understanding of the needs and viewpoints of diverse groups related to mental health crises, the information in this report will inform our collective efforts moving forward for providing education, support, and advocacy for those living with mental health conditions. Experiences and opinions shared by participants are reported here, but they do not reflect formal positions of NAMI or its Alliance.

## KEY FINDINGS:

1. **Definition of Mental Health Crisis**

   When participants were asked to define a mental health crisis, participants frequently mentioned themes centered on an acute mental health episode featuring a loss of control where the person poses a threat to themselves and/or others. Breakdown, despair, and hopelessness were also shared as distinctive elements.

2. **Perceptions of Existing Crisis Services**

   When asked about seeking help in a mental health crisis, 911 was volunteered as the number one known resource. Many participants were hard-pressed to volunteer who/which organizations offer "the best services available." They found it far easier to discuss providers of sub-optimal services and primary needs or gaps in America's mental health crisis response services. The level of demand for a better system, and a better provider of such services, cannot be over-stated.

3. **Perceptions and Expectations of 988**

   This study was conducted prior to the implementation and availability of 988, which may have contributed to many participants not knowing about 988. Building awareness and educating the public on the difference between 911 and 988 will be important to help avoid confusion. Callers need to be able to speak with a well-qualified professional, who is trained in crisis response. Participants felt that 988 must have quick connections: limited or no hold times and the services should be free of charge to the user to encourage more people to use the new number*. Protecting the privacy of those who contact 988 was also noted as highly important. Many participants felt strongly that there should be required follow-ups to monitor progress and provide longer-term care for those dealing with mental health crises.

   **Editor's note: There is no fee or charge to call 988, but the feedback does reflect the need to educate the public on this topic.*

4. **Key Differences Between Cohorts**

   While this section focuses largely on differences, key take aways are that training, cultural competency of service providers, language accessibility, and following of Diversity, Equity and Inclusion (DEI) best practices are essential.

# SECTION 1

*"A mental health crisis is when you're unable to take care of your daily needs. It would involve basically having very little control over your executive functioning skills and being able to regulate your emotions."*

– Veteran

*"Mental health conditions reach a point where you're not capable of accomplishing basic functions of day-to-day living and I would say the crisis element is something that it might take a while to progress but the last element of it comes on quick."*

– LGBTQIA2S+ Participant

*"[When in crisis] I start doubting what I'm going through and then looking back later on, you realize how terrible it was."*

– Native American

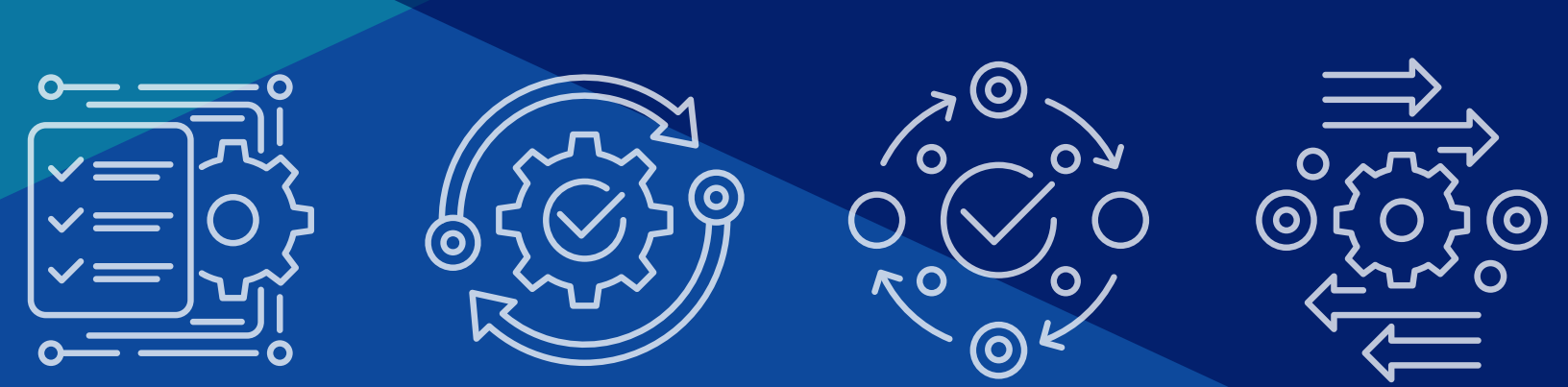
## DEFINITION OF MENTAL HEALTH CRISES

The following are personal accounts and reflections on the following mental health crisis definition tested among participants. The definition of mental health crisis used in this exercise can be found in NAMI's Navigating a Mental Health Crisis guide.

