A New Day or More of the Same?

*Our Hopes & Fears for 988 (and 911)*

Is 988 the answer? Our hopes, fears, and vision for a more comprehensive community based approach and alternatives for mental health.
A New Day or More of the Same?

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Our Hopes and Fears for 988 (and 911)

Executive Summary

This year will see the rollout of “988,” the new three-digit number for calls to the National Suicide Prevention Lifeline. 988 has been touted as the new “mental health 911.” The federal government and many states and localities are touting 988 as an alternative to and resource for the 911 system, to reduce the number of calls involving people with mental health issues to which the police are sent.

We appreciate support for 988 as part of a more effective response to people experiencing mental health crises. But 988 alone is not enough. More, and more effective, 988 call centers are only part of what is needed to help people with serious mental health issues, especially Black and Brown people who have experienced trauma from over-policing. We also need mobile crisis teams that can timely travel to help de-escalate a situation, and we need community crisis stabilization centers for those times when people need somewhere to go for help. We also need robust longer-term services, including intensive case management, peer services, Assertive Community Treatment (ACT), supported employment, and supported housing, and for children and youth “wraparound” services. These services help people with serious mental health issues live successfully in their own homes and communities—and avoid crisis situations.

This paper proposes a vision for a truly community-based response to people with urgent behavioral health needs. 988 can be part of this response, but is only a part of what we really need.
Introduction

In the wake of the COVID-19 pandemic, and following the national examination of the unjust and deadly policing of Black and Brown people after George Floyd’s murder, communities across the country are exploring new approaches to diverting people with behavioral health issues from contact with law enforcement officers and subsequent incarceration or institutionalization. A critical focus is the impact on Black and Brown people of systems that are supposed to serve and keep everyone safe, including the health and behavioral health systems, and the police, courts, and jails and prisons.

911 is a crucial part of these systems. Operated by state and local government agencies, including law enforcement, fire, and emergency management agencies, 911 employs call-takers working in call centers who screen and triage calls for help, routing them to first responders as appropriate.

In virtually all communities, a call for urgent medical care prompts a response from emergency medical technicians (EMTs), who provide support on the scene to an individual in distress or take them to a hospital emergency room. However, a call concerning an individual needing behavioral health care typically triggers a response from law enforcement officers and not trained behavioral health workers. When the person in question needs to go somewhere for help, the officer’s options are frequently limited to the emergency room or jail.

Between 6 and 10 percent of law enforcement encounters involve people with mental health issues. Police respond when 911 is called out of concern for a loved one, including that the individual may harm themself or others. Police respond when there is disruptive behavior at schools. Police respond to remove homeless individuals from places where they are not wanted, such as parks, plazas, and subways. And police respond when an individual with mental illness engages in behavior that seems disturbing or odd. Police are also deployed to transport people to the hospital, including to receive involuntary care. When police are involved, arrest and incarceration follow—and, too often, the use of deadly force.

States and localities are considering and implementing reforms to 911, such as diverting calls for help with behavioral health issues to alternative first responders with behavioral health expertise. And some communities are encouraging residents to avoid calling 911 altogether when seeking help for a behavioral health issue. National legislation is being implemented establishing a new three-digit number, 988, for behavioral health issues that routes calls to what was formerly known as the National Suicide Prevention Lifeline. The Lifeline is a national network of local nonprofit organizations funded since 2004 by federal and state governments to provide support to people calling a 1-800 number (1-800-273-TALK) who are considering suicide or otherwise need emotional support.
People with lived experience and others have expressed concerns about how the Lifeline operates. Often, a call to the Lifeline results in a visit from the police and incarceration or involuntary hospitalization. Nevertheless, we understand and appreciate the attention paid to 988 as part of a national effort to provide support to people with behavioral health challenges, including those exacerbated by the COVID-19 pandemic. We hope that the 988 rollout will spur public attention to, and additional support for, the historically under-resourced community-based behavioral health system.

It is far from clear, however, that the implementation of 988 will actually result in expanded behavioral health care for people in their homes, schools, and communities. Without an investment in community-based services, we fear that the 988 rollout will result in more of what we have now: law enforcement responding to people with behavioral health issues, needless deaths, and overreliance on jails, hospitals and emergency rooms, especially for Black and Brown people. And if the existence of a new “mental health 911” actually increases calls for help with behavioral health issues, the number of law enforcement contacts with people with behavioral health challenges may actually increase.

It doesn’t have to be this way. Below, we propose an alternative vision for a truly community-based response to people with urgent behavioral health needs.

**A Mental Health Crisis**

Even before the COVID-19 pandemic, the United States was experiencing what many have called a “mental health crisis.” In 2020, the federal government reported that 52.9 million (21 percent) adults had some mental health needs. Of these, 14.2 million adults had a condition—like major depression, bipolar disorder, or schizophrenia—that the government defines as “serious mental illness” (SMI). Another 27.6 million adults had a substance use disorder (SUD) that year, and 5.7 million adults had both SMI and an SUD. And pre-COVID-19 studies indicated that as many as one in six children and youth ages 6-17 experience a mental health disorder such as depression or anxiety or have attention deficit hyperactivity disorder (ADHD).

Many people with behavioral health conditions can’t get treatment. In 2016, 11.8 million Americans aged 18 or older needed but did not receive mental health services. In the same year, only about one in nine people with an SUD received treatment. And only half of all children and youth with a mental health condition receive treatment, in school or anywhere else. In the United States, individuals with untreated mental health conditions are far more likely to be killed by law enforcement than are others.

