NAMI Ask the Expert:
History of 911 & Lessons Learned for 988

Featuring Dr. S. Rebecca Neusteter

May 26, 2022

Teri Brister (00:00:00):

Typically, here is where I hand it over to Dan Gillison, NAMI's CEO. Dan is on a much deserved vacation day today after being at APA all week. But on behalf of Dan again, our CEO, NAMI's board, NAMI's board president, Dr. Shirley Holloway, and all of my colleagues, the staff members at NAMI as well as the leaders in the field, our NAMI affiliate and state organization leaders, I want to welcome you to the webinar today.

Today's session is going to be incredibly valuable. The launch date for 988 is looming very near in our future. As many of you know, I hope most of you, if not all of you know, NAMI has very actively been proactively, I guess, is the best way to put it, trying to drive the conversation around 988. I'm excited to hear what the latest is as well.

So before we actually begin the presentation, Jordan, will you pull up the polls? We have a few questions we want to ask you. Jordan, how do they submit the ... Oh, there you go. Now the answers have popped up. So if you'll take just a minute and respond to these. Just curious about what you know. I will tell you, I flunked. Before you close the poll down, Jordan, let's leave it up for just a minute while people finish.

Our presenter, Dr. Neusteter, will be discussing the results. She'll be sharing those with you later on in the presentation, but wanted to go ahead and capture your response at the beginning so that you're not cheating. It's a typical pretest. Let's see what you know. So Jordan, why don't we go ahead and turn the poll off, and let me hand it over to NAMI's Chief Medical Officer, Dr. Ken Duckworth, so he can introduce our presenters today.

Ken Duckworth (00:02:19):

Thanks, Teri. I just want to let people know, I did not know all the answers either, which is humbling given that I'm very fortunate to be NAMI's Chief Medical Officer. We're in for a treat today 988 is happening on July 16th, and it's a great opportunity to understand the history and what can be changed about 911. We both have NAMI's policy lead, Jennifer Snow, who is the National Director of Government Relations Policy and Advocacy for national NAMI. We also have Dr. **Rebecca Neusteter**. She's the Executive Director of the University of Chicago Health Lab and the principal investigator of Transform 911.

I want to encourage you to zip out your questions as they come to you. They get assembled by our team behind the scenes, doing a lot of heavy lifting, and they send them to me. I'll do my absolute best to cover the waterfront with our two experts. I want to thank you again for your participation, and I look forward to the Q&A when you'll see me again, although I'll introduce Dr. Neusteter very briefly after the end of Jennifer Snow's talk. Jen, take it away and thanks everybody.

Jennifer Snow (00:03:31):

Thank you so much, Ken, and thank you everyone for being part of this important conversation. So before we get into Dr. Neusteter's presentation where we're going to learn a lot about 911, which I'm very excited because similarly to Ken, there's a lot that I don't know based on those first poll questions that were asked. But we thought before jumping into 911 that it might be helpful to set the stage about what is 988. I'm sure many of you on this webinar are familiar, but there might be some who this is one of your first times hearing about it, or one of the first times you're hearing about it.

So 988 is the new universal three-digit dialing code for suicide prevention and mental health crisis. It is going to replace the 1-800 number that you currently can use to access the National Suicide Prevention Lifeline. So it's going to make it much easier for people to get to help when they need it. It will be available nationwide on July 16th of this year.

Right now if you dial 988, depending on your telecommunications carrier, you might get connected to Lifeline today, but come July 16th no matter where you are in the United States, you will get connected to Lifeline when you call 988. It's important to keep in mind that 988 is just a number, a number that makes it easier to access the Lifeline. However, we've been looking at 988 as an opportunity to revolutionize the way our country responds to people in mental health crisis by expanding access to crisis response services all around the country. So let's take a moment talking about the existing Lifeline. Next slide please.

The National Suicide Prevention Lifeline has been in effect for 17 years. You can access it 24 hours a day, seven days a week by calling 1-800-273-TALK. Calls are answered through a network of 200 local call centers that will provide free confidential crisis counseling by trained behavioral health professionals. There's over two million calls a year and about 100,000 texts. Now, given we expect that number to increase greatly once 988 goes into effect and it's easier to get to that Lifeline. Next slide please.

How does it work? When you dial 1-800-273-TALK or 988, you will first be asked if you're a veteran. If you press one, you will be connected to the Veteran's Crisis Line. If you press two, you'll be connected to the Spanish sub-network. If you press nothing, you will be routed to one of the local 200 call centers around the country based on the area code from where you are calling. If for some reason the local call center doesn't have capacity, it will default to the national backup call center. Translation services are also available in 150 languages. So while there is the Spanish sub-network, there still is language accessibility available through the existing Lifeline and through 988. Next slide please.

So why not 911? Some of you might have heard that 988 is going to be the new 911 for mental health, but I think there're some people who question, "Well, why do we need a separate number?" We all know some of the tragic outcomes that can happen when police respond to people in a mental health crisis. Fundamentally, we want people in a mental health crisis to receive a mental health response, not a criminal justice response. We do want 988 to be as well known in households as 911, but 911 one is answered by operators that dispatch other services. That's the main focus of [988 00:07:20]. It's operators that dispatch, where 988 is the intervention. 988 calls are answered by trained crisis counselors, and it's estimated that those counselors can deescalate 80 to 90% of calls on the phone and then connect people with local resources. So no one needs to be dispatched in those cases and certainly not a police response. However, we know that 988 cannot replace 911 because there still are some limited instances that are criminal in nature that require a criminal justice response. Next slide please.