> **NAMI Mental Health Crisis Definition:** "Any situation in which a person's behavior puts them at risk of hurting themselves or others and/or prevents them from being able to care for themselves or function effectively in the community."

When asked to volunteer a definition of a "mental health crisis," most participants offered a description quite similar to the above definition. When read the definition, most participants agreed with the provided statement, thinking it an apt summary of a mental health crisis. Frequently mentioned themes centered on an acute mental health episode featuring a loss of control where the person poses a threat to themselves and/or others. Participants also described a situation where immediate help is needed. Multiple participants offered the word "breakdown" to describe a crisis. Considerations, such as feelings of despair and hopelessness were also volunteered – adding additional context to the behavior-centric element of the definition.

Some participants took issue with the word "behavior," thinking it did not place sufficient emphasis on internal factors/emotions (such as how the person going through the mental health crisis is feeling during such events). A few took issue with "in the community" verbiage, thinking those words were extraneous and that the sentence should end with "effectively". When this sentiment was articulated, others indicated agreement. Those who belong to the Deaf/Hard of Hearing cohort were more likely to focus on the "carrying out daily tasks" element. Veterans emphasized the "emotional breakdown" element. Those in the Mobility Disability community and African American participants cited the "out of control aspect" more frequently than those in other cohorts. Parents were more apt to volunteer the "danger to self" element.



# SECTION 2

> *"The wait time when you're trying to get mental health help can be prohibitive. I remember literally being on a call to schedule an appointment and being told, in a very acute state, that there wasn't anything available for six weeks. You need it now, not in six weeks."*
>
> – Deaf/Hard of Hearing Community Member

> *"Wait lists are insane right now. It's six months to a year just to get therapy or a psychiatrist because everybody is in crisis right now and if you have Medicaid, you aren't going to get fast care. You're wait listed."*
>
> – Family Member

## PERCEPTIONS OF EXISTING SERVICES

When asked about seeking mental health services in a crisis situation, participants volunteered that in the past they sought help from a number of sources. The most commonly reported sources of help sought by participants included family (the most often cited population), friends, therapists, primary care physicians, psychiatrists, psychiatric hospitals, suicide hotlines (including the National Suicide Prevention Lifeline as well as, for Veterans, the Veteran Crisis Line), church and pastors, law enforcement, trauma centers, nurse practitioners, and social workers. Many participants acknowledged that they turned to multiple sources for help, frequently citing frustration with at least one source (e.g., misdiagnoses, long waiting lists for medical appointments, lack of health insurance that covers mental health treatments, being prescribed sub-optimal medications, and the fear of being held under a state's involuntary commitment law.

Regarding the usefulness of help sources, results were mixed. Most participants volunteered at least one unhelpful person, entity, or circumstance, or other barrier to receiving the care they believed that they needed to help resolve their mental health crisis. Those who engaged in talk therapy at some point in their treatment journey tended to indicate that it was helpful, as long as the listener really listened to what they had to say (and provided medical counsel accordingly). There was a widely shared concern that it often **took too long to find the help they needed**.

In general, the help received largely aligned with participants' negative expectations. Participants expected to be passed from professional to professional, have a hard time getting appointments, be unable to afford certain medications, have to deal with excessive paperwork and other barriers that impeded their ability to receive the right assistance as quickly as possible. **In short, mental health crisis response expectations are not, at present, high.**

Organizations noted as helpful received higher marks on responsiveness, offering peer support, being empathetic, and truly listening to those in need.

# SECTION 2

## PARTICIPANTS EXPRESSED SPECIFIC BARRIERS IN:

**Time constraints:** This concern was cited frequently during the focus groups, and often prior to facilitators formally asking about barriers to care, and specifically refers to delays in the ability to meet with health care professionals due to long wait times. Those experiencing mental health crises need help immediately, not weeks later.

**Language/communication:** Participants mentioned that resources are often not available in languages other than English, such as Spanish, and that resources are also needed in American Sign Language.

**Financial:** Participants reported that the costs of appointments and treatment, including prescription medication, are often excessively high/prohibitive.

**Privacy concerns:** Although participants did not frequently mention privacy concerns, those that did tended to describe them when discussing the arrival of law enforcement at their homes (i.e., not wanting neighbors to know that someone is undergoing a mental health crisis). Participants also mentioned privacy concerns related to using online chats (i.e., reduced anonymity via the identification of their IP address).