These trends are all too familiar, and far more prevalent, in our country’s Black and Brown communities. Groups that have been historically disadvantaged and discriminated against, such as African Americans and Native Americans, are engaged in mental health services at far lower rates than are other groups. Studies show that Black and Brown people are less likely to have their behavioral health conditions diagnosed, and more likely to receive
inadequate care. Black and Brown children are less likely to receive mental health services in school or in other community settings, and more likely to be punished for their behavior.

The over-policing of Black and Brown people contributes to these disparities. A study of residents of Baltimore and New York City found that communities of color had greater exposure to law enforcement and that this exposure was associated with greater likelihood of psychological distress, current suicidal ideation, suicide attempts, and psychotic experiences.

The COVID-19 pandemic has exacerbated these trends. Social isolation resulted in increased loneliness, depression, and anxiety. In January 2022, the federal Centers for Disease Control and Prevention reported that 32 percent of adults said they experienced symptoms of anxiety or depression—nearly three times as high as the 11 percent of adults who reported these symptoms in 2019. In the past year, 14 percent of adolescents report experiencing a major depressive episode, and 4 percent report having an SUD.

Black and Brown communities have been the hardest hit. During the pandemic, Black and Latinx adults were significantly more likely to report symptoms of anxiety or depression than were White adults. In addition, Black and Brown workers have been overrepresented among essential workers required to work outside the home. These workers are more likely to become ill from COVID-19, experience mental health symptoms such as anxiety or depression, and experience trauma from living with increased risk of infection or loss of income.

At the same time, the COVID-19 pandemic has limited the availability of behavioral health services. Many providers have reported reduced capacity to provide community-based behavioral health services, due to challenges in recruiting and retaining staff that have depleted already strained service delivery systems.

Policymakers acknowledge that a mental health crisis exists, and are seeking solutions. The jury is out on whether these solutions will advance an effective and equitable system of alternative first responders, or an expansion of community services that are effective in helping individuals avoid arrest and incarceration.
In July 2020 Congress enacted the National Suicide Hotline Designation Act. The Act created a nationwide three-digit number, 988, which people can call when they or others are experiencing a behavioral health crisis.

As noted, 988 is intended to expand and enhance the National Suicide Prevention Lifeline network of call centers that respond to people with mental health issues, including when considering suicide. The Lifeline is a program of the federal Substance Abuse and Mental Health Services Administration (SAMHSA). Since its inception in 2004, the Lifeline has been implemented by a network of crisis centers that provide “24/7” counseling to persons calling the Lifeline’s toll-free phone number, 1-800-273-TALK. The Lifeline offers support to callers who speak languages other than English, through a Spanish language hotline and interpreter services, and to deaf or hard of hearing callers, including through relay services. In 2007, the federal Department of Veterans Affairs partnered with SAMHSA to create a special hotline for veterans seeking emotional support. Later, a web-based Lifeline Chat program was added so that people seeking support could contact a counselor and obtain help via text messages.
988 is supposed to become operational by July 16, 2022. States are permitted to collect fees to support the Lifeline, as they do to support the 911 system. Congress has also appropriated additional federal funding to support the Lifeline network and additional appropriations have been proposed. The federal funding to date has not allowed a significant expansion of the Lifeline network, and as of March 2022 only a few states had enacted fee legislation to provide additional funding.

The Lifeline reports that its call centers have received almost 20.5 million calls since it began operations in 2005. According to the Lifeline, 95 percent of callers are connected to a trained counselor, who may be a paid staff member or a volunteer, within 60-90 seconds. Numerous studies of Lifeline calls have shown that the majority of callers are more likely to feel less depressed, less suicidal, less overwhelmed and more hopeful after speaking with a Lifeline counselor. And Lifeline call centers may provide other services within the communities they serve.

Still, there are significant concerns about the Lifeline. There are reports that many calls or texts to the Lifeline go unanswered, or that in many cases the call-taker’s response is unhelpful. Many people with behavioral health issues do not use the Lifeline because calls to the Lifeline too often result in unwanted visits from the police—much as do calls to 911—with forced treatment, hospitalization, or incarceration as a result.

Even though the Lifeline advertises its services as confidential, thousands of calls—and perhaps tens or hundreds of thousands of calls—are traced so that emergency responders, such as the police, can be sent to the scene. This happens whether or not the caller intended or desired such a response.

When someone calls the Lifeline, the call-taker makes an assessment of the risk the caller will harm themselves, including whether the means to harm are readily available to them. SAMHSA’s data indicates that about two percent of calls to the Lifeline are deemed to present an “imminent risk” of suicide, and result in police being sent to the caller. This happens whether or not the caller requests such a response, or agrees to it: the Lifeline can obtain location information from the caller’s phone service provider, or can ping the GPS chip in the caller’s cell phone. One report analyzing the SAMHSA data concluded that as many as 44,000 calls to the Lifeline resulted in visits by police in the year from October 1, 2017 to September 30, 2018. The same year, there were approximately 108,000 instances of behavioral health mobile response teams being sent to the caller. These teams were often accompanied by the police. The Lifeline projects that by 2027 its call centers will process some 40 million calls annually. If this is accurate, and the police continue to be dispatched in response to calls 2 percent of the time, police would be sent to 800,000 Lifeline callers each year. Many other callers would receive a hybrid police-behavioral health mobile team response. This would happen whether this was what the caller intended, or wanted, based on the call center’s risk assessment and protocol.
When Calling the Lifeline Does More Harm Than Good

A 2020 Mad in America article included interviews with a number of individuals whose calls to the Lifeline prompted a visit from the police and a trip to the hospital, with significant and unintended disruption to their lives.67

S., a Black veteran in his 20s, called the Lifeline during his lunch period. After 10 minutes, he ended the call and went back to work. Twenty minutes later, police officers arrived at his workplace. The police escorted S. to an ambulance. All of S.’s co-workers and his supervisor saw him get taken away. S. was detained for several hours at a veteran’s hospital. He received a bill for $1500 for the ambulance, and was laid off his job three months later.