So why the number 988? You're hearing all this talk 988. Why were those three numbers chosen? Great question. We're going to go back to 2018 when congressional leaders thought, "Hey, the Suicide Prevention Lifeline is great, but 10 digits are hard to remember.

Jennifer Snow:

When you're in a crisis, seconds can matter." So Congress said, "We really need to study this, and we need to figure out what's the feasibility of creating a three-digit number that's easy to remember." So they passed the law and asked a whole bunch of federal agencies to study it and figure out what the number should be.

At the time it was all talked about in context of N11, the notion that it would be some number, then 11. Next slide please. So the telecom experts looked at all of the N11 numbers and bottom line in short, they realized none of them were good on a national scale. They were all used in some ways in some markets. Next slide please. Just for example, 211 in many locations gets you to community info. 411 gets you to directory services. In about half of the country if you dial 511, you can learn about traffic in your area. Who knew? 611 will get you to your local telecommunications carrier. So there was basically a problem with each of these N11 numbers, which really meant that ... Next slide please.

So it really meant that then the federal agencies looked back at, "Well, what number is available that could work around the country, that is not an N11 number," and that's where 988 came in. The North American Numbering Coalition recommended 988 because it's not currently an area code for anywhere in the country, and it's also the number where there were fewer corresponding central office codes. So basically not your first three-digit codes of your telephone number, but the next three digits. 988 was used very infrequently when it came to those next three-digit numbers. The North American Numbering Coalition felt that it was the best number to create as a national three-digit line.

So they released a report identifying that. Congress took it and said, "Wonderful." They inserted it into a legislation to change the number of the Lifeline. Federal Communications did the same thing, and that's how we got the number 988. So Next slide please.

That brings us today. We have 988, which is going to be branded as the 988 Suicide & Crisis Lifeline. Importantly, for our populations there's an expanded scope. The Suicide Prevention Lifeline that exists today really focused on suicide, but the 988 Suicide & Crisis Lifeline will touch any type of mental health crisis, whether it's mental health, suicide, or any other kind of emotional distress. As I said, it will be available nationwide on July 16th. Next slide.

So, as I mentioned, 988 is just a number, but we see 988 as the first step towards a transformed crisis response system, one that can provide everyone in a mental health crisis with a mental health response. So that's not only the crisis call centers that we talked about for someone to talk to, it's also the mobile crisis teams to come out in person and deescalate those situations where deescalation is not possible over the phone. It's also crisis stabilization services for people who need a little more help and somewhere to go to then provide a warm handoff into the community.

We see this transformation much the same way that emergency medical services had expanded in the US after the establishment of 911, which is why Dr. Neusteter is here to help us understand the history of 911, and as we build out the system, what are the lessons learned that we can apply to 988. So with that, Ken, I'm going to turn it back over to you, I believe, to then turn it to Rebecca. Or perhaps I'm turning it right to Rebecca.

Rebecca Neusteter (00:12:31):

Well, hello everyone. Thank you so much for joining us today. I really want to acknowledge and appreciate NAMI for creating the space for this conversation and for so many others like it, as well as each of you who have joined us virtually today. I want to acknowledge again and to thank NAMI for this work and for all of you who are here. I also want to acknowledge May being Mental Health Month and how many people are working tirelessly this month and every other month in order to help achieve greater access to wellbeing and care. 911 and 988 are a part of that ecosystem.

I want to acknowledge that some of the conversations that we are having today may be painful or triggering for folks so please take care of yourself. Please feel free to turn off the camera, to leave at any point in time or to contact NAMI if you need additional support.

I want to tell you that what I'm presenting today is archival research. I'm not going to be editorializing as much as possible. I really am going to be presenting the facts. I'm not an editor, I am a communicator of the information that we're going to be sharing. But I want to acknowledge that we all come to this work and we have our experiences based on our own backgrounds. I identify as a White woman, and the experiences that I have had are different in accessing 911 and other services and my interactions with law enforcement than they will be for other people and people of color. I will be describing some of the origin story of 911 that specifically impacts people of color, and so I want to acknowledge that I do not have the same experiences. But I hope that this will give us some information to learn from.

I want to see if Jordan perhaps can share the results of the poll. I'm curious what people's responses were and really excited to see that there are lots of ways and learnings that we can share and do together. So I think most people like to know the answer to things, and I am not here to present a suspense novel. We're learning together so I'm not going to bury the punchline at any point in time.

But 39% of you were correct in identifying that the first 911 call was made in 1968. Interesting enough, the fewest number of you recognize that the first 911 call was actually made in Haleyville Alabama. We're going to discuss that a lot today together. Most of you have said that 911 is available nationwide. This is sort of a trick question because it is mostly available nationwide, in about 97% of the places nationwide, and we'll discuss that a little bit more together.

How many 911 centers are there in the United States? Well, we didn't try to trick you too much by saying one, which many people do believe that there is just one. But it depends on how you do the math here. There are about 6,000 primary 911 centers across the country, but if you include secondary 911 centers, you get closer to 9,000 or 10,000. Many of you recognize that there are a lot of 911 calls made every single year. Again, this is a trick question. There was no national data collection on 911, but the estimates that we have, which industry experts describe as quite conservative, is that there are about 240 million calls at least every single year that are made to 911. So great answers. Thank you for engaging in that poll. We'll learn a little bit together now about some of the details behind each of those questions. Next slide please.

