

Meeting a Mental Health Crisis with a Mental Health Response

A Report by NAMI-NYS Detailing How to Maximize the Opportunities Associated with New York State Implementing a 988 Mental Health Crisis Number

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National Alliance on Mental Illness

NAMI New York State

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ABOUT NAMI-NYS



MISSION

To provide advocacy, education, support, and public awareness so that individuals and families affected by mental illness can build better lives.

VISION

A world where all people affected by mental illness live healthy, fulfilling lives supported by a community that cares.

VALUES

- Hope: We believe in the possibility of recovery, wellness and the potential in all of us.
- Inclusion: We embrace diverse backgrounds, cultures and perspectives.
- Empowerment: We promote confidence, self-efficacy and service to our mission.
- Compassion: We practice respect, kindness and empathy.
- Fairness: We fight for equity and justice.

ABOUT NAMI-NYS

NAMI-NYS has over 40 years of experience providing advocacy, education, support and public awareness to help individuals and families affected by mental illness build better lives. It provides direct peer support to individuals with mental health issues, their families, caretakers, and friends, and also provides support in partnership with its 22 statewide affiliates. NAMI-NYS is the state organization of the National Alliance on Mental Illness (NAMI), the nation's largest grassroots organization for people struggling with mental health and their families.

NAMI-NYS is a leader in mental health with a statewide presence and has a successful and extensive record of accomplishment providing services to the community. The organization provides several different programs to peers and their families both directly and through its local affiliates throughout New York State. All programs are free and consist of teachers and facilitators with lived experience, whether as a peer in recovery for a mental health condition, or as a family member of a loved one living with a mental health condition.

NAMI classes consist of NAMI Family to Family, geared toward family members of loved ones living with a mental health condition, NAMI Peer to Peer, for people living in recovery from a mental health condition, NAMI Basics, for parents and caregivers of young children experiencing mental health challenges and NAMI Homefront, designed for family members of veterans and service members living with mental health conditions. NAMI-NYS also hosts support groups for peers and families led by facilitators with lived experience. Programs like Sharing Hope and Faithnet reach underserved and often marginalized groups to address mental health and mental wellness.

NAMI presentations like In Our Own Voice, Ending the Silence and Family and Friends serve to educate the public about mental health conditions and to offer inspiration and hope for those facing challenges due to mental health struggles, whether as the individual living with the condition or a family member. NAMI presentations are effective in dispelling the stigma associated with mental health conditions.

NAMI-NYS also operates a Helpline to connect people with mental health services in their community, as well as local resources and support.

NAMI-NYS collaborates with community stakeholders throughout New York to advocate for improved access to care. The organization is also committed to outreach and awareness, partnering with schools, businesses and community organizations to educate about mental health and mental health conditions.

Executive Summary



The National Alliance on Mental Illness-New York State (NAMI-NYS), the New York State chapter of NAMI, the nation's largest grassroots organization dedicated to improving the lives of individuals impacted by mental illness and their families, has long advocated that New York must reform the way resources are used to respond to people experiencing mental health crises.

The current system pushes too many people through the criminal justice system and diverts them away from recovery oriented services, thus turning patients, in need of support, into criminals.

The intended implementation in July 2022 of a statewide 988 line designed to handle calls from those experiencing a mental health crisis creates a great opportunity to address the social justice issues created by the overrepresentation of people living with a mental illness in the criminal justice system.

By successfully funding and implementing 988 as a resource and restructuring the way services are dispatched to handle crises by combining 988 with appropriate mobile response and crisis stabilization services, the opportunity exists to create a fully functioning system that addresses a mental health crisis with a mental health response.

Creating this system would fundamentally change the way help is provided to people experiencing the crisis.

There is much to be considered and planned for in the implementation of the 988 number and incorporating the complementary services needed to create a fully comprehensive mental health crisis response. While New York State has a historic opportunity to appropriately address a mental health crisis, we only have one chance to implement this fully and correctly. In this report NAMI-NYS makes the following recommendations:

- A mental health crisis needs a mental health response.
- 988 must not be just a replacement for 911, 988 needs to be an improvement.
- There needs to be an interface between 911 and 988.
- Incorporate a fee on telecommunications bills to sustainably fund the 988 program.
- Along with implementing 988, New York must also address the other components necessary for a comprehensive mental health crisis response: mobile response teams and crisis stabilization services.

Executive Summary



- Peer specialists need to be a part of all three components responding to a mental health crisis.
- Have standardized methods of getting support for those in crisis (standard acronyms and trainings across the state and integrate healthcare management).
- The insights of the families of those in crisis should be included when at all possible.
- Provide an appropriate mental health response to crisis situations, which will benefit both law enforcement officers and those in need of help, but also continue to fund Crisis Intervention Team (CIT) trainings that teach law enforcement how to best handle a situation with someone in a mental health crisis.
- Mental Health and other specialty courts (such as substance use and veterans' courts) must be expanded.
- Increase community-based mental health resources so people can receive appropriate care following a crisis. This includes addressing the needs of New York's mental health workforce.
- Create broad educational materials to ensure crisis call centers, mobile crisis teams, and crisis stabilization options are part of the resources for dealing with people in crisis.