H., a young white law student, called the Lifeline when she was depressed. The call-taker asked her how she would kill herself, and then suggested she go to a psychiatric hospital. H. ended the call so that she could go to a class. Fifteen minutes later, the police and an ambulance arrived. The police strapped her to a stretcher and helped carry H. to the ambulance, which then took her to the hospital. She was kept in the hospital for two weeks. She was discharged with a $50,000 bill. H. expressed concern that anything hospital staff said about her would be communicated to bar examiners, who could question her mental fitness for practicing law and deny or condition her law license after law school.

J., a Ph.D. student and transgender man of Middle Eastern descent, called the Lifeline from a disposable phone. Even though J. took the battery out of the phone after the call, police found him and took him to the hospital, where he was injected with psychiatric medication. He was discharged a week later, so traumatized that he dropped out of school.

The Lifeline is aware of concerns raised by stories such as these. A committee of people with lived experience that advises the Lifeline met in October 2020 to discuss concerns about sending police to callers without their knowledge.68 According to the minutes of this meeting, the discussion focused on a number of issues:

“[H]ow a fear of 911 being contacted can deter people from getting Lifeline help; how, in some cases, law enforcement intrusion in suicidal crises can aggravate pre-existing family conflicts (or create new ones), including creating more risks; how 911 can have financial costs (unexpected bills for unwanted service, etc); and how police encounters with historically marginalized/victimized/oppressed groups can create unintended harms, including violence, traumatization and criminalization.”69

Research has questioned the validity and effectiveness of the assessments that the Lifeline call centers use to determine risk. In a recent report, the National Council on Disability described a meta-analysis synthesizing 50 years of research and found that “science could only predict future suicidal thoughts and behaviors about as well as random guessing. In other words, a suicide expert who conducted an in-depth assessment of risk factors would predict a patient’s future suicidal thoughts and behaviors with the same degree of accuracy
as someone with no knowledge . . . who predicted based on a coin flip.” A 2018 study found that suicide risk assessment protocols all produce an “unacceptably high false positive rate.” And a 2016 study of Lifeline call centers stated that their concept of “Imminent risk” “is fraught with problems such as lack of clarity and imprecision.”

Moreover, there is limited capacity for non-police responses. In many parts of the country, including in many rural areas, behavioral health mobile teams do not exist or cannot timely respond to most calls. In these communities, by default law enforcement officers are the first responders. Even in urban areas, behavioral health mobile response teams are not always available on a 24/7 basis. They may not operate during overnight hours, when many calls are made. Also, mobile teams will not respond to certain types of calls without being accompanied by the police.

There are also concerns whether call centers will make a culturally competent response. Although in some parts of the country there are many Lifeline call centers, in broad swaths of the country there is only one statewide center, which may not be aware of the cultural norms of the caller’s community, or the resources available to people with behavioral health issues in that community. Also, when a call center cannot take a call, it is re-routed to other call centers, which may be outside the state. There is little information on the professional or life experience of call center staff and whether they have received effective training, including on implicit bias, the effect of trauma on mental health, and other areas key to ensuring cross-cultural competence.

Further, in most if not all of the country, it is unlikely that a Lifeline call will result in the caller receiving the services and supports needed to reduce the likelihood of calls to the hotline in the future. People, including those who rely on public health systems and Medicaid for support, often lack access to intensive services, such as case management or services from a multidisciplinary team such as an Assertive Community Treatment (ACT) team. For individuals who are unhoused or housing insecure, there is not enough affordable housing or providers of services that help people find and maintain housing. And for people who rely on private insurance, despite federal law requiring that coverage for behavioral health treatment be on par with other forms of care, individuals often cannot get the behavioral health services they need, either because the plan does not authorize them, or because there are not enough providers.

For all of these reasons, the rollout of 988 is at best only a partial solution for responding to behavioral health crises and the harmful involvement of law enforcement in such responses, which especially affects Black and Brown people.

There is another, better approach. And we know what investments need to be made to get there.
A More Comprehensive Solution

We share the goals behind the creation of 988, including reduced reliance on law enforcement. Law enforcement involvement in calls involving people with behavioral health issues should be reduced to as close to zero as possible. Expanding and improving the 988 network, while important, will not accomplish this. And having call centers that respond effectively to “mental health 911” calls is only a part of the solution. Every community must have a behavioral health system that provides the longer-term services and supports people need to live successfully in the community—and to avoid crises.

988 call centers should be staffed by people skilled at engaging callers and understanding what circumstances led the caller to make the call. In addition to mental health clinicians, 988 call centers should employ people with lived experience working as peers.

There are well-established call center networks, outside of Lifeline, led by people with lived experience that have created a “peer-to-peer” ethos that makes their services especially effective. These call centers maintain a strict confidentiality policy: they do not trace the caller’s location, and they do not dispatch a response unless the caller agrees and provides their location. These are best practices. Although we understand that 988 call-takers may...
feel they may need to sometimes dispatch a response without consent, they should not. This practice, which risks a police response and forcible transport to a hospital or jail, discourages many people from calling for help in the first place. Moreover, information sharing based on consent encourages trust between the caller and call-taker, and encourages the caller’s engagement with the behavioral health service system. Geolocation for routing calls to the nearest call center can be limited to identifying the area code in which the caller is located, and connecting the caller to a call center serving that area code.