So, as folks have mentioned, I today am going to talk a little bit about the history of 911, and how we think that this relates to 988 and some important factors to consider. First though, I want to sort of do a really quick breakdown of how 911 even works.

Rebecca Neusteter:

So when someone calls 911, a call taker, sometimes also referred to as an operator, sometimes referred to as a dispatcher or a call handler, they gather information from the caller. The caller can be a first party caller so, I'm calling about something I'm experiencing myself, a second party caller, I'm calling about something that happened to my mom, someone who I know, someone who I'm in close proximity to. Usually that's emotional proximity, not necessarily physical. Then there are third party callers who are observing something, but they may not have much context or knowledge about the subject of the call and are reporting something. That information that's collected by call takers, entered into a computer, [inaudible 00:17:45] a dispatch system, and then it's transferred to dispatchers who prioritize the level of response and deploy it to first responders.

First responders typically are police, fire and other emergency medical services. But increasingly there are other first responders who are playing a role in the behavioral health continuum and in thinking about alternative responses. 911 has, for sure, saved countless lives. It continues to deploy people 24 hours a day, seven days a week, virtually all across the country. It's important to acknowledge that 911 particularly as a gateway to deploying police responses also results in countless situations that police are put in that they're ill-equipped to handle and can escalate situations and cause harm and danger to the first, second or third party callers.

As I mentioned before, most of the 240 million calls that are coming in to 911 every single year are stemming from a whole variety of different things. But it's important to keep in mind that the vast majority of these calls are not related to an emergency. They're non-criminal issues such as noise complaints, parking issues, complaints about unhoused persons, and that these calls ultimately end up being defaulted to the police to respond. In essence, this has made police the responders to all of society's ills, which has put police and communities in an untenable situation.

Some of these calls that come in to 911, and this is a real lesson for us to sort of think about and to be attuned to for 988, are calls that have been motivated by racist notions of order or disorder. We have seen many, really at this point, countless examples of people implicitly or explicitly using 911 as a way to sort of express what they believe as disorderly conduct. Most often this is applied to people of color, often young people of color.

In some instances, these calls actually result in the death of people. There may be really, really positive motivations behind these calls. For example, Tamir Rice. A neighbor saw a young child playing in the park, thought that they were probably playing with a fake gun, but called 911 to say, "Somebody should just check it out and make sure that this is a play gun." Unfortunately, that information was not transmitted in a way that there was any skepticism or ambiguity related to that this might be a child playing. Instead, the 911 dispatch went to police as a Black male with a gun in the park. We all know the tragic ending of that story, like so many others and what ended up in these calls, like so many, is that the police fielded their power of the state resulting in the deaths and often of Black Americans.

Really since the inception of the 911 system, police officers have become the weaponized embodiment of social and racial bias, and they're dispatched at the behest of often anonymous or semi-anonymous callers who either know or don't know what the end results of these situations may be. It's also resulted in the criminalization of poor people and people of color and resulted in funneling, millions, hundreds of millions of people into the criminal justice system.

But the crucible of the 911 system itself had a very White, racist motivation coming out of the Johnson administration in 1968. I want to explore that a little bit with you all now today. Next slide please.

Rebecca Neusteter:

Before doing so, I really want to acknowledge my collaborator in this space, Katrina Feldkamp, a very talented lawyer and archival researcher. She is absolutely essential to the work that you will hear today. What I want to communicate is that prior to 1968, on this story around 911, telephoning an emergency was a really thorny process. Local jurisdictions, which often overlapped, had their own local telephone numbers, and when a person needed the police or the fire department, they had to figure out the relevant jurisdiction that they were in and then find the phone number and dial directly and hoped that somebody was there to answer.

President Lyndon Johnson administration is credited with solving that problem by the creation of a centralized emergency number, which we know today as 911. But again, these motivations were not entirely benevolent, and I want to explore that with you today. So, a little sneak peek of this story. This phone that you're seeing before you, depending on the age range of people who are on the webinar, some folks maybe have never even used a phone like this. This is a rotary telephone. This is the kind of phone that was in mass production and operation in 1968. This phone is the phone that the very first 911 call was made from in 1968 in Haleyville, Alabama. Haleyville, Alabama has become celebrated as a result of the innovation and introduction of 911. Next slide please.

What you'll see here, and these are famous markers that are all over Alabama. The Alabama Historical Association has marked places all across the country. You'll see the Alabama state flag here in that picture. This is in front of the location where the first 911 emergency phone call was made. It was made from the office of the mayor on February 16, 1968. Tells a little bit of background about how AT&T, who had a virtual monopoly on telephone service at the time, began to pursue 911 and the Alabama Telephone Company, one of the sort few alternative telephone companies beat AT&T to the punch. They were able to first launch 911 here. Talks about some of the people who were involved in that, specifically US Congressman Tom Bevill, who answered this telephone call from the Haleyville police station. Next slide.

This is a picture that Katrina and I found through our archival research. So in the hand of this gentleman is the telephone that you've seen before you. We also have the Alabama Telephone Company President, B.W. Gallagher, standing above watching very proudly. In the middle of this picture, you have Eugene, also known as Bull, Connor, who many folks are familiar with Bull Connor. Bull Connor had served as the Director of Public Safety for many years. He was responsible for the very violent suppression of protests in Alabama, including the Birmingham Children's Crusade, in which hundreds of children were brutalized when they were protesting segregation and conducted mass arrests of young people. Bull Connor is acknowledged very much so as a White supremacist. That is not a controversial statement. The US Department of Parks on their website describes Bull Connor as a White supremacist, and he was central to the implementation and operation of 911 being developed in Alabama.