The federal Suicide Designation Act of 2020 created 988 as the dial code for the National Suicide Prevention Lifeline. In July 2022, all telecommunications companies will be required to route 988 calls to the Lifeline, which has a nationwide network of call centers. States and communities are scrambling to build their 988 crisis response systems and infrastructure to effectively respond to mental health crisis calls. The three key elements in the crisis response system are:

- Crisis Call Centers
- Mobile Crisis Teams
- Crisis Stabilization Programs

All of these services should be available 24 hours a day, seven days a week. All three components must include Peers among their staff. NAMI-NYS also believes that no one should have to travel more than an hour to access mental health crisis services.

Throughout the country, states and communities are implementing crisis response models ahead of the realization of the nationwide, 3-digit 988 hotline for suicidal and mental health crises by July 2022 deadline. 988 implementation requires for not only 24/7 crisis call centers, but also mobile crisis teams and crisis stabilization programs.

Ensuring appropriate response begins with the ability to identify the situation as a mental health crisis and address it accordingly. Having trained mental health professionals and Peers with lived experience recognizing and intervening in mental health crisis situations generates more positive outcomes and diverts people from the criminal justice system and towards recovery. Trained mental health responders use more appropriate communication and de-escalation techniques, and responders in plain clothes do not pose the perceived threat that may be associated with a police uniform.

Establishing the use of crisis stabilization centers as a best practice provides the opportunity to further de-escalate a crisis situation and often averts the need for expensive hospitalizations or incarceration; currently the only option in many communities is hospital emergency rooms and police departments.

An appropriate response should take into consideration the wide range of mental health crises that a person can experience, from mild to acute. When factoring the severity of the crisis, considering the services needed to sustain the person's recovery following the crisis must be taken into account. Specialty courts must be utilized to divert people away from incarceration and towards recovery. There needs to be adequate community-based mental health services to help an individual address their mental wellness and prevent another crisis.

With these considerations in mind, NAMI-NYS believes that implementation of 988 and restructuring

the way emergency services respond to crises allows the individual to pursue meaningful recovery and successful integration within the community, rather than the most common outcomes of criminal justice system involvement, long-term revolving door inpatient hospitalizations or early death by suicide or drug overdose.

In order to be most successful, Peers must be part of all three parts of the 988 crisis response system. People with lived experience are critical to creating rapport with people in crisis, engaging people in care, and offering hope. The inclusion of Peers that represent the diversity of their communities will greatly increase the success of the crisis response. Increasing the Peer workforce will help ensure that needed Peer Specialists are trained, certified, and ready to take paid positions throughout the 988 crisis response system.

With the implementation of 988 coming in 2022, New York State has the opportunity to rethink and improve the response it offers to people in mental health crisis. NAMI-NYS wants to ensure that the promise of 988 and a reimagined crisis response is dictated by the needs of the people this crisis response system is intended to serve.

A key to this is ensuring that when someone dials 988, there are a range of services available to meet the individual's needs and de-escalate the situation – getting the person the help they need to get well and stay well.

An effective response has three main parts: crisis call centers, mobile crisis teams, and crisis stabilization options. For 988 to achieve its intended purpose, these other two components must also be introduced and funded in New York State.

A sustainable funding source must be defined and introduced to ensure that 988 continues to successfully operate.

A solid interface between 911 and 988 is an essential component of successful implementation. By having these two systems work in parallel, mental health crises can be diverted to the 988 call center, while imminent physical emergencies can be directed to 911 dispatch.

NAMI-NYS Family Member Story

"In March 2015, my adult son living with schizophrenia was going through a medication change. This led him to have a psychotic episode and express his desire to take his own life. Once he mentioned suicide, I called the police with the hopes that they would be able to get him to a hospital to receive care.

It was the worst decision I ever made and one I will always regret.

Three officers responded and my son was terrified of the police and locked himself in the bathroom. I tried to explain my son's condition to the police, but was ignored. After about an hour, the police got him to open the door. My son was so scared that he could not even look at the police officers. My son was crying and hunched over and despite the fact that he posed no threat to the police, they got physical with him and violently put their hands on him, handcuffed and arrested him.

Following his arrest, I contacted the chief of police and my local mental health agency to explain that my son was arrested and despite the fact that he was genuinely suicidal, did not have a weapon or posed any threat to the police.

Nobody listened to me."

Policy Recommendations



Section One: Appropriate Responses to Mental Health Crises



The Three Elements Needed for a Mental Health Response

To create a coordinated crisis continuum, an appropriate mental health crisis response has to have three necessary elements:

1. A 988 call center designated to handle calls of a mental health nature.
2. A mobile response team composed of mental health professionals instead of police.
3. Crisis stabilization options if the person in crisis needs to be removed from the place where the crisis took place.

