



Utah Department of
Health & Human
Services

Utah's 988 Consumer Engagement Summary

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EXECUTIVE SUMMARY

This document shares responses from various focus groups, conducted in Utah, to help inform development and deployment of the 988 crisis line and the overall crisis system. It includes key findings associated with the type of help individuals seek when they call a crisis line and ideas about ways help should be provided. Based on shared experiences across community groups, a list of twelve recommendations are provided for the 988 crisis line and the crisis system. These recommendations are listed at the end of this report.

INTRODUCTION

Utah is transitioning from the 10-digit National Suicide Prevention line to 988, the three-digit suicide and prevention lifeline. This transition is in accordance with National Suicide Hotline Designation Act of 2020, which requires all telecom providers to activate the three-digit number by July 16th 2022. This rapidly approaching transition draws comparisons to the creation of 911 for access to public safety services. 988 will provide immediate access to the crisis line as well as a bridge to a continuum of services in Utah including statewide Mobile Crisis Outreach Teams and a developing network of Receiving Centers. To develop a comprehensive and effective system, administrators, stakeholders, and providers must understand crisis needs, effective services, barriers to seeking or receiving help, and ideas for overcoming barriers from a variety of consumer perspectives. Furthermore, administrators need to know how to best "get the word out" about crisis services statewide in a way that is responsive, culturally respectful, and linguistically competent.

To support this effort, a research team from Utah's Division of Substance Abuse and Mental Health conducted eight focus groups with consumers of crisis services and other stakeholders. Focus groups were held between July 2021 and October 2021. The purpose was to learn about crisis needs, barriers, and solutions from a variety of different perspectives.

PARTICIPANTS

Representatives from a variety of potential user-groups that have traditionally been underserved or underrepresented participated. Focus groups were held with the following groups:

1. [Rural law enforcement and crisis responders](#)
2. [Youth of Utah Advocacy Coalition](#)
3. [Parents of children with disabilities](#)
4. [Black Lives Matter Utah](#)
5. [Crisis service providers with Utah Strong](#)
6. [Utah's refugee population](#)
7. [Providers from Utah Navajo Health Systems](#)
8. [Utah's LGBTQ+ community](#)

Participants in these groups included representatives from rural, youth and young adult, disability, LGBTQIA and Black, Indigenous and People of Color (BIPOC) communities.

METHOD

Focus groups were facilitated by small teams of researchers and administrators. Participants responded to questions addressing six key topics during the focus groups. Surveys with the questions were also emailed to participants after the session and to participants who signed up for focus groups but were unable to attend. The six key topics were:

Problems	Awareness about crisis resources
	Unique crisis needs
	Barriers or challenges with current resources
Solutions	What an ideal crisis line would look like
	Ways to make a 988 line effective in the community
	Ways to connect with underserved groups

Focus group discussions were recorded and transcribed into text records. The text records were coded into themes, some of which are summarized in this document.

Anything included in this document is a topic that was addressed by participants in three or more of the eight focus groups but not necessarily addressed by three or more of the five communities. See Appendix 1 for common themes across focus groups, and Appendix 2 for recommendations and challenges unique to specific communities.

For the purposes of brevity, clarity and anonymity, direct quotes are not used. Consumer voice is summarized and indented to the right as well as italicized. For example:

Mental health crises can become disasters if we don't know enough, don't prepare enough, and don't set callers up for success more than we are right now.

FINDINGS

During focus groups, topics of suicide and suicide intervention were discussed less often than were factors upstream from suicide. Much of the conversation revolved around drivers of suicide such as lack of basic resources such as housing and food, mental health symptoms such as anxiety and depression, and the need to connect to people and resources.

I think reframing [what a mental health crisis is] to include depression, anxiety and feelings of self-harm would help. During COVID people were really alone, especially as school went online.

So, having that resource [like a mental health crisis line] would have been key, as well as knowing that it could do more than just help if you were feeling suicidal.

Other conversations were focused on a larger mental health continuum that would include a crisis line.

So, if you're talking about the ideal [mental health] emergency system, it would be to have a continuum of care available within every county.

It was apparent that ideas about what crisis is and what people in crisis need have to be collaboratively developed with consumers with firsthand crisis experience.