So keep this picture in mind, and that story as now will go a little bit deeper into the history and how this was set up. Next slide please. Some folks are familiar with the Kerner report. The Kerner report was initiated after the summer of 1967, which represented the culmination of several years of civil rights protests. There were 159 civil rights protests in that summer of 1967 alone. In response and then trying to sort of understand these protests, Johnson appointed the National Advisory Commission on Civil Disorders, which is better known as the Kerner Commission, and the Kerner Commission was tasked with the responsibility of studying 24 of these so-called disorders that had occurred in 23 cities over the course of that summer. There were 11 members who were appointed, all White men with the exception of one woman, and 118 staff people and assistants who were working very hard in order to understand the root causes of these protests.

Rebecca Neusteter:

Essentially they issued recommendations for preventing future riots, and that was released in February 1968. The report is often most remembered for condemning White America's racism as the primary cause of civil unrest in Black communities. It called for investment in housing and social services and a restructuring of the police. It recommended federal action to challenge discrimination in employment and education. It cited numerous instances in which the police escalated peaceful protests that ended up ensuing into riots. This was not a super progressive or liberal body, and these were the conclusions that they drew. This report is most remembered for these recommendations, but there was more to this story and how 911 came into be. Next slide.

One of the folks who was involved in this work, Arnold Sagalyn, he was focused on a supplement of the report that is very infrequently published ... It was actually quite difficult to put our hands on ... Known as the Supplement On Control Of Disorder. This section, again, that was often left out of published copies of the report, it looked at some very different mechanisms and in some ways offered a very different tone than the rest of the Kerner Commission report. It advised state and federal government officials to intervene in civil disorders. It recommended that local police departments adopt militaristic riot control, training and equipment, including the use of tear gas, and it encouraged the police departments to infiltrate Black communities in order to prevent future protests. So these were some endorsed strategies. In doing this research and Sagalyn's own career in law enforcement, he started to look at some examples of international law enforcement techniques and was briefed about a service akin to 911 that had been implemented by the United States in Caracas, Venezuela in 1963 in order to aid the military and the police there to address counterinsurgency efforts.

That universal call system had worked quite well in Central America and Sagalyn became very interested in it. He started working with other members of the Kerner Commission as well as the FCC, the Federal Communications Commissioner Chairman, who at the time was Rosel Hyde. In 1967, he expressed that the Kerner Commission really should be trying to drive home implementation of 911. As I mentioned before, and as that Haleyville plaque acknowledges, AT&T held a virtual monopoly over phone service at the time so they were integrally involved in these conversations at the executive levels. They essentially set up the same sort of system that's been happening in the background over the past year-and-a-half to make 988 an operable and an accessible number across the country.

So just a few months after these recommendations started to be put into place, and it was moving quite quickly in early 1968, there were a number of warnings that had been offered that demonstrated that while there might be great value in having a universal hotline in order to prevent public safety concerns, address fire and medical needs more quickly, these were not necessarily new conversations. In fact, the National Academy of Sciences recommended such an approach in 1966. Back in 1957 the International Association of Fire Chiefs had lobbied for a singular number for fires, but it really wasn't until this Kerner Commission supplement came that 911 got the political will was there in order to make 911 a reality. Johnson argued to Congress that this would be an important and expedient way to decrease emergency response times and to increase arrests and "provide a more immediate solution to crime."

Johnson advisors, including folks at the FCC, however, they expressed concern from the outset that 911 would attract calls that didn't necessarily involve crime or emergent harm and that calls may result from racial biases and other kinds of incidents. We have seen that actually play out as I've described in the opening of my remarks. Next slide please.

What we saw is once the ecosystem existed for 911 to enter into many cities across the country following Haleyville's example, that rather than be a universal number for all emergency services, in many cities 911 became equated with police services.

Rebecca Neusteter:

So for example, New York City, which was an early adopter of 911. They implemented 911 in July 1968 exclusively only for police initially. What we saw was that half of the calls that were made in that first year were for non emergencies. Yet at the same time, almost 8% of those calls resulted in an additional police deployment, even though police may not have been the best or most equipped responders.

So in short, America rejected the recommendations of the Kerner Commission. All of the staff members were fired. Demands from across the country to confront the racism and the poverty and the root causes of these protests were largely ignored. The pieces of the Kerner Commission that ended up being installed into the fabric of our access to well-being and safety in this country really were focused on expanding law enforcement's capacity and investing in ways to suppress Black communities' demands for equality and for access to greater services. Essentially, 911 and the system that operates today is very much a direct result of that choice. We've seen that the 911 system has exasperated racial disparities in communities across the country, that there are communities and people who will not call 911 no matter how dire the emergency, which is devastating and very costly to those individuals, the communities and the nation at large.

We are recommending that we need to prioritize community-based responses that center on health and wellness and transformative approaches to harm, and that we limit police response to the most necessary of conditions and to provide parity for people who are accessing 911 and other alternative hotlines, increasingly what 988 will look like going forward. Just one final note about this on the next slide please, in sort of fast forwarding to today and taking these lessons into the future, there's really robust conversation and many, many thanks to Jen for sharing the landscape of 988 as it's currently expressed. We are also taking these lessons of history and trying to apply them to think about what our recommendations to improve and transform emergency crisis response.