Hotlines—and warmlines—must also be accessible to all people, including people with disabilities that affect communication. This means ensuring that every call center (or, perhaps, one national back-up center) can provide an ASL-trained counselor or ASL or other interpretive services for people who are deaf or hard of hearing and a text or chat option for people for whom that mode of communication is their preference. There should be ongoing training on communications with people with intellectual or developmental disabilities, and with autistic people.

Call centers should be part of, and integrated into, the behavioral health system, so there is truly a “mental health 911.” The 988 system should not stand alone, but should be part of, and should help manage, a comprehensive, non-coercive system for addressing behavioral health crises that includes mobile teams and an array of short-term residential options.

Call centers can resolve many calls by providing advice, making referrals, and/or providing transportation to a community-based service provider. Other calls will require dispatching a mobile team to respond quickly and de-escalate situations, and connect individuals with needed services. Over the past few years, many communities have implemented mobile services modeled on Oregon’s CAHOOTS program, in which an emergency medical technician (EMT) and a mental health clinician, both unarmed, are dispatched to respond to calls involving people with behavioral health issues instead of the police. Some communities, like San Francisco, have adapted the CAHOOTS model so that it includes a peer on the team. And other communities, like Baltimore, are expanding their capacity to send teams consisting of a peer and a clinician to respond to behavioral health calls instead of the police. Such teams should be available 24 hours a day, seven days a week, 365 days a year, and should respond within a time frame that is comparable to that of law enforcement, so that these teams are a meaningful alternative to a police response.

In addition, there should be an array of facilities for crisis resolution and stabilization, including for overnight stays. These facilities should include respite apartments, apartments for short term stays staffed by mental health professionals including (and often led by) peers, and urgent care centers using a “living room” model. They should be scattered in neighborhoods in urban areas. Inpatient hospital care should be a last resort and used only when necessary, for example, when a person’s physical health care must be provided in an inpatient setting. Short-term detox facilities should be available as well, followed by offers of treatment of substance use disorders, including community-based
medication assisted treatment (MAT). People with lived experience are providing care and support, and often leading, the operation of all these types of crisis facilities. Communities should adopt a “no wrong door” approach: any facility operating within the crisis system should be able to accept referrals, walk-ins, and first responder drop-offs, at any time.

These components of a behavioral health crisis response system—someone for a person to talk to, someone to go to the person, and somewhere for the person to go—provide a robust and effective response to individuals in crisis. They are also a resource for the 911 system, which can connect calls to 988 if they involve a person known to have or who appears to have a behavioral health issue. Such calls should be handled by 988 and the behavioral health system. (It would be helpful for mental health professionals, including clinicians but also peers, to work within the 911 call center, to help appropriately triage and route calls.)

In a limited number of cases, it may be appropriate for the police to respond jointly with or as backup for the behavioral health system. Communities should collect and analyze data, adopt policies, and provide training to 988, 911, and police staff, identifying those situations that can and should be handled entirely by 988 and the behavioral health system and those situations, such as those involving imminent violence to others, in which the police should also respond. 988 and 911 service providers, and law enforcement agencies, should audit those instances when police are dispatched, to better understand whether involving the police was appropriate. The police should not be deployed when an individual only poses a threat of self-harm and presents no risk to others.

**Core Values in Responding to Behavioral Health Crises**

In 2009, the Bazelon Center convened a panel of experts who identified ten essential values for responding to behavioral health crises. The experts’ report was subsequently reviewed by a second panel of subject-matter experts. The ten core values are:

- **Avoiding Harm.** An appropriate response to behavioral health crises considers the risks and benefits attendant to interventions and whenever possible employs alternative approaches, such as controlling danger sufficiently to allow a period of “watchful waiting.” In circumstances where there is an urgent need to establish physical safety and few viable alternatives to address an immediate risk of significant harm to the individual or others, an appropriate crisis response incorporates measures to minimize the duration and negative impact of interventions used.

- **Intervening in Person-Centered Ways.** Appropriate interventions seek to understand the individual, their unique circumstances, and how that individual’s personal preferences and goals can be maximally incorporated in the crisis response.

- **Shared Responsibility.** An appropriate crisis response seeks to assist the individual in regaining control by considering the individual an active partner in—rather than a passive recipient of—services.
• **Addressing Trauma.** It is essential that once physical safety has been established, harm resulting from the crisis or crisis response is evaluated and addressed without delay by individuals qualified to diagnose and initiate needed treatment. There is also a dual responsibility relating the individual’s relevant trauma history and vulnerabilities associated with particular interventions; crisis responders should appropriately seek out and incorporate this information in their approaches, and individuals should take personal responsibility for making this crucial information available.

• **Establishing Feelings of Personal Safety.** Assisting the individual in attaining the subjective goal of personal safety requires an understanding of what is needed for that person to experience a sense of security (perhaps contained in a crisis plan or personal safety plan previously formulated by the individual) and what interventions increase feelings of vulnerability (for instance, confinement in a room alone). Providing such assistance also requires that staff be afforded time to gain an understanding of the individual’s needs and latitude to address these needs creatively.

• **Based on Strengths.** An appropriate crisis response seeks to identify and reinforce the resources on which an individual can draw, not only to recover from the crisis event, but to also help protect against further occurrences.

• **The Whole Person.** An individual with a behavioral health issue who is in crisis is a whole person, whose established psychiatric disability may be relevant but may—or may not—be immediately paramount. An individual’s emergency may reflect the interplay of psychiatric issues with other health factors. And there may be a host of seemingly mundane, real-world concerns that significantly affect an individual’s response: the whereabouts of the person’s children, the welfare of pets, whether the house is locked, absences from work, and so on.

• **The Person as Credible Source.** An appropriate response to an individual in crisis is not dismissive of the person as a credible source of information—factual or emotional—that is important to understanding the person’s strengths and needs.