You don't really get to decide what my crisis is.

Overall, Utah's focus group responses aligned with the needs described in the National Alliance on Mental Illness's brief, [988: Reimagining Crisis Response](#). Based on the focus groups, when Utahns call a crisis line, they are most likely looking for someone to talk to, somewhere to go for treatment, or someone to respond to an urgent situation. These needs are outlined in the following section from the perspective of the consumers.

NEED ONE: SOMEONE TO TALK TO

Across focus groups, the need that emerged most often was for someone to talk to; participants wanted someone who could provide the caller with information and emotional support but not necessarily initiate further action.

What I would like is a little 411 [information], I would like to be directed to the right person or the right place.

If I just want someone to listen, then that should be it, it should not be escalated.

The need for information was often precipitated by the need for basic resources during situations in which callers were unable to come up with their own solutions.

There are a lot of crises that you don't need therapists for. Like needing to get food, to get housing, finding places that will help pay for medical care.

When I had my crisis, I didn't think things through, so I needed a way to get clothes.

It is unsurprising that people in low resource situations need help navigating and connecting to available resources. This is due to a well-established cycle in which lack of resources increases stress and the increased stress reduces the brain's ability to make decisions and process information.

When you're in a crisis, you can't think of solutions. It might seem easy to other people. But you're not thinking when you're in the crisis. So for me, when I can't think to come up with the solution, I want for somebody who is in their right mind to give me some options.

211 is a local service provided through the United Ways of Utah. This service connects community members to resources including housing and utilities, food, legal aid, employment and more.

Collaboration between 988 and 211 was recommended by consumers but there were also concerns about some outdated information in the 211 system.

To even say that 211 exists on a 988 call could be helpful.

We had issues because some of the 211 information was outdated. A lot of time you call and the resource doesn't exist anymore.

Another key need was for someone to talk to, even if the issue didn't rise to the level of crisis at that moment.

People need attention, everyone needs attention. And so I think when you're presenting this idea of a crisis line you to youth, let them know that this is a place that can give them attention when they need it. Offer that so youth don't feel that they have to go to the drastic of routes that we talked about [such as self-harm and suicidality].

What ideal service delivery looks like: someone to talk to

A number of crisis service users described less-than-ideal responses from past experiences when calling for help during crisis.

And they'd be like, "Oh, we can only speak for a certain amount of time" and after that you kind of have to deal with it on your own.

The big question that I have when I get really strongly suicidal is, why is suicide such a bad thing? Why does society put so much effort into prevention efforts? But you cannot ask that on a crisis line. Because they hang up on you.

These situations highlighted a desire for crisis line services, as well as 911 dispatch, to provide a broad range of services, with linguistic competence and with compassion.

Linguistic competence typically brings to mind services in the service recipient's preferred language. However, linguistic competence also includes understanding that [stress can divert resources away from the expressive speech center in the brain](#). These brain changes may [reduce overall speech fluency](#), result in flat affect and other [typical expressions of emotion](#), or cause a caller to [switch to their native language](#). Respondents shared experiences of disrespectful treatment, not having enough time to communicate needs, or being disconnected from calls due to speech markers that can be impacted by stress.

She [the participant's mother] was nervous so her accent came out. And the 911 operator started making fun of her accent. Saying 'tell me clearly, please. I don't understand. You don't know English.' He was totally rude.

[A young adult with disabilities] needs someone that's going to wait, like a minute, for him to answer a question, but they don't wait and he can't connect.

I've had people hang up on me. I don't know if it's just because my communication skills tank or because I get a flat affect. My best guess is that they thought I was trolling them but I've had them actually hang up on me.

When asked about the minimum standard for responses to crisis calls, most focus group participants suggested that a compassionate response was crucial to providing the needed support.

Kindness is everything.

Unfortunately, several participants had experienced a lack of compassion when calling a crisis line. Those experiences did not help to resolve the crisis.

What I've heard from clients that used to call the crisis line was that people would be rude to them.

No matter what the motivation for calling is, even if you're a troll, don't despise us. Don't despise the person for calling.

I mean, what percentage of crises are from people sucking? So when you call out for help, and the people suck, it all sucks.