**Involvement of law enforcement:** This concern was mentioned among a number of cohorts. With the notable exception of Veterans, most cohorts/participants agreed that law enforcement personnel are generally not well trained to resolve mental health crisis situations.

*"I was having a mental health crisis due to my classes and it was obvious that my GPA was falling. I really felt like talking to somebody about that but I was reluctant going to my school therapist. I know that they have a privacy policy but I can't trust it. I really didn't want to reveal information that was going to go to the Dean of Students and then I'll be in trouble."*

– Young Adult

## WHEN ASKED ABOUT RESOURCES THAT WERE NOT UTILIZED AND WHY, THE FOLLOWING WAS SHARED:

**911**: Of the known resources that focus group participants were aware of but opted not to use – 911 topped the list. Participants provided many reasons why individuals may not receive adequate help by calling 911, including a perceived lack of empathy from 911 dispatchers and a lack of training in responding to people in a mental health crisis. A majority of participants considered calling 911 to be a bad idea because of its association with law enforcement, and the potential for negative outcomes, such as arrest or officer use of force against them. Several participants had positive things to say about past interactions with law enforcement and how they responded to a mental health crisis, highlighting a wide variation in experiences or perceptions. This sentiment aligns with findings from the May 2022 poll: less than a third of those who sought help from the police/911 during a mental health crisis received all the help they needed. Participants also mentioned the disproportionate impact of policing on African American and Hispanic communities, and the increased risks they might face during a mental health crisis. They also expressed other apprehensions including not wanting to be embarrassed by a heavy police presence arriving at their dwelling, fear of arrest or incarceration, fear that child protective services might be called, and the trauma their children might undergo seeing a family member or parent being treated poorly.

# SECTION 2

**Hospitals:** Some participants mentioned fear of being institutionalized as a reason to not go to a hospital when one is experiencing a mental health crisis.

**Church:** A handful of participants thought that their churches were either too judgmental or that they offered generic or nonapplicable advice that does not fit their needs.

**VA Hospitals:** Veteran participants were very critical when it comes to VA hospitals. Participants were dissatisfied due to long referral times, poor treatment and a dearth of patient advocates leading to overall feedback that participants viewed the VA as a sub-optimal solution when people are experiencing mental health crises.

**Suicide hotlines:** Multiple participants described two main reasons why they avoided suicide hotlines in the past: first, that their crisis doesn't rise to the level of being suicidal, so they felt such a line "isn't for them;" and second, that they feel the people on the other end of the line do not have the expertise to help them and/or aren't really listening to what they have to say.

> *"They [law enforcement] are not trained to handle mental health crisis. They're not counselors. They don't appreciate that you're going through something where you're going to hurt yourself. If nobody else is involved, they really don't act like they care."*
>
> – Deaf/Hard of Hearing Community Member

> *"I would fix insurance because I have financial difficulties paying for my insurance and making sure that I can see a mental health professional, and so it has to do with this country and how they deal with people that have crises or people that are homeless and they have to have a place to go."*
>
> – Asian American/Pacific Islander Participant

# SECTION 3

*“I think it will be wonderful because instead of necessarily calling the police or being afraid of calling the police because of what might happen, now there’s this other number that you can call, call quickly and hopefully have a resource that’s familiar with how best to handle the situation.*

– Family Member

*“I would expect there to be a variety of specialties that the professionals focus on and I would expect there to be almost just like a classification intro when you first call just to get an idea of, number one, what the patient prefers but also, number two, what area would be best for them to talk to in terms of counselor.”*

– Blind/Low Vision Community Member

## PERCEPTIONS AND EXPECTATIONS OF 988

As of early 2022, at the time of data collection for this report, awareness among the study participants of 988 was extremely low. This lack of awareness was unsurprising insofar as the number was not yet available nationwide. Polls conducted by NAMI from 2021 and 2022 reflected a similar lack of awareness from the general public. A handful of focus group participants indicated that they had seen, read, or heard about 988. Of them, only a couple were able to offer a semi-detailed explanation of 988.

When asked for their initial thoughts, most participants raised questions as opposed to expressing firm opinions about 988. Frequently asked questions centered on the qualifications of the mental health crisis counselors, if any costs would be incurred for using it, and how 988 would be different than 911. There is widespread agreement among participants on the most significant barriers to contacting mental health professionals during a crisis. Across many cohorts, participants cited barriers such as cost, insurance, long wait times/ limited access, being prescribed medication that doesn’t work, and concerns over the involvement of law enforcement in mental health crises. *Editor’s note: Data was collected prior to 988 implementation. Support and services received from 988 are provided at no charge.*

Regarding the initial thoughts on 988, those in the Mobility Disability community were more likely to volunteer a first impression, that the number is easy to remember. Parents want to know the training and background of the mental health counselors working with 988 as well as their specializations such as experience working with various age groups.