Coordinated Crisis Continuum

Core Elements of a Crisis System

- Someone to talk to
- Someone to respond
- Somewhere to go



Office of
Mental Health



A 988 call center should be quite different from a 911 dispatch center. It is imperative that 988 call centers do not simply replace 911 dispatch centers but improves on 911 by providing a more skilled staff rooted in knowledge of mental health disorders and how to properly communicate and de-escalate a mental health crisis.

For the 988 Crisis lines to be successful, those staffing the call centers should be mental health professionals (including peer specialists) trained in mental health focused language and de-escalation best practices and communication strategies. Peers with lived experience should be a part of call center staff. The goal should be to defuse crisis calls via the initial phone call without having to utilize a mobile response unit in as many cases as possible.

The call centers should also have the capability to handle calls from non-English speaking callers as well as the ability to properly receive calls from those in the deaf community.

The call center must also be locally focused, with the staff properly educated on the availability of local services. Along with the ability to communicate what direct psychiatric services are available locally in the hospital and community settings, it is also imperative that call responders know what non-profit mental health services are also available in the community.

Call responders should be able to communicate the availability of local services for both individuals living with a behavioral health issue as well as education and support services for families. In order to achieve this goal the call center should have resources from multiple non-profit organizations such as the local NAMI, Mental Health America (MHA), and the American Foundation for Suicide Prevention (AFSP) affiliates or chapters.

Section One: Appropriate Responses to Mental Health Crises



The primary goal of the 988 call center would be to bring a resolution to the crisis over the phone without utilizing a response team.

For those calls that require an in-person response, whenever possible it is essential that mobile crisis teams, staffed by trained mental health professionals, be the ones to respond and intervene. Having trained mental health professionals (which should include Peers with lived experience) intervene in mental health crisis situations will generate more positive outcomes and divert people from the criminal justice system and towards recovery.

Mental health responders would use more appropriate communication and de-escalation techniques, and responders in plain clothes would also be beneficial as they would not pose the perceived threat that may be associated with a police uniform.

Mobile Crisis Teams have the ability to come to the scene of the crisis, assess the individual and determine needs beyond de-escalation, including supportive counseling, information or referrals to community-based services, further crisis stabilization in an alternate setting (like a crisis stabilization center) or inpatient services.

NAMI-NYS supports A.4697/S.4814 which would create "Daniel's Law," ensuring that professional mental health responders are utilized in communities throughout the state.

Providing a Community Informed Response

The legislation is titled "Daniel's Law," after Daniel Prude, a 41-year-old African-American man. On March 23, 2020, Mr. Prude suffered a mental health crisis, exacerbated after ingesting PCP, and was discovered walking naked in the street. He was physically restrained by police officers and taken to the hospital but died several days later. The medical examiner's autopsy report ruled Mr. Prude's death a homicide as a result of complications of asphyxia in the setting of physical restraint, with contributing factors of excited delirium and acute intoxication by PCP.

Daniel Prude's death could have been avoided had a mobile mental health crisis team been available. Daniel's Law will help communities create properly equipped and trained mental health responders to address a mental health crisis. In certain communities, responding to a mental health crisis can pose an especially significant challenge for law enforcement because there exists a lack of trust in law enforcement and limited mental health services. Law enforcement officers are not health care

Section One: Appropriate Responses to Mental Health Crises



professionals and they should not be responsible for evaluating and treating individuals experiencing mental health crises.

It is essential that communities provide their unique perspectives on how best to respond to crisis situations. Daniel's Law will establish regional councils that provide input specific to their communities which is a crucial element of a successful crisis response team.

Understanding the unique needs in all of New York's diverse communities and providing a community informed response is also an essential element of an appropriate mental health crisis response. Varying challenges that exist in New York's different counties such as lack of mental health services, misconceptions about mental health care, substance use and lack of internet and broadband must be factored in when establishing the most appropriate response for that.

Mobile interventions can only be successful with the existence of the third element of a mental health response: proper crisis stabilization services such as crisis stabilization centers. Crisis stabilization centers are a recognized alternative to a hospital emergency department. These centers can be a walk-in facility for people feeling overwhelmed by mental health or substance use issues or an option where mobile crisis responders can bring people.

Centers offer services to address mental health and substance use crises. Staff evaluate and match individuals to the services they need. Guests are connected immediately to resources and support, either on site or within the surrounding community. For the centers to be most effective, no appointments or referrals should be necessary, and the centers should be open 24 hours a day, 7 days a week, 365 days a year.

The services provided at these centers are crisis counseling and mental health assessments, supervised outpatient withdrawal services, addictions and substance use counseling, peer advocacy and supports, youth and family counseling and links to community-based resources.

Centers should provide a safe, secure and welcoming environment. They include showering and clothes washing facilities for people who don't have access to those services, a comfortable room for families who are there with their loved ones in crisis and multiple service providers for both mental health and substance use crises.

Use of the center's services are limited to a period of less than 24 hours, but if additional care is needed the center professionals connect the individual with additional services in the community. The center also commits to following up with those accessing services to ensure that after-care appointments were effective.