NEED TWO: SOMEWHERE TO GO

When consumers reach out for help in a crisis, they may be seeking solutions to complex and co-occurring needs. These consumers need an appropriate place to go for acute mental health treatment, as well as connections to long-term solutions.

I wish there was a place, you know, really to go.

Although medical services (emergency rooms, hospitals and clinics) are often used as a place to go during mental health crises, consumers did not view these services as effective.

It is a constant circle, go to the ER, nothing really happens and you don't get help, and then you go back home and things are calm for a week, and then it starts back around again.

When you go to the emergency room, you sign a paper with their emergency plan, their safety plan that you're going to follow. And then they send you home with that paper that they've signed and you're right back into a cycle, with no real solutions.

In some cases, encounters with medical facilities were seen as exacerbating the crisis.

[A young mother of color taken to a clinic during a panic attack] was very stressed and anxious about getting back to her children, but she wasn't allowed to because she was stuck at this clinic until the medical team passed her off to be discharged. And because she expressed her anxiety about getting back to her children, they kept saying, nope, she's aggressive, she's not safe to be around her children. So it spiraled.

And when the police came [after calling a crisis line for help], they said they were going to take me to the hospital. I said, please don't, because I don't have insurance, I'm living under the poverty level and that's going to make everything worse. I had no option, I had no choice in the matter, they dragged me there.

In the worst-case scenarios, consumers described individuals arrested and taken to jail during mental health crises.

[A young man with physical and developmental disabilities and mental health diagnoses] was arrested and put in the medical unit in County Jail. However, they didn't give him his meds, he had seizures and they released him in the middle of the night. When we picked him up, he was bruised from head to toe, because he had seizures in jail and had fallen off the bed or whatever. Jail is not a place for someone like him.

One place mentioned repeatedly as providing the support needed by some consumers was the University of Utah's [Huntsman Mental Health Institute](#) (HMHI). HMHI (formerly known as "UNI" and still referred to as such by focus group participants) provides inpatient psychiatric care for adults, children and teens and is the Mobile Crisis Outreach Team provider in Salt Lake County. Unfortunately, this resource was viewed as a high barrier resource, accessible primarily to people living on the Wasatch Front and not available to those with private insurance.

There are services that I need her to access that are only available if she lives on the Wasatch Front. Even though I have moved to the Wasatch Front, I cannot get her into a UNI Home. Which is something she desperately needs. She needs some coordinated health care.*

*[*UNI home refers to the Neurobehavioral Home Program, which is a coordinated care program that addresses the needs of people with dual diagnoses including mental health and developmental disabilities].*

But it was really frustrating to me to not even have UNI as an option, because of our private pay insurance.

The other resources that were described as helpful were receiving centers. In Utah, receiving centers offer assessment, crisis counseling and mental health or substance use assistance. These centers are available in Salt Lake, Davis, and Utah counties and accept walk-ins, referrals and law-enforcement drop-offs. Receiving centers were viewed as helpful by those that had used them and as desirable by those who had not yet used them or did not have them available in their communities.

For the youth, there is a resource. People utilize the juvenile receiving centers. I think it is 24 hours that they can stay there and get help. That's really helpful.

I like the idea of a receiving center. Not necessarily for emergency medication or something like that. I just need a place to be until I can be stable. I need other people. I need to see some eyes and be safe for a minute and breathe. To get out of my own mind in a place like that would be helpful.

We need a receiving center. I mean, that's a piece that we're missing.

What ideal service delivery looks like: somewhere to go

Transportation issues added a further complication to finding somewhere to go. Consumers often encountered less than desirable options for getting to help, including expensive rides in ambulances or traumatic rides in police cars.

I can't take an ambulance to the hospital because it is going to cost so much money and I don't want to take the bus or an uber when I'm suicidal. Like, I don't want to be crying on the bus.

We had a 13-year-old, where the sheriff's department said the policy was to handcuff him all the way to Provo Canyon [a five-hour drive] because they couldn't risk him jumping out of the car.

Similarly, challenges of transportation were described by rural law enforcement providers.

We didn't hire these guys to be medical transport for mental health. My guys are getting hammered with transportation calls. Day and night, we're getting called out and we don't have money for that and we don't have the staff.

[Transporting people during mental health crises] *is an unfunded mandate.*

Transportation was also seen as a challenge by rural providers of mental health services.