My colleagues and I at the University of Chicago have been working with over 100 different leaders across the country in order to develop some concrete recommendations to transform and advance 911, very much related to the emergent 988 number. We will be unveiling a policy blueprint to speak to transforming the national emergency response system from call taking and dispatch through field response and resolution. These recommendations will be released publicly on June 29th. I invite you to learn more about that at transform911.org/convenings. Thank you for the opportunity to share a little bit of what we've learned in terms of the history of 911.

Ken Duckworth (00:36:58):

So thank you. This is Ken Duckworth. I'm sorry. I had a domestic moment, and I failed to introduce Dr. Neusteter. Please accept my apologies. She's a PhD in Criminology, and I've learned so much in this conversation that I was completely unaware of. I'm very grateful to you. So we have a number of questions for both Jennifer Snow and Dr. Neusteter. I'm going to start with a few basic questions. "Does 988 provide crisis services, or is it an improvement on the current number?"

Jennifer Snow (00:37:36):

Sure, Ken, I can take that question. So 988 itself is an easier way to access the existing National Suicide Prevention Lifeline. We know, however, we have been using 988 as an opportunity to advocate for a revolutionized crisis response system, which would include to your point, mobile crisis and crisis stabilization services. The ideal is that someone who's calling 988 who needs more than just someone to talk to, that 988 would be able to dispatch mobile crisis to help that individual.

Jennifer Snow:

Recognizing the vast majority of people can be handled on the phone or deescalated on the phone, we know that doesn't work for everyone. But at the same time, this is very much a work in progress. We will not have nationwide availability of mobile crisis, but it's something that we are advocating for, and communities are expanding their ability to have those mobile crisis teams. I'd like to say that every day we get a little bit closer to our goal of having the ability to have a mental health response to everyone in a mental health crisis.

Ken Duckworth (00:38:47):

Thank you. It's a great answer. Let's talk about the current Suicide Prevention Lifeline. "Will that still be functional while the 988 transition is happening?"

Jennifer Snow (00:38:58):

Yes. 988 and the Suicide Prevention Lifeline will basically be one in the same. So I know there was a written question of if someone is familiar with the 1-800 number, can they still call that? The answer absolutely is yes. Both 988 and the 1-800 number will connect you to the same service.

Ken Duckworth (00:39:19):

This might be a question for Dr. Neusteter. "I was unaware of the racial component to 988. Do you feel that it got better over time? I understand the origins of it." There was a question about how your take is on it now in terms of a service for people.

Rebecca Neusteter (00:39:40):

Yeah, that's a great question. I just want to maybe reflect on the prior two questions in order to contextualize and answer that one, Ken. 911 and 988 now, similarly is a patchwork system. There's not one set approach. There are not national set of standards for how calls must be answered. There are guideposts and there are some resources available, but essentially, as I mentioned earlier, before, there are at least 6,000 primary 911 centers. In that, there are 6,000 ways in which calls are answered, and whether or not there are mobile crisis teams to be deployed is very situationally dependent.

In thinking about that, the way people use 911 is quite different as well. We know that in some communities 911 will not be used at all. For example, we have partners who have been developing an oral history of 911 in rural parts of Alabama, sort of building on the archival research that I had shared with you. One of the really striking findings is that there are some communities that literally have no access to 911, and I suspect will have no access to 988 because cell phone service doesn't work there, and they don't have access to broadband wireless service. 10 years ago they may have had better access to some of these emergency services when we were more reliant on landlines than is the reality today. Just sort of thinking about all of those factors.

Similarly, technology has given us a far different understanding of how things are working in communities. As everyone, almost, has a cell phone in their pocket and the ability to record a video, we have a much clearer sense as White middle class people of what it's like to be a Black person operating in the world, performing innocuous routine activities: walking your dog, bird watching, taking a nap in the library as a college student, playing at the park with a toy. These are likely activities in which the police had been engaged and called by members of White communities for decades since 911 or even preexisting 911. But that information is entering into our living rooms in a very different way.

Rebecca Neusteter:

George Floyd is not the first person to be killed by the police. He's one of the first people that everyone virtually in the world saw access to and recognized that that interaction from the police was motivated by a 911 call. So I don't believe that we can answer certainly, Ken, whether or not this problem has gotten worse or better, but I think that we have to acknowledge that the problem still exists.

I know that there are advocates in communities who fear that the introduction of 988 will essentially have two systems and that people who have access and knowledge of 988, because we know that many people still are not familiar with what 988 is ... I think I even saw some comments to that effect in the chat today ... That just having that information is privilege and power. Recognizing or giving somebody the benefit of the doubt that what they are experiencing is a mental health crisis rather than a crime may result in us handling these calls quite differently. There are people who fear that 911 will continue to be used on people who are experiencing crisis who are of color, but are not seen as being in crisis and their experiences are being criminalized. That 988 may be a better, more straight pathway to care for people who are not of racial minorities or is seen as being different and needed to be controlled.

Ken Duckworth (00:44:04):

Here's a question for both of you. "I have a family member who has been violent with basically an untreated mental health condition. How can I know whether to call 911 or 988? Can I know if the person has undergone CIT training, which is a kind of deescalation strategy?" NAMI does a lot of this work. There are many other groups as well. That's the question. Now we're into a different question, which is the risk of harm within the family and how people who are untrained might deal with a person who has a mental health condition. You mentioned, of course, people of color, and here's another layer of complexity.