Section One: Appropriate Responses to Mental Health Crises



The Importance of Utilizing of Peer Specialists

Peer specialists should be utilized in all three elements of an appropriate mental health crisis response. Incorporating Peer Specialists who have lived experience with mental illness and have been successful in their recovery process and support others and their families experiencing similar situations, into the crisis response system is of the utmost importance. Peer Specialists should be used in the 988 Call Centers as part of the mobile response teams and in the crisis stabilization options including crisis stabilization centers.

Peer Specialists are certified by New York State and through shared understanding, respect, and mutual empowerment, Peer Specialists help people become and stay engaged in the recovery process and reduce the likelihood of relapse. Peer support services effectively extend the reach of treatment beyond the clinical setting into the everyday environment of those seeking a successful, sustained recovery process.

The shared experience of being in recovery from a mental health and/or substance use condition or being a family member is the foundation on which the peer recovery support relationship is built in the behavioral health arena. Substance Abuse and Mental Health Services Administration (SAMHSA) provides many resources for Peer support such as its publication, "Value of Peers," that describes how peer support advances recovery and adds value to behavioral health systems.

The NYS's Office of Mental Health(OMH) recognizes that Peer support is gaining recognition in almost every sector of health care, and that should include the mental health crisis response system.

Section Two:

Funding the 988 Crisis Line and Other Crisis Response Services



Having a sustained funding source is integral to 988's success. It is important to note that the 988 bill passed by the New York State Legislature entitled the "988 Suicide Prevention and Mental Health Crisis Act," (S.6194B/A7177B), an act to amend the county law, in relation to a 9-8-8 suicide prevention and mental health crisis hotline system, fails to stipulate how the 988 system would be funded in New York State.

Fees on telecommunications bills are the most straightforward and effective way to create a sustained funding source for the 988 crisis line. Federal law(P.L. 116-172) specifically permits user fees to pay for the efficient and effective routing of calls as well as "personnel and the provision of acute mental health, crisis outreach and stabilization services by directly responding to the 988 national suicide prevention and mental health crisis hotline." This language had the full support of Congress with a unanimous vote in both chambers and was signed into law by President Trump.

The ability to collect a fee on telecommunications bills provided by federal law presents an important funding stream to help ensure the range of services needed are in place in every community. This is why NAMI-NYS has suggested the following:

1. Establish a monthly statewide 988 fee on each resident that is a subscriber of commercial landline telephone, mobile and/or IP-enabled voice services at a rate that provides for the robust creation, operation and maintenance of a statewide 988 suicide prevention and behavioral health crisis system and the continuum of services provided pursuant to national guidelines for crisis services.
2. Allow for the fee to be adjusted as needed to provide for continuous operation, volume increases and maintenance.
3. Create boards or committees or assign tasks to existing agencies, boards or committees to accomplish the planning required for implementation or ongoing oversight of this act in coordination with designated hotline center(s), 9-1-1 centers, state mental health authority, state substance abuse agency, law enforcement, hospital emergency departments and the National Suicide Prevention Lifeline.

Funding the other components needed for a comprehensive mental health crisis response system is as equally important as funding the 988 line.

NAMI-NYS has expressed tremendous support of Subpart A of AA of the Fiscal Year 2021-22 New York State Health and Mental Hygiene Budget Bill, which would expand the use of crisis stabilization centers. NAMI-NYS support the New York State Office of Mental Health (OMH) 's efforts to use support through federal block grants to initially fund mobile crisis response and crisis stabilization services, but funding must be identified to sustain these vital programs beyond the grant funding period.

Section Two:

Funding the 988 Crisis Line and Other Crisis Response Services



Earlier this year, OMH provided SAMHSA with New York State's initial priorities and allocations for the Coronavirus Response and Relief Supplemental Appropriations Act (CRRSAA) expanded block grant funding, which includes:

- Development of New York State's comprehensive crisis system, including 988 Call Center preparation, Mobile Crisis Response program start-up, Crisis Residence program start-up, Crisis Stabilization program start-up, and integration of crisis services across state agencies;
- Eight new Assertive Community Treatment (ACT) teams across New York State and enhancing the ACT service model, expanding hiring and utilization of Certified Peers across service settings, and a modernization of the Personalized Recovery Oriented Service (PROS) program model to support the development of off-site services, telehealth options, and specialty programming; and
- Prioritize the expansion of certified Peer capacity (inclusive of adult peer, youth peer, family peer) including resources for recruitment, education/training, career pipeline investments, and expanding workforce training opportunities.

While the CRRSAA funding will be used to launch these endeavors, New York must start planning to sustain the funding for these programs. Sustainability of crisis stabilization centers can be maintained through billing to insurance and Medicaid.

Section Three: **911-988 Interface**



This system must be highly coordinated and leading up to the 988 implementation, 911 dispatch staff should be engaged to provide feedback about the types of mental health calls they receive so a proper routing system can be defined.