Transportation is the number one issue in rural Utah when it comes to mental health.

NEED THREE: SOMEONE TO COME

During an active crisis, many focus group participants described needing someone to come and help.

The bare minimum should be, how can we get somebody out there to help you de-escalate versus having [the consumer] end up in jail?

Two types of in-person responses were described by consumers:

- Responses from Mobile Crisis Outreach Teams
- Responses from law enforcement

Mobile Crisis Outreach Teams (MCOT)

MCOT provides community-based interventions in which a two-person team of qualified professionals respond to crisis situations. Availability of MCOT was generally viewed as helpful by both consumers and law enforcement.

MCOT came out once and that's a helpful service. If they could expand that, that would be nice.

I think I speak for all of our law enforcement staff when I say I think MCOT's going to be a positive thing and we have a great relationship with them.

The only complaint that emerged from people who had used MCOT was that the service was loosely associated with a police response.

We don't really have anything against MCOT but they call the cops. Yes, the cop, that's the problem.

Law Enforcement

In every conversation about law enforcement response, the presence of law enforcement was viewed as unhelpful, often exacerbating an already-stressful situation (see Appendix 1 for a breakout of which populations mentioned minimizing police interactions).

Well, for a lot of people, the police get involved and it becomes a legal thing. Nobody wants to have to go to court and stuff like that for something as simple as a mental health crisis.

I was in a crisis and the cops came. I was standing looking at the cop and he was yelling at me for not moving fast enough and I was looking his gun trying to decide if I could commit suicide by cop. It never occurred to him that I was looking at him thinking about suicide by cop. He was too busy yelling at me.

When the police come, even if you were the one who called for help, you automatically become the one they're not going to help. My whole family was detained. I am speaking of elders, children, women, sick people, everyone because someone said that there was someone in our house that [was undocumented]. In the end, there wasn't anything like that.

It is important to note that law enforcement representatives viewed their own involvement as often needlessly exacerbating the situations.

If they aren't violent and there's not a safety risk then I don't think that our officers need to be standing by. A lot of times, just our presence agitates the person.

What ideal service delivery looks like: someone to come

Key service delivery ideals included reduced interactions with law enforcement agencies as well as a need for client-specific services.

Responses to interactions with law enforcement were described in the previous section. To reiterate, there are a number of reasons that interactions with law enforcement are seen as detrimental to community members in crisis.

There's a lot of fear around [law enforcement involvement], like they're going to come, ICE is going to come. But it's not only undocumented who are afraid. It might be people with warrants, mental health, or substance use issues.

People with mental health issues are afraid to call because they don't know that CIT is available.*

[*[CIT](#) is a program that supports partnerships between criminal justice services, behavioral healthcare and community members. The program was seen as positive by focus group participants.]

The other ideal expressed across three or more focus groups was for specific services for clients with unique needs who opt in to services.

If there's some way that we can have a customer profile, for people who maybe need more consistent help. Instead of having to explain my story again, maybe a profile that pops up. Where you can see past calls or past resources rendered. It would make the person feel like you guys actually take time to get to know people individually. Like I'm not just another caller.

I like that idea of some kind of database that might include possible sensory triggers. Someway that you could tell a responding unit, please don't arrive with sirens or with lights.

Tools to provide specific services have already been developed and are being used by some police and fire departments as well as the medical system. Expansion of this type of service would have a positive impact on community members with unique needs.

So anytime anything comes up, the cops, they have this flag that tells them that I am an autistic person who is vulnerable. Having that stopped much of the horror.

Utah has something called the [Utah special needs registry](#). It's for, like if 911 was coming, so they would know about [the respondent's son with multiple disabilities], they would know where to get his information, his prescriptions, and maybe his life saving items. It would be really cool to have a registry like that, somehow, for mental health issues.

CULTURALLY-RESPONSIVE SERVICES

Although not specific to any one of the three key areas of need (i.e., someone to talk to, somewhere to go, someone to come), the necessity for culturally-responsive services was apparent across communities and service types.

How you approach the crisis is going to be culturally significant.

We all know that [crisis line services] is not for [undocumented immigrants]

The need for cultural responsiveness begins with communication, so people know the 988 services are for them. Responsiveness in communication may include targeting materials to specific communities or working with community members to translate materials into multiple languages.