Rebecca Neusteter (00:44:46):

Jen, do you want to answer first?

Jennifer Snow (00:44:49):

Sure. I can start, but then definitely would encourage you to jump in. So to the person who asked, as we indicated, our goal with 988 is to see a nationwide build out of mobile crisis teams, where basically you would be guaranteed to have a mental health professional respond. We're not there yet in terms of having that availability nationwide.

So what I would truly recommend for you in this situation is become familiar with your local community. Is a mobile crisis team available? Is that something that exists in your community now? If it does, the likelihood that calling 988 would be the best option for you significantly increases.

But if mobile crisis has not yet been established in your community, well, first I would encourage you to become a NAMI advocate so we can have you advocating at the state local and federal level for more dollars for mobile crisis teams. That's a little plug. We always need more advocates. We can't build this system without people yelling and screaming that we need it to be built. That being said, if you learn that mobile crisis is not available in your area, police might be the only response for you. In which case, we know that the CIT training can be life saving at times to have someone who is trained in a mental health crisis. It's different than having a mental health professional respond, but it certainly provides individuals with the skills for deescalation that are so critical. But Dr. Neusteter, please, I would encourage you to jump in here.

Rebecca Neusteter (00:46:20):

Thank you. Yeah. First I want to acknowledge what an awful choice that any family member has to make and to be in that situation. I'm really sorry for that reality for the person who posed the question and for the many people for whom that question relates to. We hear stories all the time of mothers of children of color, who will lock their kids in a bathroom for fear of calling for the people who are supposed to help us, but they do not trust that that will necessarily relate to access to care and well-being. This is a really awful situation to be in.

Unfortunately, I have to share the same answer that I shared before in that there's not one right answer here. There's at least 6,000 of them because every jurisdiction handles these things quite differently. One of the recommendations that we are considering and would love to hear from folks is this idea that there should be a caller's bill of rights and a baseline of what to expect when you are calling no matter where you are calling from. That you should expect to be able and receive a similar level of service. If your community exceeds that, fantastic. But we should all be able to receive a requisite level of care and compassion. Today that expectation cannot be met evenly across the country. So you really will have to look deeply into your own community, and please feel free to reach out to NAMI or to my organization if you need any help to access those resources.

The question about CIT training, an excellent question. Again, really dependent on your jurisdiction. In many police departments, that information is not known, not to the 911 center anyway. Oftentimes folks who are deploying police resources know the car or the footpost that an individual is serving in, but may not know their name or any of the training or their success in relating to people in the community. I think that there's huge opportunity to grow that knowledge and sort of that collective management of mutual aid. There may be some bright spots and examples across the country, but it certainly isn't universal today.

Ken Duckworth (00:48:58):

Two questions that are very related. One is, "This is great. How do we get the word out? How are you communicated?" And the related question, "If people don't know about it on July 17th and they call 911, is 911 gearing up to route people to 988 when it's a mental health concern?" So it's both the integration question and getting the word out, advertising this.

Rebecca Neusteter (00:49:26):

Well, I'll take a stab at answering this question first, and then hand it to Jennifer. But what I will say is I'm in regular communication with 911 professionals across the country doing interviews and focus groups on a variety of topics. Just this week in major cities, I'm hearing from 911 professionals that they've never heard of 988 and have no idea how that interoperability function will work or if it will at all. So we've got a lot of work to do in a very short period of time to make sure that the professionals are able to support these systems and that consumers are able to access them.

Ken Duckworth (00:50:08):

Jen, do you have any comment on that question?

Jennifer Snow (00:50:10):

Sure. I can take the other part of your question, Ken, about kind of public awareness of 988. The person who asked this question raises a really great point. NAMI did a poll near the end of last year, and that poll showed on only 4% of people were at all familiar with 988, which just goes to show what a huge issue public education is going to be.

Jennifer Snow:

Right now the federal government does not have any immediate plans to do any advertising in this year, but are looking to 2023. In part, that's to continue to give call centers the time to build out their systems, for mobile crisis teams to take effect in more places. But we know that communication is going to be critical to make sure that we are making people aware of the increased availability of services and the easier way to get to 988. So I think the bottom line is stay tuned, more is coming. We know we've got a huge job ahead of us.

Ken Duckworth (00:51:16):

Here's a classic NAMI question. "What can I do to help?" That's your NAMI sweet spot, right? What can I do to help?

Jennifer Snow (00:51:23):

Absolutely. I would say at a federal level, go to nami.org and sign up to be an advocate. We'll send you easy-to-handle emails where you can just click a button and send a letter to your member of Congress and tell them to fund crisis response services, fund mobile crisis, fund crisis stabilization, fund the services in the community for a handoff after the crisis has happened. We will try to make it as easy as possible for you on the federal level to become an advocate. I would also encourage you, contact your state NAMI. They're doing amazing work in their state capitols trying to advocate for state funding. Then there's your local NAMI as well, likely could be working with their local jurisdiction on some of those services that are provided at the very local level. So please become an advocate.

Ken Duckworth (00:52:11):

Next question probably for Dr. Neusteter. "The training of a person who answers the Suicide Prevention Lifeline, is that staffed by volunteers or professionals? Is it different in different jurisdictions? Is it different with 988 than the 800 number?"