Proper training for 911 operators and dispatch staff to recognize calls that are of a mental health nature and more appropriate for the 988 system is imperative. 911 operators also need to be trained how to properly communicate the call transfer to someone experiencing a mental health crisis, as not effectively communicating this could further agitate a caller in crisis.

Mental Health First Aid certification should be provided to all operators to support recognition of and understanding for individuals experiencing mental health crises due to the fact that many community members will continue to utilize the 911 system, and operators must be prepared to understand the nature of crises; act swiftly to engage the callers and then transfer them to 988.

Designated dispatchers (including managers and supervisors) should be given “train the trainer” certification in Mental Health First Aid to ensure there are established and recurring trainings delivered to dispatchers. When educating 911 dispatchers it would be most effective to have these trainings come from within, as the shared background and the knowledge of experienced dispatchers will best resonate amongst their peers.

The ability to quickly transfer mental health crisis calls from 911 dispatch centers to 988 call centers is also essential. The technology must be in place to ensure that the 911/988 interface is operating efficiently.

Section Four:

Necessary Training to Ensure a Proper Mental Health Response to a Mental Health Crisis

Training for 988 Call Centers, Mobile Response Teams and Crisis Stabilization Staff:

In order to be most effective NAMI-NYS recommends that the trainings for 988 Call Centers, Mobile Response Teams and Crisis Stabilization staff be conducted by the New York State Office of Mental Health (OMH) and develop the training curriculum in partnership with mental health non-profit organizations such as NAMI, Mental Health America (MHA), and the American Foundation for Suicide Prevention (AFSP) affiliates or chapters along with other organizations that are Peer focused such as the New York Association of Psychiatric Rehabilitation Services (NYAPRS). Including mental health non-profits will ensure education about local services as well as assist in peer recruitment to staff the call centers.

Trainings should be conducted in person. Following the initial in-person training, NAMI-NYS recommends an annual follow-up training which can be conducted in person or online, in order for staffers to be kept up to date on the availability of local services.

Information about the realities of the Health Information Portability and Accountability Act (HIPAA) should be incorporated in the training for 988 call center staff, mobile responders and crisis stabilization staff. The importance of gaining family insight should also be an element of the training and staff should be trained to speak with a family member to gain a better understanding of the individual and the crisis situation. It must be emphasized in the training that HIPAA does not prevent crisis responders from speaking and gaining insights from family members.

NAMI-NYS Family Member Story

"One day I had made arrangements to meet my brother in the city to deliver a bag of groceries. Having been diagnosed with schizophrenia many years prior, he still lacked proper and consistent treatment necessary to care for himself.

As I drove to his neighborhood, I spotted him standing on a street corner gesturing with his hands, speaking out loud answering to the voices only he heard. Extremely thin and borderline emaciated for his tall frame, he wore a snowsuit on this humid 90° day. My heart sank seeing him in this condition, having witnessed him in various similar states many times before.

As I handed him the groceries and sat with him on the curb a police car was driving by- my brother stood up and yelled obscenities, the officers pulled over, exited the vehicle and approached my brother requesting him to clarify his remarks. My brother was immediately slammed to the ground and handcuffed, his head smashed to the sidewalk several times by the Officer who warned me not to intervene as I stood stunned in disbelief, explaining he had a mental illness.

My brother was hauled away screaming my name to help him, the side of his head and mouth bloodied. I was outraged at this inhumane treatment-he was so seriously psychotic-how could the police miss identifying this? He was taken to jail, not provided treatment and released back to the streets to decompensate further.

It is next to impossible to obtain treatment for him due to his lack of insight (anosognosia), HIPAA laws and an inefficient system. We are heartbroken and powerless as a family watching our loved one be so completely disrespected over and over again for having a mental illness."

Section Four:

Necessary Training to Ensure a Proper Mental Health Response to a Mental Health Crisis

The Importance of CIT Training for Police for When Their Involvement is Needed:

While a professional mental health response to mental health crises is ideal, there will be times when police response is unavoidable. This is why it is critical that law enforcement and other first responders receive Crisis Intervention Team (CIT) training.

CIT programs provide a 40-hour training for police and first responders on how to properly intervene with someone in a mental health crisis. NAMI-NYS believes for CIT to be most effective the officers should participate on a voluntary basis as the program thrives best when populated by officers who choose to learn about mental health issues. NAMI-NYS is grateful to all the officers across New York State who have volunteered to take this training, as not many people would take a week out of their lives to better comprehend what it is like to live with a mental illness. These trained officers have made a tremendously positive impact in communities across New York State. CIT programs have greatly reduced harm and fatalities to both police and those to whom they respond. NAMI-NYS wants to see further investments in this vital program.