When asked their expectations and hopes for 988, focus group participants, frequently mentioned the importance of being responsive (i.e., no hold times or very brief hold times). In terms of the crisis counselors answering 988 calls, the participants wanted to experience empathy and greater cultural competence compared to existing mental health crisis resources they had experienced. Participants expressed wanting 988 counselors to use best practices in diversity, equity and inclusion (DEI), that confidentiality should be a priority, and that callers should be able to be referred to or made aware of local services.

# SECTION 3

Participants expressed that calling by telephone was the preferred means of contacting such a service. There was a feeling expressed by those who opted for calling that texting takes too long or may be subject to misinterpretation, was too impersonal, or not secure. That said, some participants indicated that they would prefer text or online chats (for the latter, participants expressed that video conferencing would be ideal). Those who preferred texting cited accessibility advantages or greater comfort using that medium. A couple of participants preferred online chats with video capabilities (like a Zoom conference) so they could talk and/or type if they wanted while actually seeing the counselor with whom they are engaging. Language accessibility was identified as being important. Participants hoped for services to be provided in a variety of languages - including spoken language as well as American Sign Language (ASL). Minimal hold times, no need to push multiple menu buttons to reach someone, and live, well-trained, and empathetic mental health counselors (no bots) were also mentioned as important 988 contact considerations.

*"Texting takes away some of the anxiety-- I mean other than my specific family, I text more than I talk on the phone. It would make a huge difference to me."*

– Deaf/Hard of Hearing Community Member

*"I feel that texting would just be more aggravating because you don't know when you're going to get a response like how long it's going to take or if they read your text but then they don't respond for like seven days later."*

– Asian American/Pacific Islander Participant

*"Calling is just easier for me to just get it all out there and then they can hear me and we can just have an actual conversation that way."*

– African American Participant

In terms of demographic specific preferences, Parents and Veterans were the cohorts most likely to indicate that they would prefer to call using the telephone for such crises. Those in the Deaf/Hard of Hearing community were more likely than the other groups to prefer online chats. Native Americans and those in the Mobility Disability community were among the groups most likely to volunteer texting as the preferred communications method. Young Adults, interestingly, were split. A majority of this cohort opted for telephone calls with a minority indicating their interest in texting for such purposes. Family Members were more likely to express concerns about texting (e.g., no human touch, takes too long to type things out).

## THOUGHTS ON 988 SYSTEM COMPONENTS:

Focus group participants were asked about the key components of 988 systems: 24/7 crisis call centers , mobile crisis teams, and crisis receiving and stabilization options. Participants were read and visually presented the following descriptions and asked for their feedback.

### COMPONENT 1: 24/7 Crisis Call Centers

**Focus groups were read the following quote and asked to react to the information.**

**"**In an ideal system, 988 should include 24/7 crisis call centers, someone to talk to. All calls to 988 should be answered locally by staff who are well-trained and experienced in responding to a wide range of mental health, substance abuse, and suicidal crises. Crisis call centers should be able to connect people to local services, including dispatching mobile crisis teams and scheduling follow-up appointments with local providers."

Most participant responses to this system component were positive, but somewhat cautious. In general, the local element particularly resonated with participants. The promise of follow-up appointments also was well-received. The "wide range" of help was seen as a distinct plus. The "24/7" element was viewed favorably. A handful of participants voiced concerns, including the availability of follow up services and the involvement of law enforcement if

*"I would imagine the best possible experience would be to connect me to the service that I need at that point in time without having me become more symptomatic, so also without questioning insurances and all of that, just to get me to where I need to be or whoever I need to be with and then ask questions later as far as insurance and things of that concern. But I would like the best possible service to [involve] sensitivity and privacy."*

– Mobility Disability Community Member

**Editor's Note: Insurance information is not requested when calling the Lifeline.*

*"The fact that you can talk to that initial person that you call for as long as you need to is really valuable."*

*– Asian American/Pacific Islander Participant*

*"I like where it says about should be closely collaborating with law enforcement. Officers everywhere already have enough things going on that trying to connect one police officer to every situation is going to be more of a problem to law enforcement than it probably should. But especially for high-risk situations, of course, that's important."*

– Veteran

mobile crisis teams were dispatched. There was also some concern that local providers would not be available. This feedback speaks to the concerns with the high degree of variability of services community-to-community and the need to clarify what services are available in a given jurisdiction.