Rebecca Neusteter (00:52:31):

Yeah, I'm not an expert on 988 and the workforce, so maybe Jen can answer that. But what I will share and sort of the intersection that I think is incredibly important for this audience to be aware of is that there's this whole other history around the classification of 911 professionals and the feminization of it. As a result of those decisions, the people who answer 911 calls are classified through the Bureau of Labor Statistics as secretaries and administrative assistants, which completely cuts them off from access to post-traumatic stress disorder. We're talking about mental health. We need to also talk about the mental health of the workforce that do incredibly stressful and really important work around the clock, taking them away from their families through the pandemic.

When I had the luxury of working at home, they were there and in many states not acknowledged as first responders and even prioritized for COVID vaccination or the like. We see a sort of similar trend with the professionalization of 988, and that it's not being taken seriously that these are first responders and that they need to be treated and have access to the supports in order to do that job over the long term well. I do know that in many places, Lifeline is at least assisted by volunteers, that there was a smaller call load when it was Lifeline than likely what it will look like in 988. So there's some really big considerations about how this field 911 alone is expected to grow at a pace higher than the population. Right now 911 centers are suffering and that many have 50% vacancy rates. Staff are mandated to work overtime. Very, very stressful, hard work conditions. We think that very likely may be replicated on the 988 front unless there's immediate action to prioritize the needs of this workforce.

Ken Duckworth (00:54:32):

So the supply-demand mismatch that we're seeing in all of mental health holds true, even for the people answering the phone.

Rebecca Neusteter (00:54:39):

Yeah, I think may actually be more attenuated.

Ken Duckworth (00:54:43):

There was an article in the New York Times about that exact problem, that risk that 988 would make it easier for people to call, whether it be the capacity, and NAMI was quoted extensively in that. One person asked the question, "I don't use the suicide prevention lifeline because I'm concerned by calls are traced." Is that accurate? What do we know about that?

Rebecca Neusteter (00:55:06):

I know that the FCC next week is holding a public hearing ... I'll see if I can find the link to that ... If not, maybe NAMI can send that out to folks ... Where they're accepting public comment and that the FCC was supposed to put together a task force to look at this issue. We're pretty close to implementation. So I think there are a lot of unanswered questions about how this will be handled. I know that some folks have expressed deep concerns and use Lifeline because they appreciate the anonymity and the fact that the police will not be deployed. Other folks see that there could be great advantages to having geolocation and being able to send responders who may not otherwise be able to be found. I think it's a very complicated issue. I think that we're overdue communicating with the public what this practice is actually going to look like.

Ken Duckworth (00:56:05):

Jen, will you be able to add that hearing to the notes or slides? Is that possible?

Jennifer Snow (00:56:12):

I can, yes. Rebecca, I believe that the hearing you're referring to actually happened this Tuesday, so it has already happened. I will tell you NAMI, we testified during this forum and shared some of the concerns that we're hearing from the community about while geolocation for purposes of routing calls to the local call center is definitely a needed service ... Because you can imagine if you have a cell phone from where you lived 10 years ago and are connected to that local call center, that's not going to be able to help you get connected to services in your community. We need to be able to have people connected to the call center where they are physically located. However, when you get into geolocation for more specific issues, it is much more complicated because people have legitimate concerns about privacy and not wanting to have their information available in the small instances where an active rescue is required.

Ken Duckworth (00:57:13):

Yeah. I had a meeting today with a person with a Tennessee phone number, and she lives right here in Boston with me. So this illustrates the point. If you don't have geolocation, she'd be routed to a center in the Tennessee area. Is that one of the pieces?

Jennifer Snow (00:57:30):

Ken, you have hit the nail on the head. If you call 988 or if you call the National Suicide Prevention Lifeline at their 1-800 number today, you are going to be routed based on your area code. We know at least 10% of the population doesn't live in the location where their area code is. Someone on our team has a New Hampshire area code although they live in Virginia. If she calls 988 or the Suicide Prevention Lifeline, she will get connected to resources in New Hampshire. This is an issue we have to address. I think that we shared that with FCC and we are very hopeful that they will ... I don't think there was much disagreement in the notion that getting routed to a call center in your state is the right thing to do.

Rebecca Neusteter (00:58:20):

Yeah. Thank you, Jennifer. You're absolutely right that the forum that I was referencing was this week. So we'll be able to find out more, and thanks NAMI for participating in that.

Ken Duckworth (00:58:35):

A bunch of questions on additional services. I just want to go back to this point because it keeps coming up. 988 itself is a convenient way to exist the current system while providing a platform for advocacy. So it does not track peoples who've been discharged too early. It does not do some of the other things we might like to have in a fragmented system. I know I already asked it. I'm asking it a little differently because it's come up a couple times in the questions. Is it still true? It's still true.

Jennifer Snow (00:59:09):

I think Ken, what you're asking is the notion of people getting discharged from hospitals too early or not being able to find outpatient care. That is still an enormous problem, and part of the reason that NAMI exists is to advocate for expansion of those services.

Ken Duckworth (00:59:28):

Yeah. One more question. "How can I help be part of training police officers? I'm a person of color, and I'm reluctant to contact the police. How can I be part of that process?" I know you have several programs, Jen, within NAMI where people share their experience with law enforcement. I just wanted to develop that. So here's a person who wants to be part of that.