Section Five:

The Importance of Engaging Family Insight During Crisis Situations



In the March 2018 edition of SAMHSA 's Recovery to Practice newsletter it states "Family engagement and involvement in health care decision-making and treatment can be a key to recovery for individuals diagnosed with a serious mental illness. When practitioners, people in recovery, and their families work collaboratively, clinical outcomes and quality of life often improve."¹

Engaging families is especially important in a mental health crisis situation. It is imperative that 988 call center staff, mobile crisis responders and crisis stabilization staff seek to engage families and obtain their insights about the individual and what led to the crisis. Often times, families can provide a more accurate picture of the situation than the individual in crises who may be experiencing either psychosis or be impaired by drugs or alcohol.

HIPAA considerations

Misunderstanding of the Health Information Portability and Accountability Act (HIPAA) has been a stumbling block for law enforcement, hospitals, and those responding to a crisis. A major concern NAMI-NYS has is that the misunderstood and misused HIPAA law will be a major impediment to involving the family in the care and support of the individual in crisis. These laws can often prevent appropriate care and coordination between a family and their loved one in crisis. NAMI-NYS makes the following recommendations regarding HIPAA and people in crisis:

1. Do not let HIPAA interfere with care; when a patient calls and is suicidal, crisis response needs to engaged their family for corroboration and support.
2. Family needs to be informed regarding where a loved one is being taken for evaluation, whenever possible.
3. Family contact information should be made available to the emergency treatment team and likewise that the treatment team contact information is available to the family. This ensures seamless coordination and the highest opportunity for success.

988 responders need to always ask the person in crisis for family contact information and if the information is provided or it is stated in a personal advance directive (PAD). All attempts should be made to contact the family for corroborative history. If permission or a PAD is obtained, once the patient is in the system, the family needs to be contacted and told of the individual in crisis' location, and the family should be given the contact information of the evaluating team.

¹ https://www.ahpnet.com/files/RTPNewsletter14_March_2018.pdf

Section Six:

Other Services That Need to be Implemented and Available for Serious Cases That Need More Than Crisis Stabilization Services

While the goal of an enhanced mental health crisis system is to resolve the situation over the phone, through a mobile crisis team or crisis stabilization centers, it is important to recognize that this will not always be possible especially with more challenging cases and for those where the crisis has led to a law being broken. That is why other community-based services must be in place to help those who need more intensive help in recovering from a crisis.

Generating the Best Outcomes When a Law Enforcement and Criminal Justice Response is Needed:

While NAMI-NYS wants to see a professional mental health response to mental health crisis situations, we also understand that there will be times when police response and entry into the criminal justice system will be necessary. In these situations NAMI-NYS wants to ensure that all efforts are made to divert those experiencing a mental health crisis away from incarceration and towards recovery oriented services.

As stated earlier, it is critical that New York continues to fund Crisis Intervention Team (CIT) initiatives in order to ensure that when police need to be involved in a mental health crisis response they are properly trained to de-escalate these situations and avoid interactions that can lead to dangerous and deadly results for both the police and the respondents.

When the individual in crisis has broken a law (in non-violent situations), NAMI-NYS wants to ensure that their psychiatric impairments are considered in their judicial review. This is why NAMI-NYS believes it is critical to expand mental health and other recovery oriented problem-solving courts such as veterans' and drug courts (henceforth termed problem solving courts). Problem solving courts are crucial to generating the most successful outcomes for people living with a mental illness or behavioral health issues.

Judges presiding in these courts evaluate each case individually to determine the best plan for each offender. If that person lives with a mental illness, recovery oriented treatment programs are often deemed to be better alternatives than incarceration. Problem solving courts can be an essential point of entry to recovery services that can contribute to a reduction of arrests, recidivism, emergency room visits and long term in-patient care. Problem solving courts are a sound investment as they can save the state and local municipalities money by proactively addressing issues that often lead to potential long-term expenses such as hospital stays and prison sentences.

NAMI-NYS Family Member Story

"After a lengthy trial, where the police testified that my son did possess a weapon and threatened them, he was found guilty. Fortunately, he was not given jail time as he received probation.

While the outcome could have been worse if he did receive jail time, this continues to be a traumatic nightmare causing severe damage to my family. My son now suffers from post-traumatic stress disorder from the ordeal and the trial and he continues to blame me for the incident. Honestly, I also blame myself and I constantly ask myself:

"Why did I call the police?" That decision will always haunt me."

Section Six:

Other Services That Need to be Implemented and Available for Serious Cases That Need More Than Crisis Stabilization Services

Crisis Level Housing

True Crisis Stabilization cannot be achieved without proper funding and support for both crisis respite and long-term mental health housing programs. When individuals who are experiencing a mental health crisis are picked up by a mobile mental health crisis response team or the police, there can be adverse effects for the individual if there are no resources for safe and supported mental health housing following the evaluation and treatment of the crisis situation.

Crisis stabilization centers are designed to address the immediate crisis for a 24-hour period and in many cases a person might not be ready to return to the living situation where the crisis took place and would greatly benefit from mental health housing programs with wrap-around support services.

Currently, homeless shelters, motels or single resident occupancy facilities are over utilized for people following a crisis. None of these options are properly equipped to provide the empathetic and resource rich support that is needed after an individual is discharged from an emergency room or crisis stabilization center.