• **Recovery, Resilience, and Natural Supports.** An appropriate crisis response contributes to the individual’s larger journey toward recovery and resilience and incorporates these values. Accordingly, interventions should preserve dignity, foster a sense of hope, and promote engagement with formal systems and informal resources.

• **Prevention.** An adequate crisis response requires measures that address the person’s unmet needs both through individualized planning and by promoting systemic improvements.
People who receive crisis care often lack access to ongoing behavioral health services. The crisis response system should link individuals to providers of longer-term, community-based services, which can help the person in meeting needs for on-going behavioral health care, other supportive services, and stable housing. Every community should have an array of community-based services, of adequate quantity and intensity. First responders should quickly and easily connect people to these services.

Among the services that should be available to those who have used the crisis system are: intensive case management, peer support services, Assertive Community Treatment (ACT), supported employment, and supported housing. For children and youth, available services should be wrapped around the child and family, through a plan developed by a multi-disciplinary team partnering with the child and family. In addition, there should be access to suicide risk-reducing treatments such as Cognitive Behavioral Therapy (CBT), Dialectical Behavioral Therapy (DBT), and Collaborative Assessment and Management of Suicidality. Providers of on-going services should help individuals put together “crisis plans” and should be the preferred “front line” crisis responder for the individuals they are serving. If provided as needed, these services significantly reduce contact with the police and visits to the emergency room.

To be effective, all of these services must be culturally competent and non-discriminatory. Outcomes must be measured. Services should be adapted to make them effective for all communities. Services must be delivered in a way that acknowledges the trauma community members have experienced, and that uses a trauma-informed, person-centered, recovery-focused approach.

Agencies providing services must ensure that staff understand the cultural norms and socio-economic challenges of their communities, including through involving community members with lived experience. Staff should be trained in how to avoid both implicit and explicit bias in providing supports to Black and Brown people, English learners, LGBTQ people, individuals with substance use histories, homeless people, and others. Studies show that biases about such persons are as likely to be found among staff in social service agencies as anywhere else. Regular training to help eradicate these biases is a must. Incorporating peer workers as service providers should help.
Federal Support for an Effective Behavioral Health Response to 988 Calls

In addition to collecting and allocating their own revenues, states and localities should take advantage of existing federal resources to help them develop a comprehensive behavioral health system that functions as a meaningful alternative to a law enforcement response to calls for help. But the federal government can and should do more.

In 2021, Congress enacted the American Rescue Plan Act (ARPA), which contains significant support for community-based services. The ARPA created a new funding stream within Medicaid for states to use to make behavioral health mobile response services more available to people who need them. The funding stream can be tapped for three years during a five-year period, beginning April 1, 2022. When a state applies for this new funding, the federal government pays for 85 percent of the cost (or more in the few states with a regular match greater than 85%). The State must file an amendment to its Medicaid plan or seek or amend a waiver to secure the additional funding. ARPA-funded mobile response teams must be available 24/7, include a mental health clinician, and provide a timely response, as defined by the state.

The ARPA also increased the amount of federal reimbursement available under the Medicaid program for one year for what the law calls Home and Community Based Services (HCBS). For the year beginning April 1, 2021, the ARPA added an additional ten percent to the federal “match” rate. If a state’s match rate was 60 percent—meaning the federal government paid 60% of the cost of HCBS—the new match rate would be 70 percent, with the federal government paying 70 percent of the cost. States could use this money to pay for the array of services that help people with behavioral health issues live successfully in the community.

Now that ARPA’s increased support for HCBS has ended, Congress should act to extend that support. In November 2021, the House of Representatives passed the Build Back Better Act, which included $150 billion, the largest investment ever, in federal financial resources for HCBS. The Build Back Better Act also allocated another $150 billion in federal support for affordable housing. These investments are urgently needed to help states and localities build the behavioral health system that we need in this country.

Conclusion

A new day, or more of the same? This year’s rollout of 988 may improve our nation’s capacity to respond to individuals who need immediate help. But 988 is only part of the answer, and should not be the end of the story. We need a comprehensive and coordinated approach. In addition to a “mental health 911” we need the longer-term community-based services, in adequate quantity and intensity, identified here, including intensive case management, peer support services, Assertive Community Treatment (ACT), supported employment, and supported housing, and for children and youth “wraparound” services. These services help people avoid crises and subsequent arrest, incarceration, emergency room visits, and
hospital stays. They should be available to every person who needs them in every community across the country. Only when these services are widely available to those who need them can we say that we have addressed our national mental health crisis.

Anything short of that is not enough.

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2 The term “behavioral health” has been defined as “the emotions and behaviors that affect your overall well-being.” *Behavioral Health*, CMS.gov, https://www.cms.gov/outreach-education/american-indianalaska-native/behavioral-health (Nov. 17, 2020). The term “mental health” is sometimes used interchangeably with “behavioral health,” id., but mental health is sometimes said to be a subset of behavioral health, which also includes substance use issues. Many people with behavioral health issues are protected by civil rights laws such as the Americans with Disabilities Act; for that reason, this paper sometimes refers to people who have “mental health disabilities.” However, many people do not use any of these labels to describe themselves. Some people refer to having “lived experience” with mental health conditions. Other people use other terms to describe themselves and others with such issues. See, e.g., u/MadQueerResearcher, *Queer MMIND (Mad, Mentally Ill, Neurodivergent, and Disabled) College Student Experiences*, Reddit (Oct. 15, 2021), https://www.reddit.com/r/SampleSize/comments/q8ouhg/academic_queer_mmind_mad_mentally_ill/.