Jennifer Snow (00:59:54):

We do. We definitely have opportunities to share your story with law enforcement where we help people kind of understand how to share their stories and talk to their local jurisdictions to help understand the experiences that they have as a person with a mental health condition as a person of color as you indicated. That is certainly something that is a valuable resource. I also wonder, Dr. Neusteter, from your perspective, are there other ways that you would encourage individuals to get involved?

Rebecca Neusteter (01:00:25):

Yeah, I think there are a lot of opportunities to get involved in your local police departments. One of the things that we are really pushing for through our work is increasing access for community members and people who have lived experiences to be part of governing boards as well. I think that, that's something that absolutely needs to happen at the local level.

Rebecca Neusteter:

I encourage everyone to look at the transform911.org website. We have a map there that allows you to see where your 911 center boundaries are. They may or may not be the same as your police department. That's the other thing to be really clear on here is of those 6,000 primary 911 centers, some of them fall under police department, some of them fall under sheriff's department, some of them fall under fire departments, some of them are nonprofit, regional authorities, some of them are even private for-profit corporations running these centers.

It's really important to try to become familiar with the governance structure within your own communities and to advocate. So it may not be city or county. It may be regional, or it may be even more hyper local, like the [inaudible 01:01:35]. In LA County where I currently am, there are about 70 different 911 centers in that ecosystem, primary and secondary ones. There are, I think, 40 something police departments in the County of Los Angeles. But as you start to reach out to folks, there often are what they call civilian police academies, opportunity for community members to be a part of police cadet training and in some jurisdictions, even to be a part of hiring panels for police officers. I think that's absolutely critical and for 911 professionals as well.

Ken Duckworth (01:02:12):

Dr. Neusteter, can you name a couple mistakes that we as a country made with 911 that we should make sure don't get repeated with 988?

Rebecca Neusteter (01:02:21):

Yeah. A couple of mistakes are that we allowed this patchwork system to be able to become the norm without enforcing any sort of standards or baseline of service. Peoples' experiences vary considerably. Some of that's based on your demographic features and how you are perceived by people in the world. But a lot of it is simply dictated by your zip code or where you're calling 911 from. That there's a real opportunity to hear and to think about parity of service and expectation. We have created this sort of national system and, as the second point, with very little federal infrastructure or investment in it. So there's an unfunded mandate that 911 exist in communities and increasingly so 988, yet we have not made an initiative in order to fund or understand these systems.

Going back to the poll and one of the trick questions that we offered about how many calls are made to 911, one of the real failures here is that we haven't ever introduced a national data collection to understand how many people call 911. What are they calling for? What are the outcomes? Are they satisfied? Are we engaging people who actually are in harm's way? Do they feel safe to call? Are they having their needs met? Those are really fundamental, basic questions that we should be able to answer that we simply cannot. Unfortunately, 988 is following that same path.

Ken Duckworth (01:03:51):

Thank you, Dr. Neusteter. These aren't easy questions, right? Last question. Jen, another person has said, "I want to tell my story to law enforcement." Should they contact their local NAMI affiliate? There's 650 across America. Is that the best route, Jen?

Jennifer Snow (01:04:09):

I believe it is. Contact your local NAMI. If they are not collecting, sharing your story with law enforcement, reach out to me. I'll make sure you get connected to the right place.

Ken Duckworth (01:04:22):

Well, I can't thank you enough, Dr. Rebecca Neusteter, Jennifer Snow. You've done amazing work on understanding the history and also in creating the advocacy for 988. Clearly there's a lot more to be done. So let's hop onto the next slide please.

Oh, it turns out NAMI's writing a book. What do you know? All the proceeds go to NAMI. For this book, my team, Jordan Miller and I, interviewed 130 people who use their real names and tell their stories, what they've learned, what's helped them, what helped their family communicate things, how telling your story to law enforcement worked out for them. The history of CIT is in this. Turns out it was started by two NAMI mommies, along with Sam Cochran in Memphis, Tennessee. The book will be on the shelves in September, and there's a book tour that's going to be happening for this if you want to be part of NAMI's first book where all the proceeds go back to NAMI. Next slide please.

Save the date. We're going to have another conversation. This is The Blueprint for Youth Suicide Prevention, and we're going to have national experts from NIMH, the American Foundation for Suicide Prevention, the American Academy of Pediatrics. Basically an all-star team. Next slide please.

The NAMI convention is coming right up. The NAMI convention is virtual, and you can join for a very nominal fee and we'll have people telling their story, all-stars of American research and expertise teaching you things that you might not know. The convention is a beautiful community when it's in person. This year due to the pandemic, it's not in person. But they've been quite successful, and we attract many thousands of people to our convention. That's coming right up. Next slide please.

Remember. You are not alone. This is what the good Dan Gillison, our CEO, would say. If you're interested in things like this or you want to be part of this, feel free to donate to NAMI. We'd be happy to entertain your support. We provide these resources because we love to do it, and it's a free service to the public.

I want to thank everybody. You will get an email with the content of this. This will be up on the NAMI website, nami.org/asktheexpert and you can find it. They are all there. All the previous amazing people that we've had on every topic under the sun. It's an easy time to listen to it. You don't have to watch slides or anything. You can do this while walking your dog or doing the dishes.

I want to thank you for joining us today. Next slide please. The next slide is a blank slide. So I want to say thank you. Nice picture of Jennifer Snow. Certainly a nice picture of Dr. Neusteter. We can do this together. 988 is a project we have to undertake. So the first part, the phone number, is here. The rest of it is up to us as advocates. Thank you everyone, and take care.