When asked what the best possible outcome could be when connected to a mental health crisis counselor, the focus group participants volunteered several potential outcomes:

- No (or at least minimal) law enforcement involvement
- Diverse, culturally aware, and DEI-informed counselors reflecting a variety of backgrounds should be available
- The counselors should connect the caller with local resources
- Follow-ups from the counselors would be ideal
- Staff should be available to arrive on scene and help de-escalate situations
- Veterans still need to have their own line
- Experienced, trained, well-credentialed counselors from a variety of specialties would be available to speak with callers
- Counselors should be available who speak (fluently) languages other than English, such as Spanish and ASL
- Needs to communicate that the line is for those undergoing a mental health crisis even without the presence of suicidal ideation
- The simple, easy-to-remember number is helpful

## COMPONENT 2: Mobile Crisis Teams

**Focus groups were read the following quote and asked to react to the information.**

**"***In an ideal system, 988 should include mobile crisis teams, someone to respond. These teams should be available for people in crisis who need more support than can be offered over the phone. Staffed by mental health professionals, including peers, these teams can de-escalate crisis situations and connect a person to crisis stabilization programs or other services. Mobile crisis teams should collaborate closely with law enforcement, but only include police as co-responders in high-risk situations."*

Participants were generally positive about the idea of utilizing mobile crisis teams, especially the team composition of mental health professionals and peers. Parents expressed concerns about the peer verbiage, thinking it would not apply for children who are experiencing mental health crises. However, the final sentence on this system component raised concerns. While some (most notably Veterans) had fewer issues with law enforcement involvement, others stressed the importance of law enforcement playing only a limited role. One key question raised by participants: who decides when a situation is high risk? Blind/Low Vision community members indicated their support – although a bit tentatively so – for the idea of limited law enforcement engagement for high-risk situations only. With fewer caveats, some Blind/Low Vision community members also stated their backing of mobile crisis response teams. This feedback indicates a need for more clarification for the public of the role of law enforcement, and how those decisions will be made in a crisis situation.

# SECTION 3

*“I just think [warm hand-off] is open to a lot of interpretation and if I’m considering seeking help or resources, I want it to be clear and concise and just direct and I want it to be like, okay, we’ll provide resources for follow-up care and it’s from these people.”*

– Young Adult

*“Warm hand-off, for me that means that if we’re going to connect me to someone else, it’s not going to be just connect me to the person and drop the call. You’re going to stay on. I’m assuming you’re going to tell them what’s going on and then you’re actually going to speak to the next person that you’re being connected with.” – Family Member to man a hotline like this.”*

– Family Member

## COMPONENT 3: Crisis Stabilization Options

**Focus groups were read the following quote and asked to react to the information.**

“In an ideal system, 988 should include crisis stabilization programs, somewhere to go. Some individuals in crisis will need more assistance that provides short-term observation and stabilization. These trauma-informed programs may also identify additional treatment needs and provide a “warm hand-off” to follow-up care, from peer supports and outpatient services to more intensive services, such as hospitalization.”

Participants supported the “trauma-informed” component of the statement and supported somewhere to go, as a positive attribute, although they would like assurances and clarification that “somewhere to go“doesn’t mean being involuntarily held or institutionalized. The idea of a “warm hand-off” was generally viewed in a favorable light insofar as it meant that the mental health counselors would play a role in getting the help seeker the help they needed. However, some found the expression off-putting, as if it meant “passing the buck”. This feedback suggests a disconnect between industry/provider language (like “warm hand-off”) and understanding from people using the services.

Participants raised questions about cost (who will pay for any stabilization center or hospital stays?) as well as if the infrastructure would allow for such a treatment approach, expressing concerns that many facilities are already limited in their capacity. Veterans reacted particularly favorably to this service component, thinking it a personalized, thorough, and comprehensive mental health crisis response solution. The follow-up care verbiage tested particularly well among Hispanic focus group participants. Some Native American participants deemed it to be a “holistic” approach with the creation of new resources, which was seen as positive.