Funding must be enhanced for both crisis and mental health housing programs and should be distributed through an RFP process to non-profit Mental Health Housing Providers in all New York State counties. The current mental health housing system is under extreme duress due to flat-funding for many decades. This flat-funding has had a tremendous negative impact on these necessary programs. Currently, the limited non-profit mental health housing programs that do exist are operating at 43% of where they should be when factoring in inflation over the decades of flat-funding.

The Bring it Home NYS Campaign states the by-product of this flat-funding includes:

- Increased number of residents and not enough beds;
- Direct Care Staff who make just at minimum wage;
- Rising housing and property costs;
- Need for Technology such as computers, internet, electronic health records, etc.;
- Enhanced security;
- Staffing ratios too low;
- Resident's medication and healthcare needs are more complex, requiring 14-16 medicines daily;
- Higher food, fuel and fringe benefits costs;
- Personal Protective Equipment (PPE) and Sanitizing Items;
- Programs historically losing 40-70% of their funding due to inflation.

Section Six:

Other Services That Need to be Implemented and Available for Serious Cases That Need More Than Crisis Stabilization Services

Bring it Home NYS states the following must be done to address the impact of flat-funding: ²

- Update the “New Housing Model” to incorporate the program needs listed above.
- Increase funding from New York State, which would:
 - Offset costs to providers so they can provide better care for residents.
 - Reduce the current workforce shortage by giving providers the ability to increase pay, benefits and training for mental health direct care workers.
 - Reduce the need for private fundraising to prop up already underfunded programs.
 - Increase and strengthen the mental health housing workforce to avoid staff turnover so residents are able to build a rapport to aid in their recovery.

Innovative and supportive options are needed to prevent a cycle of emergency room use, hospitalization, incarceration and homelessness that begins with a mental health crisis. Funding and availability of mental health health housing programs in all regions should be reviewed on a continual basis to reduce episodes of homelessness and over-utilization of emergency rooms thereby reducing reliance on the 911/988 system. To break this cycle there needs to be mental health housing programs that prioritize people who have been in a crisis situation and should not return to the living situation where the crisis took place.

Effective Prevention and Crisis Response for the Most Severe Cases and for Those Requiring the Highest Level of Care

People with serious mental illnesses and those requiring the highest level of care often fall through the cracks of our fractured mental health system. Among the challenges are a lack of providers and a lack of both long-term beds and community-based treatment centers designed to meet their more complicated needs.

The lack of appropriate services results in too many people with serious mental illnesses not being treated, but ending up in the corrections system, in the streets or worse. Those with a serious mental illness who present in a psychotic and possibly agitated manner are most at risk of being arrested and potentially injured or killed. It is important to have an appropriate crisis response as well as a path of treatment for those with a serious mental illness.

NAMI-NYS Family Member Story

“When my daughter was a college student, she became manic at a bar and the bouncer ejected her. The restaurant door slammed while she was being evicted, the glass panel in the door broke, and my daughter was charged with a felony because of the damage. She was sent to the prison unit of a hospital and placed with murderers. This was a very traumatic experience for her. If 988 and appropriate crisis stabilization options were available and a treatment plan in place, my daughter would not have been charged as a criminal.”

² <https://www.bringithomenys.org/mh-housing-model>

Section Six:

Other Services That Need to be Implemented and Available for Serious Cases That Need More Than Crisis Stabilization Services

A trained 988 call responder must be able to differentiate between a person in an acute crisis who can be de-escalated on the phone from someone who needs a more intensive intervention with responders trained to handle more serious cases.

If someone with a serious mental illness willingly goes to a Crisis Stabilization Center and then from there could be sent to a hospital, if clinically needed, that could be a pathway towards recovery and a more sustained stabilization. One of the benefits of utilizing Peers in the all three components of a crisis response is their increased ability to encourage those in crisis to receive the treatment they need.

A proper mental health response includes the ability to appropriately address situations involving individuals with serious mental illness in order to generate positive recovery oriented results. Responders need to be trained to effectively communicate with those experiencing the inability to be aware of their mental illness which is known as anosognosia.

If a hospitalization is deemed appropriate, the facility must be able to keep the person until stabilized. It is imperative to have hospital beds available for those with a serious mental illness and to restore those psychiatric hospital beds that were taken away to allow for COVID patients to be treated. Time and resources must be placed on improving the number of beds the state has for these individuals.

Addressing the Mental Health Workforce Shortage

To achieve all of the initiatives above, New York State must address the issues surrounding the difficulty of sustaining a caring and knowledgeable mental health workforce.

The COVID-19 pandemic has had a significant effect on the mental health workforce. Even prior to the pandemic, non-profit mental health organizations were continually struggling to hire and retain a skilled and caring workforce.

Direct care staff in the mental health housing field often make little more than minimum wage despite the fact that they work complex jobs with individuals that have serious needs. The staffing patterns in many housing programs are limited and many do not include medical professionals such as nurses. Individuals in mental health housing programs have co-occurring mental health, substance use and medical needs that require continuous support to avoid hospitalization. Direct care staff provide this support, but the system is severely taxed at this time due to underfunding, heavy regulatory requirements that are not backed by state funding, and the results that the COVID-19 pandemic has had.