6 Corey Mitchell, Joe Yerardi & Susan Ferriss, *When schools call police on kids*, The Center for Public Integrity (Sep. 8, 2021), https://publicintegrity.org/education/criminalizing-kids/police-in-schools-disparities/ (explaining that Black children and students with disabilities are the most impacted by law enforcement interactions in school).

Results

Eunice Park
Disorders and Disparities of Mental Health Care Use in Children, 173 JAMA Pediatrics 389 (2019),
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beginning in July 2022. See National Suicide Hotline Designation Act of 2020, Pub. L. 116-172 (2020); see
also Designating 988 for the National Suicide Prevention Lifeline, 47 CFR § 52.200 (2020). The federal
government has appropriated additional funding to support the transition to 988, including to expand
and strengthen the Lifeline’s call center network.


13 See, e.g., Rob Wipond, Government Forum Reveals 988 Call Tracing Remains a Threat, Mad in America
(May 31, 2022) [hereinafter Call Tracing] (calculating that an estimated 60,000 people, or 8 percent of
callers to the Lifeline who express suicidal worries, received unwanted visits from police or other forms

14 Rachel Roubein, A new 9-1-1 for mental health is on the way, Wash. Post (Mar. 21, 2022),
https://www.washingtonpost.com/politics/2022/03/21/new-9-1-1-mental-health-is-way/.

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Part 1. Defining the crisis, 26 J. Psychiatric Prac. 52 (2020); Maddy Reinert, Danielle Fritze & Theresa
Nguyen, The State of Mental Health in America 2022, Mental Health America (October 2021).

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H-56, Key substance use and mental health indicators in the United States: Results from the 2020
National Survey on Drug Use and Health 3 (2021).

17 Id.

18 Id.

Daniel G. Whitney & Mark D. Peterson, US National and State Level Prevalence of Mental Health
20 Eunice Park-Lee et al., Receipt of services for substance use and mental health issues among adults:
Results from the 2016 National Survey on Drug Use and Health 16 (2017) (estimate of perceived unmet
need based on responses to survey question asking whether there was any time in the past 12 months
when participants thought they needed treatment or counseling for mental health issues but did not
receive services).

21 Id. at 4.

22 Daniel G. Whitney & Mark D. Peterson, US National and State-Level Prevalence of Mental Health

23 Alexandra Sifferlin, Untreated Mentally Ill 16 Times More Likely to Be Killed By Police, Study Says, Time
Overlooked in the Undercounted: The Role of Mental Illness in Fatal Law Enforcement Encounters
(2015)).


29 Jordan E. DeVylder et al., Association of exposure to police violence with prevalence of mental health symptoms among urban residents in the United States, 1 JAMA Network Open (2018).


33 The Impact of COVID-19, supra note 10, at 185; Panchal, supra note 33.

34 The Impact of COVID-19, supra note 10, at 88, 192.


40 id.

FAQ, Nat'l Suicide Prevention Lifeline, https://suicidepreventionlifeline.org/faq/.

See supra note 43 at 4.


See supra note 39.


See generally Arlene Stephenson, States’ Experiences in Legislating 988 and Crisis Services Systems, Nat’l Ass’n of State Mental Health Program Directors 6 (2022).

Suicide Prevention By the Numbers, Nat'l Suicide Prevention Lifeline, https://suicidepreventionlifeline.org/by-the-numbers/ (last visited June 1, 2022).

Id. However, when calls are rerouted out of state, callers in crisis “often wait two to three times longer, receive fewer linkages to effective local care, and are more likely to abandon their calls.” See Lifeline State Reports, Nat’l Suicide Prevention Lifeline (last visited May 31, 2022), https://suicidepreventionlifeline.org/lifeline-state-reports/. In the first quarter of 2022, only 20 states and DC had in-state answer rates at 80 percent or higher; states like Ohio (56%), Arkansas (53%), and Texas (45%) fell far short. In-State Answer Report Jan-March 2020, Nat’l Suicide Prevention Hotline, https://suicidepreventionlifeline.org/wp-content/uploads/2022/04/2022-01_2022-03-31_instate_report-3.pdf.

See supra note 53.

See, e.g., Didi Hirsch Mental Health Services, Suicide Prevention & Counseling Center (Lifeline network member organization that also provides peer support groups, individual and family therapy, and “therapy step down” services for individuals who are discharged from hospital after suicide attempt), https://didihirsch.org/services/suicide-prevention/ (last visited May 15, 2015).

Laderer, supra note 6. In addition, roughly 17 percent of calls, 41 percent of texts, and 73 percent of chats to the Lifeline are abandoned before a caller can get help. Steve Eder, As a Crisis Hotline Grows, So Do Fears It Won’t Be Ready, N. Y. Times (Mar. 17, 2022), https://www.nytimes.com/2022/03/13/us/suicide-hotline-mental-health-988.html.

Laderer, supra note 6.

30 (“[T]he use of involuntary interventions paired with technologies like geolocation could prevent people in crisis from initiating contact if they are worried about their privacy or safety.”); What happens if I call the Suicide Prevention Lifeline?, Mental Health America, https://screening.mhanational.org/content/what-happens-if-i-call-suicide-prevention-lifeline/layout-ah-topics (“We know that a lot of people may be scared to call the Lifeline because they are concerned about the police coming to their house”); Rob Wipond, Suicide Hotlines Bill Themselves as Confidential – Even as Some Trace Your Call, Mad in America (Nov. 29, 2020) [hereinafter Suicide Hotlines] (estimating that 44,000 Lifeline callers were visited by police in fiscal year 2017-18), https://www.madinamerica.com/2020/11/suicide-hotlines-trace-your-call; see also Call Tracing, supra note 14 (“Many times—I have had this happen in my own life—we’re calling for help, and it ends up in harm, it ends up in handcuffs. And worse, for many people, it also ends up in death; not at their hands, but at the hands of the response team.”)