We want to see things translated into our languages, we want to be able to say that those types of things are very serious.

Participants from Navajo nation talking about commercials made without their input: *They showed us some of their commercials with big houses, grass and a lot of trees. And we were like, someone's going to see that and change the channel; that's not our life.*

Once people are connected to crisis support, the solution for ensuring cultural responsiveness that came up most often was to invest in, as one focus group participation put it, “*the resource of representation.*” Demographic and experiential representation were both discussed.

[The ideal would be to] create a space where we feel represented and are comfortable to ask for help.

As a person of color, if I go to a facility, even if they are trained and they're not judging, and I only have a highly educated white person to talk to about my hardships in my life. They wouldn't even understand.

It's definitely comforting to talk to someone who actually understands and has gone through what you've gone through, rather than just someone who's just trying to support you.

Although many participants highlighted the importance of a representative workforce, it was also commonly understood that developing a representative workforce will take time and effort.

If you really want representation, you've got to do the work to find that.

In light of the fact that crises are happening now and investing in representation takes time, some focus group members identified training as one way to increase cultural responsiveness in the short term.

When you have someone from a completely different cultural background facing different barriers than others might, and they express themselves, it looks a different way, and it is important to educate responders about what those differences look like.

I think our biggest problem is that it's not just a mental health crisis, it's a mental health crisis in an individual with a developmental disability, or with a physical disability or different cognitive levels. The training that individuals get to respond to mental health crisis doesn't always serve our population.

Other participants spoke to the importance of working with sponsors, cultural liaisons or ambassadors to collaborate with 988 and represent diverse cultures.

I don't know how you could implement it, but sponsorship is exactly what we are thinking of. If you think about AA [[Alcoholics Anonymous](#)], for instance, they have built a complete network of support with people who have experienced similar things and it's been successful.

And part of what I've seen working in mental health has been having a cultural liaison, that has been very helpful to us.

Much like sponsors through Alcoholics Anonymous, Peer Support Specialists are people with real life experience receiving mental health services. [Peers are currently part of Utah's mental health support system](#). Among other [research findings](#), working with peers has been shown to [reduce readmittance into acute care after a crisis](#). Similarly, the usefulness of working with cultural liaisons is supported by [research](#) and is perceived as particularly useful when working with [refugee communities](#).

RECOMMENDATIONS

Based on shared experiences across Utah's community focus groups, the following are recommendations for 988 and the overall crisis system:

1. Increase the scope of crisis line services to include any crisis, as defined by the consumer.
2. Develop policy and practice standards to connect callers to 211 resources, and work with 211 to bolster resources and ensure that resources presented as options are up-to-date
3. Provide training so that crisis line workers can appropriately accommodate speech and language differences including delayed response time, non-English language, lack of fluency, and flat affect.
4. Develop policy and practice standards to ensure that communication with the crisis line is perceived as respectful by the client.
5. Build resources specific to mental health, such as HMHI and receiving centers, that provide people in crisis with a place to go for acute and long-term mental health support.
6. Develop an appropriate transportation option for individuals experiencing mental health crises, particularly for clients in Utah's rural areas.
7. Reduce interactions between individuals in crisis and law enforcement agencies.

8. Expand training, such as CIT training, so that law enforcement officers who respond understand mental health and how to appropriately serve individuals experiencing mental health crises.
9. Build or connect to resources, such as the [Utah Special Needs Registry](#), so that frequent callers do not have to retell their stories and so appropriate resources can be directed to callers with unique needs.
10. Invest in the *resource of representation*. This may include expanding peer support services and diversifying the workforce.
11. Increase collaborations with Utah's diverse communities for the purposes of communication, policy development and practice guidelines.
12. Employ cultural liaisons who can help providers with culturally appropriate services, particularly for newcomers.

CONCLUSION

In sum, consumers and stakeholders hope that the 988 crisis line will provide callers with

- someone to talk to,
- somewhere to go, or
- someone to respond

In the long-term consumers need mental health care solutions that work for them. Consumers emphasized the need for an individual response developed with them rather than for them and to be able to define their own crises. They expressed the need for collaborative and culturally responsive approaches to the crisis. The overall perception was that services lacked collaboration and cultural responsiveness.