NAMI-NYS Family Member Story

"My daughter suffers from anosognosia, meaning she is unaware of her own mental health condition, but can hold it together long enough to fool judges and inexperienced people. She does not believe she is ill or that she needs help with an episode."

NAMI-NYS Family Member Story

"When my daughter was a freshman at college, she had her first manic episode and was hospitalized. Her hospitalization allowed her to come out of her mania and return to college. She was able to pursue her academic and life goals because she had the opportunity to go to a hospital bed to become stabilized, not a jail cell."

Section Seven: Youth in Crisis:



NAMI-NYS believes in person-centered treatment and care and this includes when responding to a mental health crisis. This is especially true when dealing with children and adolescents who have unique needs.

There has been concern among advocates that New York State's new crisis response system will treat children as small adults and not as children with unique needs. In many cases involving children, removing them from the home and taking them to a crisis stabilization center or hospital, is not only not the best option but it can exacerbate their symptoms and increase the amount of trauma they experienced.

NAMI-NYS wants services best suited to meet the needs of children incorporated into New York's crisis response system. These can include Assertive Community Treatment (ACT) teams designed for youth.

Section Eight:

Education on 988 and Crisis Services:



New York State must engage in a vigorous marketing campaign leading up to the implementation of 988 in order to both let people know that 988 is coming and distinguish it from existing numbers such as 911, 311 and 211.

Key messages for the marketing and education campaign are:

- A mental health crisis needs a mental health response
- 988 is more than a number.
- 988 provides hope of better outcomes
- 988 is not just a replacement for 911, 988 is an improvement.

For this campaign to be successful several criteria should be met. Marketing materials should be culturally sensitive, diverse, and provided in multiple languages. Multiple forms of marketing materials should be created, these include: digital, social media, print and broadcast media. Various actors, settings and images should be used to capture the various backgrounds of all New Yorkers. Marketing initiatives should address specific subgroups and communities including communities of color, the elderly, rural communities and the LGBTQIA+ population.

988 should be advertised on a large scale across NYS. It is also crucial that 988 is advertised in settings where there is a targeted audience of people impacted by behavioral health issues, including other hotlines, community programs, clinics, hospitals and doctor's offices to make sure that individuals who may need these services are educated about the services. Information about 988 also must be discussed in peer-led support groups and educational services.

The New York State Office of Mental Health should also host regional town halls events to educate the community on 988. Non-profit organization with a focus on behavioral health issues (including but not limited to NAMI-NYS, the Mental Health Association in NYS (MHANYS), the New York Association of Psychiatric Rehabilitation Services (NYAPRS), Families Together in New York State) should have educational sessions on 988.

It is imperative that when marketing 988 there needs to be a focus on care and that calling 988 is a different experience than calling 911. It needs to be specified that 988 will not be staffed with operators or dispatchers but with professionals who are trained to mainly de-escalate situations over the phone and without a mobile response. It must also be stipulated that when a mobile response is needed that in most cases those responding will be mental health professionals and not police.

Conclusion

Too many New Yorkers have suffered and lost their lives due to the lack of a system that meets a mental health crisis with a mental health response. New York now has an opportunity to create such a system with the implementation of the 988 Mental Health Crisis Call line. However, New York only has one opportunity to implement this system correctly. This is why it must pair 988 with the other necessary components of a mental health crisis response, mobile crisis responders and crisis stabilization services.

Funding streams to initiate and sustain these programs are identified and tangibly available.

For these programs to be successful, peer specialists need to be a part of all three components responding to a mental health crisis. New York must standardize methods of getting support for those in crisis. The insights of the families of those in crisis should be included when at all possible. Communities also must be able to provide their insights on how to properly respond to their specific needs.

Providing an appropriate mental health response to crisis situations will benefit both law enforcement officers and those in need of help. However, New York must also continue to fund Crisis Intervention Team (CIT) trainings that teach law enforcement to best handle a situation with someone in a mental health crisis. CIT must also be paired with Mental Health and other specialty courts to ensure the best outcomes for people experiencing a mental health issue when it intersects with the criminal justice system. It is also essential that New York increase community-based mental health resources so people can receive appropriate care following the crisis. This includes addressing the needs of New York's mental health workforce and mental health housing system.

Finally it is critical that New York creates a broad educational effort to ensure crisis call centers, mobile crisis teams, and crisis stabilization options are a known entity to all members of New York's communities.

NAMI-NYS Family Member Story

"I wish my son received a mental health response instead of a police response for his psychotic and suicidal incident. If he had a mental health professional or a peer who could properly communicate with him, his arrest, trial and criminal record could have been avoided. I also wish my community had a mental health court which would have handled his case more effectively and put him on a path towards recovery and not punishment.

We desperately need these reforms so other families are not permanently damaged the way my family has been damaged."