## Success Indicators of 988:

**A variety of factors would, in the minds of the focus group participants, indicate that 988 is a success, including:**

- Reduced wait/hold times
- Getting the help people need, quickly
- A decrease in suicides, self-injury cases
- Accessibility in multiple languages
- Fewer people in psychiatric wards
- Understanding the specific needs of the person seeking care
- Follow-up after the call
- Awareness, utilization of local resources
- Transparency (on costs, on law enforcement involvement)
- More calls coming in (increased utilization of hotline services)
- Reduced mental health illness stigma

# SECTION 3

*“I would say the primary thing that it would really need to have for me personally to be useful would be follow-up care, case management, not just temporary one-off crisis management.”*

– Native American Participant

*“Transparency on who is being involved as far as mental health professionals, what is the training and how are they going to interact with people in the marginalized communities is important.”*

– Mobility Disability Participant

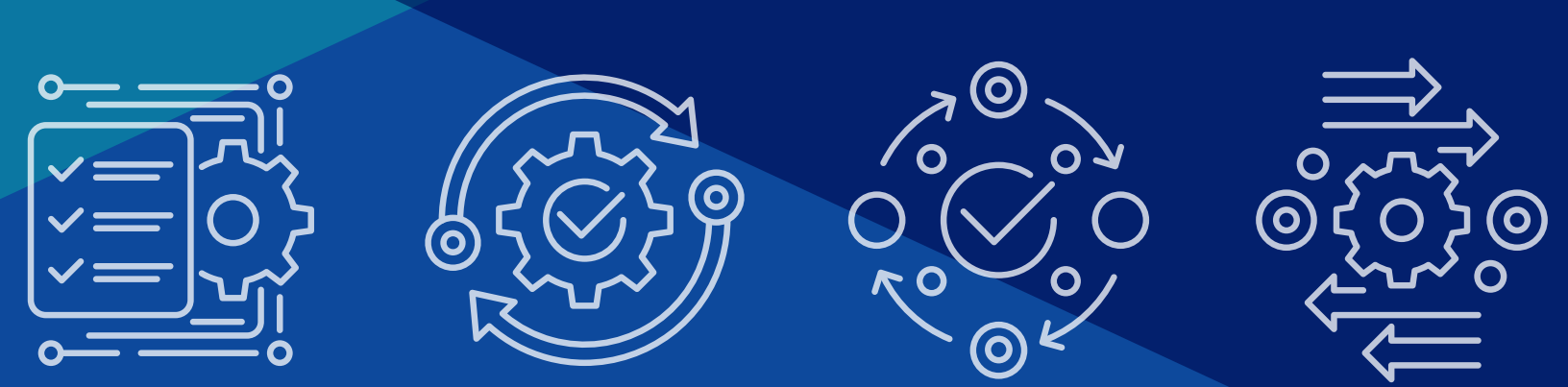
*“It’s pretty well known that mental health care is dominated by white women dominated by white women and what white men. There needs to be communication that the folks who are providing services come from diverse backgrounds and have diverse perspectives and that that should be a priority for the folks who are doing the hiring is making sure that the people that are answering the phone have diverse backgrounds.”*

– Native American Participant

- Long-term tracking of key analytics (people following up to access services, success of de-escalation techniques)
- Hiring of trained staff
- More health care treatment options, less institutionalization
- Success stories from those who contacted 988

Most participants agreed with the statement that 988 would be effective for people in a mental health crisis. Having trained specialists providing aid and reducing the role that law enforcement plays in responding to such crises are plusses. Being a shorter, easier-to-remember number alone should, in the minds of the focus group participants, make 988 more effective than past and some current mental health crisis service hotlines. Most participants believed that the line would be effective for those dealing with mental health crises, this was seen across the various cohorts.

Parents emerged as the most skeptical cohort, stating that it depended on the quality of the person answering the call and/or the situation. Family Members were also more likely to mention the expertise/credentials of the person answering the line as important considerations when asked about their confidence in the line’s ability to help those dealing with such crises.



# SECTION 4

## KEY DIFFERENCES BETWEEN COHORTS

### AFRICAN AMERICAN

**Compared to other cohorts, those in the African American cohort are more likely to:**

- Cite the "out of control aspect" of a mental health definition more frequently than other cohorts
- Mention concerns over being judged by others (family, their church) as barriers to receiving mental health crisis response support
- Volunteer friends as the resources to whom they turn most often
- Remark on positive experiences with outpatient therapy
- Be split on the role of law enforcement as mental health crisis responders. Some were very opposed while others noted quick response times or empathetic officers (e.g., quick to respond, empathetic)
- Focus on negative experiences with the current Suicide Hotline (e.g., feeling dismissed, no follow-ups)

### ASIAN AMERICAN/PACIFIC ISLANDER

**Compared to other cohorts, those in the Asian American/Pacific Islander cohort are more likely to:**

- Volunteer therapists/psychiatrists as sources of help to whom they reach out
- Say that therapists do a good job in terms of helping them assess and sort through their feelings
- Believe that privacy-related issues (the stigma attached to mental illness; the potential impact on their reputation if their issues were known to others) are salient concerns
- Voice their support for improving health insurance coverage of mental health issues
- State their expectation that 988 staff will be well-trained and represent multiple specialties compared to the other cohorts
- Indicate that the 988 mental health counselor training is a particularly important factor in their decision to use such a service