57 Suicide Hotlines, supra note 58; see also Call Tracing, supra note 14.

58 Suicide Hotlines, supra note 58 (noting SAMHSA data indicating that some Lifeline calls to which police have been sent reportedly involve caller “collaboration,” but that this number includes calls where callers felt some pressure to agree to police response).


60 Suicide Hotlines, supra note 58; Call Tracing, supra note 14.

61 Suicide Hotlines, supra note 58 (citing methods for call tracing in paper published by National Emergency Number Association); see also Public Safety Considerations for Smartphone App Developers, Nat’l Emergency Number Ass’n (describing how cell phones with location services enabled will provide GPS coordinates to 911 centers), https://www.nena.org/page/SmartphoneApps?hhsearchterms=%22gps+and+phone%22 (last visited May 15, 2022).

62 Suicide Hotlines, supra note 58.

63 Id.


65 The Impact of COVID-19, supra note 10, at 196.


67 Suicide Hotlines, supra note 58.


69 Id.


Madelyn Gould et al., Helping Callers to the National Suicide Prevention Lifeline Who Are at Imminent Risk of Suicide: Evaluation of Caller Risk Profiles and Interventions Implemented, 46 Suicide Life Threatening Behav. 172 (2016).

Nat’l Suicide Prevention Lifeline, Policy for Helping Callers at Imminent Risk of Suicide 28 (Dec. 2010).

Id. at 16 (“Mobile outreach services vary considerably in their availability in communities around the country, with differences in hours of operation (some 24/7, others not), capacity to respond urgently (within an hour in some regions), and staff make-up.”).

See, e.g., Isselbacher, supra note 66 (quoting leader from CAHOOTS program that “we rely on law enforcement to sometimes back us up”).

Cultural competence is the ability to provide effective services that are responsive and accessible to the unique cultural needs of diverse populations, taking into consideration factors such as race, ethnicity, religion, language, age, sexual orientation, gender orientation, socioeconomic status, and geographic location. Substance Abuse & Mental Health Serv. Admin., Treatment Improvement Protocol 59, HHS Pub. No. (SMA) 14-4849, Improving Cultural Competence 5 (2014). “Cultural competence provides clients with more opportunities to access services that reflect a cultural perspective on and alternative, culturally congruent approaches to their presenting problems [that] will likely provide a greater sense of safety from the client’s perspective”. Id. at 7. Although the Affordable Care Act necessitates culturally responsive services, studies show that a lack of cultural competence contributes to “disparities in access, utilization, and quality in behavioral health services” and can translate to “ineffective provider-consumer communication, delays in appropriate treatment and level of care ... and poorer outcomes.” Id.


New Research, supra note 79.

See, e.g., Spivak et al., Availability of Assertive Community Treatment in the United States: 2010 to 2016, 70 Psychiatric Serv. 948, 948-9 (2019) [defining ACT as “a multi-disciplinary clinical team approach, [which] helps those with serious mental illness live in the community by providing 24-hour intensive community services in the individual’s natural setting,” and noting that study of all mental health facilities in the U.S. indicated that, “[a]lthough a higher proportion of facilities that provided ACT reported offering all the required [components] in 2016 compared with 2010, this proportion accounted for less than 20% of the programs”).

See, e.g., Nat’l Low Income Housing Coal., The Gap: A Shortage of Affordable Rental Homes 3 (Apr. 2022) (reporting that in the U.S. only 36 rental homes are affordable and available for every 100 extremely low-income renter households); Henwood et al., Availability of Comprehensive Services in Permanent Supportive Housing in Los Angeles, 26 Health Soc. Care Cmty. 207 (2018) (study of 23
housing providers in Los Angeles indicated that, “although services may be available to some residents .
. . staff members indicated that services are not necessarily routinely accessible to all residents depending on
factors such as housing location or different provider contracts. In addition, the availability of services does not
imply that they are integrated or even well-coordinated, which is especially important for individuals with complex
health and social needs”).

82 See, e.g., Guin Becker Bogusz, Health Insurers Still Don’t Adequately Cover Mental
2020/Health-Insurers-Still-Don’t-Adequately-Cover-Mental-Health-Treatment.

83 See Tenn. Dep’t of Mental Health & Substance Abuse Serv., Crisis Responder Training 13 (describing
Lifeline guidelines for call-takers, including “active engagement” with callers “to establish sufficient
rapport” with callers, and collaborating with callers in order to “[i]nclude the individual’s wishes, plans,
needs, and capacities” to reduce risk of suicide), https://www.tn.gov/content/dam/tn/mentalhealth/documents/Crisi
s%20Responder%20Training%20All _PDF.pdf (last visited May 15, 2015); but see Laderer, supra note 6 (concerns about when Lifeline call-
takers “parrot” the caller’s words, and use “reflective listening in a really obtuse and unhelpful way” that
prompts acts of self-harm, rather than prevents them).

84 See, e.g., Online and Phone Supports, Wildflower Alliance, https://wildfloweralliance.org/online-
support-groups/ (last visited May 15, 2022) (hosting peer-led suicide-related support groups both online
and by phone).

85 See Privacy Policy, Wildflower Alliance, https://wildfloweralliance.org/privacy-policy/ (last visited May
15, 2022); Central London Samaritans Privacy Statement, Samaritans UK,
https://www.samaritans.org/branches/central-london/central-london-samaritans-privacy-statement/
(last visited May 15, 2022), (“Our telephone helpline is designed so that Samaritans volunteers can’t see
your phone number when you contact us……In general, we try to keep as little information about you as
possible. Volunteers may take notes when they talk to you to assist in the conversation. These notes
are shredded at the end of the call. We don’t record your phone calls to the helpline but volunteers and
staff may from time to time listen in to calls for training, support, or research purposes. … [Also,] [i]f we
need to investigate a call or series of calls (e.g. if you make a complaint), we can use an encrypted
telephone number shown on our central system to identify the specific calls.”).