As Utah transitions to the three-digit 988 crisis number, we hope that the feedback from Utah's focus groups and the recommendations drawn from that feedback are used to inform the service continuum and service delivery.

APPENDIX 1: FOCUS GROUP THEMES

988: Crisis continuum needs specific to diverse populations

The recommendations in the 988 Consumer engagement report were made if the need was expressed in more than two focus groups. The following table summarizes the needs expressed, as well as the communities articulating those needs.

Articulated need:	Rural community members	Youth and young adults	People with disabilities	LGBTQIA+ community members	BIPOC community members
Linguistic competence			✓		✓
Respectful communication				✓	✓
Transportation	✓	✓	✓		✓
Minimize police interactions	✓	✓	✓	✓	✓
Training and guidelines for police who respond			✓		✓
Cultural responsiveness				✓	✓
Representation				✓	✓
Expand "crisis" scope		✓			✓
Connection to resources		✓	✓	✓	✓
Expand availability of crisis continuum services	✓		✓	✓	
Crisis registry for frequent callers			✓		✓

APPENDIX 2: UNIQUE NEEDS

In addition to the needs and subsequent recommendations included in the report, there were other needs and ideas for crisis services that were unique to specific communities. Below you will find a summary unique needs, recommendations, and challenges expressed by the communities that participated in the focus groups.

Rural community needs and ideas:

- Need access to locally-available crisis-continuum resources
- Need long-distance transportation when resources are not locally available
- Are challenged by difficulty finding crisis workers and staffing positions
- Are challenged by reduced access to internet, high-speed internet or strong cell phone signals
- Are challenged by the stigmatization of needing or receiving mental health services due to “hardscrabble, bootstraps mentality”

Youth and young adult needs and ideas:

- Need a safe space to discuss issues of sexuality, including sexual assault and consensual sexual experiences
- Need choices about who to involve in crisis mitigation and when
- Recommend expanding services available through texting
- Recommend that crisis workers learn more about the cultural context of being a young person
- Are challenged by privacy concerns especially with regard to parents
- Are challenged by the “attention seeking” narrative

Parents of children with disabilities needs and ideas:

- Need more resources for people who are dually diagnoses with intellectual or developmental disabilities and mental illness
- Need resources in communities so they don’t have to move to get help
- Need to know where to get help
- Need follow-up after crisis
- Need long-term solutions
- Recommend training crisis staff to work with non-verbal clients
- Recommend responders not use lights and sirens when approaching people with disabilities
- Recommend a registry or database that has important client-specific information for responders
- Recommend medical community do more to educate about mental health and crisis resources
- Recommend that 988 makes it clear in advertising and outreach that 988 serves people with disabilities and their families
- Are challenged by rules that are detrimental to people with disabilities (for example, not allowing parents to stay in in-patient facilities)
- Are challenged by child and adult protective agencies, justice agencies, mental health providers, etc. that aren’t prepared to serve individuals with disabilities and families their families.
- Are challenged by the DSPD waitlist and other Medicaid restrictions and limitations

LGBTQIA+ community needs and ideas:

- Need follow-up with resources
- Need more time to work through complex crises with crisis counsellors
- Recommend giving the caller a choice about the types of over-the-phone services that are offered including when or if a crisis call will be escalated
- Recommend crisis workers receive training to understand interactions between crisis and identity issues
- Are challenged by high incidence of mental health condition and high risk of suicidality
- Are challenged by fear of police and lack of body privacy in jails and hospitals
- Are challenged by mis-gendering and assumptions of heterosexuality by crisis workers

BIPOC community needs and ideas:

- Need information about services to be available in multiple languages
- Need racial and ethnic representation among service providers, or community responders
- Need translation services
- Need safe services for undocumented folks
- Recommend training crisis system staff on
 - historical traumas,
 - unique symptom manifestation among BIPOC and
 - different cultural conceptualizations of mental health and crisis
- Recommend less invasive responses, with minimal exposure to law enforcement
- Recommend that law enforcement respond without weapons whenever possible
- Recommend use of cultural liaisons to mediate between diverse communities and the crisis system
- Recommend that systems collaborate with BIPOC community and religious networks