# SECTION 4

**BLIND/LOW VISION**
**Compared to other cohorts, those in the Blind/Low Vision cohort are more likely to:**

- Voice privacy concerns more frequently
- Identify that finding the right therapists (quickly) and getting the right medication(s) as particular barriers
- State the importance of mental health counselors receiving the proper training
- Cite the importance of being connected with local resources when dealing with a mental health crisis
- Indicate their support, even tentatively so, for the idea of limited law enforcement engagement for high-risk situations only. With fewer caveats, they also stated their backing of mobile crisis response teams.
- Cite reduced suicides as an indicator of 988 success
- Suggest avoiding number-based telephone menus

**DEAF/HARD OF HEARING**
**Compared to other cohorts, those in the Deaf/Hard of Hearing cohort are more likely to:**

- Focus on the "carrying out daily tasks" element of a mental health crisis definition
- Cite their frustration with long wait times to get mental health help
- Identified law enforcement officers should never be involved in cases involving mental health crises
- Prefer online chats as a preferred means of communication
- State that texting, TDD, closed-captioning or video-related options would be helpful
- Cite reduced suicides as an indicator of 988 success

**FAMILY MEMBERS**
**Compared to other cohorts, those in the Family Member cohort are more likely to:**

- Express concerns about texting as a preferred means of communication
- Cite the importance of being connected with local resources when responding to mental health crises
- Volunteer that limited or no hold times (a fast response when contacted) would constitute a measure of 988 success
- Mention the expertise/credentials of the person answering the line as important considerations when asked about their confidence in the 988 line's ability to help those dealing with such crises

**HISPANIC**
**Compared to other cohorts, those in the Hispanic cohort are more likely to:**

- Mention insurance costs, language barriers, and concerns regarding immigration status when discussing issues faced when seeking help for mental health crises
- Cite insurance as a past barrier to receiving mental health crisis support
- Voice fears regarding contacting 911 for help in response to a mental health crisis
- State the importance of being connected with local resources when facing a mental health crisis
- Highlight the importance of language inclusivity and cultural sensitivity

**LGBTQIA2S+**
**Compared to other cohorts, those in the LGBTQIA2S+ cohort are more likely to:**

- Mention negative experiences with law enforcement when experiencing a mental health crisis
- Lists specific groups, as positive for mental health resources, known for their work in their community (e.g., The Trevor Project, PFLAG, the Trans Lifeline, the Human Rights Campaign, and the LGBT Task Force)
- State the need for more training on empathy among those who respond to mental health crises
- Vocalize the expectation that the service/responders act in a professional, empathetic, and non-judgmental manner
- Focus on care and compassion as to what they would hope for when connected to a mental health counselor, genuine concern and someone who can provide them with help, quickly
- Cite the importance of 988 being gender-affirming and inclusive in communications

**MOBILITY DISABILITY**
**Compared to other cohorts, those in the Mobility Disability cohort are more likely to:**

- Cite the “out of control aspect” of a mental health crisis definition
- Volunteer the lack of help received from primary care physicians
- Mention the frustration with the time lost trying to find the right therapist and/or the right medication
- State financial barriers/issues with insurance as reasons why they were not satisfied with the help they sought out
- Cite insurance as a past barrier to getting mental health crisis help
- Volunteer that the 988 number is easy-to-remember
- Indicate having issues when calling the National Suicide Prevention Lifeline, mentioning “arguments” with, and not being taken seriously by, the counselors with whom they communicated
- Volunteer texting as the preferred communications method

# SECTION 4

**NATIVE AMERICAN**
**Compared to other cohorts, those in the Native American cohort are more likely to:**

- Mention cultural competence as a significant barrier to receiving help for a mental health crisis
- Volunteer texting as the preferred communications method
- State that the follow-up component of mental health crisis response care is a particularly important element
- Indicate their willingness to advocate for 988 services to come to their state as soon as possible
- State the importance of simply providing more people with the tools they need to help deal with mental health crises