86 See Wireless Competition Bureau, Fed. Commc’n Comm’n, 988 Geolocation Report – National Suicide
Hotline Designation Act of 2020 11 (Apr. 15, 2021) (“[S]ome commenters have raised concerns that the
conveyance of geolocation information with 988 calls could undermine the benefits of the Lifeline by
dissuading at-risk and vulnerable populations from using the service in a time of need, out of fear of
embarrassment, aversion to intervention by authorities, or other similar reasons.”).

87 Rob Wipond, Roll-out of 988 Threatens Anonymity of Crisis Hotlines, Mad in America (Jan. 29, 2022),
https://www.madinamerica.com/2022/01/roll-988-threatens-anonymity-crisis-hotlines/ (reporting
ACLU Disability Rights Program director’s statement that “[i]t would be better and technologically
feasible …to connect callers with their nearest call center by geolocating them based on the general
area they were calling from while disclosing no other personal information”).

88 A “warmline” is a phone line, often operated by people with lived experience with mental health
issues, that is designed as an alternative to “hotline” services, for people who are not actually in crisis
but who are still seeking support. See, e.g., Warmlines (last visited May 31, 2022),
https://warmline.org/. Warmlines that can help callers by listening, providing feedback, and helping link
them to other resources are also a crucial component of a community behavioral health system.

89 See, e.g., Nat’l Assoc. of State Mental Health Program Directors, NASMHPD Recommendations for
Effective Communication Planning and Response with Deaf Communities for 988,
https://mh.alabama.gov/wp-content/uploads/2022/03/NASMHPD-Recommendations-on-988-and-Deaf-
Culture Change, hospital visited May 16, 2022) (“Rose Houses are short-term crisis respite centers, an alternative to psychiatric hospitalization... [The] Living Room is a calm, peaceful, and inviting space with plenty of natural light. ... Staff at The Living Room help guests through a screening and assessment process in a natural, comfortable setting.”).

96 Types of Treatment Programs, Nat’l Inst. on Drug Abuse, https://nida.nih.gov/publications/principles-drug-addiction-treatment-research-based-guide-third-edition/drug-addiction-treatment-in-united-states/types-treatment-programs (last visited May 16, 2022) (“Detoxification, the process by which the body clears itself of drugs, is designed to manage the acute and potentially dangerous physiological effects of stopping drug use... [It should] be followed by a formal assessment and referral to drug addiction treatment.”); Medication-Assisted Treatment, SAMHSA, https://www.samhsa.gov/medication-assisted-treatment (last visited May 16, 2022) (“Medication-assisted treatment (MAT) is the use of medications, in combination with counseling and behavioral therapies, to provide a ‘whole-patient’ approach to the treatment of substance use disorders.”).


98 See, e.g., No Wrong Door Reference Guide, Montgomery County Human Services (2017) http://www.mcohio.org/2017_No_Wrong_Door_Brochure_FINAL.pdf (“No Wrong Door refers to a service system that welcomes people in need and assists them in connecting with desired services regardless of the agency where they are trying to gain access. ‘No Wrong Door’ policies commit all service agencies to respond to the individual’s stated and assessed needs through either direct services or linkage to other appropriate programs.”).

A New Day or More of the Same?

Harris County, Texas, and Phoenix, Arizona, for example—have seen improvements in the appropriate triaging of behavioral health-related 911 calls.”).


102 Diversion to What?, supra note 10.

103 The Impact of COVID-19, supra note 10, at 197.

104 See, e.g., D.C. Dep’t Behav. Health, DMH Policy 340.6, Provision of Assertive Community Treatment to Adult MHRS Consumers 1 (May 8, 2014) (“Service coverage by the ACT team is required to have specific program hours but to be available for crisis services 24 hours per day, seven days a week.”).

105 Diversion to What?, supra note 10, at 3-12.


107 See, e.g., Benjamin Lê Cook et al., Assessing Racial/Ethnic Disparities in Treatment Across Episodes of Mental Health Care, 49 Health Serv. Rsch. 206 (2014) (Blacks and Latinx individuals had lower adequacy of care than white individuals); Yumiko Aratani & Janice Cooper, Racial and Ethnic Disparities in the Continuation of Community-Based Children’s Mental Health Services, 39 J. Behav. Health Serv. Rsch. 116 (2012) (non-English speaking children of color less likely to continue receiving services than were English-speaking white children); Lyndonna Marrast, David U Himmelstein & Steffie Woolhandler, Racial and Ethnic Disparities in Mental Health Care for Children and Young Adults: A National Study, 46 Int’l J. Health Serv. 810 (2016) (Black and Latinx children received less outpatient mental health care than white children did); Ana Balsa, Thomas G McGuire & Lisa S Meredith, Testing for Statistical Discrimination in Health Care, 40 Health Serv. Rsch. 227 (2005) (people of color less likely to have depression diagnosed than were white people; evidence found that race affects medical care decisions); Seth Prins et al., Exploring Racial Disparities in the Brief Jail Mental Health Screen, 39 Crim. Just. Behav. 635 (2012) (Black and Latinx individuals less likely to be screened positive for mental health issues; Black and Latinx individuals were 50% less likely than whites to have been hospitalized or to be taking psychiatric medications).


109 Id. at § 9813.


111 Id.

112 Id. at 8-9.


115 Id. at 2 & App. B.