**PARENTS**
**Compared to other cohorts, those in the Parents cohort are more likely to:**

- Cite the "danger to self" part of a mental health crisis definition
- Mention school therapists as known resources whose help is nonetheless not sought out (privacy-based concerns)
- Be split on the role of law enforcement with one of the Parent groups vehemently opposed while the other reported some positive experiences (e.g., quick to respond, empathetic).
- Volunteer emergency rooms as places where they have gone but were disappointed in the help they received
- Want to know the training of the 988 mental health counselors. They also want to know more about the specializations they have, including working with various age groups.
- Volunteer the importance of de-escalation skills
- Indicate that they would prefer using the telephone for such crises
- Express concerns about the peer verbiage, thinking it to be not tailored for children who are experiencing mental health crises
- Indicate an interest in obtaining resources for parents
- Mention increased utilization of the 988 line as evidence of success
- Be the most skeptical cohort, stating that 988 efficacy depended on the quality of the person answering the call and/or the situation

**VETERANS**
**Compared to other cohorts, those in the Veterans cohort are more likely to:**

- Emphasize the "emotional breakdown" element of a mental health crisis definition
- Mention Post Traumatic Stress Disorder (PTSD) and medication mismanagement by the VA as particular concerns
- State that they found the Veterans Crisis Line helpful when going through a mental health crisis

- Volunteer a lack of responsiveness when they sought help from healthcare providers (e.g., overwhelmed systems, no follow ups)
- Cite the VA as a source for help of which they are aware but are less likely to reach out to for a variety of reasons (e.g., uncaring, referral process takes too long)
- Have a positive impression of law enforcement and how they respond to mental health crisis situations
- Volunteer the importance of greater cultural competency as a significant need for veteran community
- Need to be reassured that they will still have a dedicated Veterans Crisis Line
- Agree that the Veterans Line helped in terms of being able to discuss their issues at length while receiving good advice ("they had the right things to say to get me out of that mind frame")
- Indicate that they would prefer to call using the telephone for mental health crises
- Volunteer fellow veterans as optimal champions/validators

**YOUNG ADULTS**

**Compared to other cohorts, those in the Young Adults cohort are more likely to:**

- Volunteer school therapists as a known source that is not sought out, citing privacy-based concerns
- Voice fears regarding contacting 911 to help respond to a mental health crisis
- Suggest improving mental healthcare access through lower costs as a means of reducing or eliminating barriers to mental health crisis response services
- Indicate both telephone calls and texting as preferred communications methods when dealing with a mental health crisis
- Felt it was particularly important for 988 crisis counselors to help with a wide range of crises

# SECTION 5

## PATH FORWARD

The results of these focus groups will support the ongoing conversation around how to best serve those who seek care during a mental health crisis. NAMI is actively working to build a mental health crisis response system that works for everyone, no matter what their background, income level or disability status to get the care they need. While the feedback represents only a snapshot in time, prior to the implementation and nationwide availability of 988, the information provides insight that can be considered by a variety of stakeholders working to create a robust, culturally competent care system for mental health crises in months and years ahead.

**Additional Resources:**

Public Opinion on 988 and Crisis Response (2022)

Public Opinion on 988 and Crisis Response (2021)

988: Reimagining Crisis Response | NAMI: National Alliance on Mental Illness

Divert to What (nami.org)

NAMI
National Alliance on Mental Illness

988
IS NOW AVAILABLE
NATIONWIDE

## FOCUS GROUP PARTICIPANTS SHARED THESE MAIN CONCERNS ABOUT USING THE 988 NUMBER:

- Qualifications of the mental health crisis counselors
- Cost for utilizing*
- How 988 would be different than 911

** Data was collected prior to 988 implementation. Support and services received from 988 are provided at no charge.*

## FOCUS GROUP PARTICIPANTS HAVE THE FOLLOWING HOPES/EXPECTATIONS FOR 988:

- **More empathetic and show greater cultural competence compared to existing resources**
- **Calling by telephone but also text or video conference option available also**
- **Improved language accessibility- including spoken language as well as American Sign Language (ASL)**
- **Minimal hold times, no need to push multiple menu buttons**
- **Live, well-trained, and empathetic mental health counselors (no bots)**
- **Local services available for referral and connection**

## FOCUS GROUP PARTICIPANTS STATED THAT THESE BARRIERS KEEP PEOPLE FROM CONTACTING MENTAL HEALTH PROFESSIONALS IN A CRISIS:

- **Concerns over law enforcement involvement**
- **Long wait times/limited access**
- **Being prescribed medication that doesn't work**
- **Cost/Insurance limitations**

## FOCUS GROUP PARTICIPANTS PREFERRED THE FOLLOWING MEANS OF COMMUNICATION FOR 988:

- **Phone call (91 votes)**
- **Texting (46 votes)**
- **Online chats/video conferencing (40 votes)**