Testimony before the NYS Attorney General
Western New York Public Hearing on Mental Health
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Presented by
Chacku (he/him/his) Mathai
NYS Behavioral Health Services Advisory Council member
585-369-9691

My name is Chacku Mathai, and I currently reside in Rochester, NY. I am formerly a resident of Washington Heights in New York City, as well as in Albany, NY. I am an Indian American, born in Kuwait. My family immigrated to the United States in 1972. We struggled, especially in the context of explicit xenophobia and racism, and as a teenager, my own trauma, psychiatric, and substance use issues led to drug overdoses, a suicide attempt, and being diagnosed with poly substance use disorder, schizoaffective, and PTSD.

I identify as a person in recovery and trauma survivor for over 37 years now. I am grateful to be married, as well as a father, with a 14-year-old daughter. I have been an advocate from the start of my recovery at 15 years old, starting some of the first advocacy and peer support groups in Rochester, worked as a Psychiatric Rehabilitation Practitioner in Rochester's residential and community mental health systems. I trained clinicians, designed innovative, recovery-oriented service models, and was the first ex-patient, person of color to be a CEO of a mental health advocacy organization in WNY. I currently work with OnTrackNY, in the division behavioral health policy and research at Columbia University and the Research Foundation for Mental Hygiene. I am a Governor appointed member of the NYS Behavioral Health Services Advisory Council, President of Friends of Recovery – New York, a statewide advocacy organization representing thousands of people in recovery across NYS, and a nationally recognized content expert, often called upon by the Substance Abuse Mental Health Services Administration (SAMHSA). I'm speaking today independently as a person with lived experience in WNY and a member of the NYS Behavioral Health Services Advisory Council.

I extend my thanks to all of you for this hearing, the opportunity to give testimony, and for the focus on access to mental health care for those of us who are experiencing the challenges of serious mental illness and co-occurring substance use conditions in the Western New York region.

For too long, many of us in WNY have only accessed any kind of behavioral health care as a result of a serious crisis, and our first contact with the system was through police and emergency rooms, hospital beds, and meds. Even then, I believe we were the fortunate ones.

In March 2020, Daniel Prude was experiencing an acute mental health crisis when his family called 911 for help. He was naked in the street, posed no threat to any other person. Yet, Rochester police responded in force, handcuffed him, placed a hood over his head, and held him face down on the cold pavement, until he could no longer breath and died. Daniel Prude was mocked, treated cruelly, and killed, by officers with no understanding, or even attempts to

understand, his needs. This event was the culmination of a continuing inability of our systems and our communities to see people like me and Mr. Daniel Prude, as people who deserve the dignity and respect of a caring and supportive system. A system that recognizes our mental health issues as the cumulative consequence of failing systems and adverse, traumatic experiences, rather than something that is simply wrong with us, with our brains, or our cultures and communities.

Access must begin with the fundamental understanding that we are not dangerous people. Our issues are not a public safety issue for the police to respond to. The Person in Crisis Teams initiated in Rochester are a great start to making some meaningful changes in the ways we are supported during our most challenging times; however, we must not stop there.

There are great examples of initiatives that are working for people traditionally viewed as lacking insight or requiring involuntary treatment. Voluntary engagement and outreach approaches such as Project INSET, a peer-led community engagement model that gets out in front of avoidable hospital admissions of people with major mental health challenges. A program of this kind in Westchester County has successfully engaged 80% of a cohort of people with significant unmet needs who have previously not engaged in mental health care and support and who might otherwise be forced into Kendra's Law's involuntary community treatment orders.

We must continue to invest in voluntary services, as they are always the most effective and, most importantly, provide the most lasting impact and relationships that we can offer.

I applaud the historic investments in mental health services recently proposed by Governor Hochul, including improved community outreach and engagement services, post hospitalization transitional and support services, and access to flexible, permanent housing for people living with the most challenging mental health and social needs.

There is often a call for more hospital beds as a form of accessibility. While more beds may get some people off the streets for a few days or even weeks, beds alone will not substantially improve people's health and lives, nor will they help break the cycle of repeated relapses and readmission. Instead, we must move away from the failed discharge policies of the past and create a systemic shift to improved voluntary outreach, engagement, crisis, and hospital diversion services.

We need to further invest in community-based housing and make sure that the majority of these are permanent and are operated according to the 'Pathways Housing First' model that accepts rather than excludes people with recurrent and often active mental health and addiction related needs. These can also be linked to recovery oriented Assertive Community Treatment teams.

With increased investments, we could increase the number and use of hospital-to-community Critical Time Intervention Teams and make use of wrap around dollars to help people get better established in their community.

We need significantly increase the investment and use of peer supporters, both around outreach and engagement efforts that can prevent relapses and readmissions and as post hospital transitional supports.

For example, peer bridgers (many of which are deployed by agencies that are operated by people in recovery), have been proven to be very effective here. I was involved with NYAPRS in developing this peer bridger model in 1990's. Programs that featured peer led teams of bridgers demonstrated powerful results, cutting readmissions by over 50% and saving millions of dollars, that would have otherwise been spent on avoidable hospitalizations that should be reinvested in a further expansion of community services.

Better hospital discharge plans are essential, but effective community engagement that prevents the need for such hospitalizations is far better.

On May 14, 2022, a mass shooting occurred here in Buffalo, at a Tops supermarket on the East Side. Thirteen people were killed, eleven of whom were Black. This racially motivated hate crime cannot be separated from a conversation about mental health. The trauma of this event is not experienced in a vacuum. WNY must be supported to change the systemic racism experienced in our communities, especially as it intersects with our experiences with the mental health system.

Unequal access to opportunity along the lines of race, class, gender, psychiatric history, and other aspects of identity have deep roots in American history. Institutional racism continues to perpetuate significant racial inequities in health and mental health. Understanding race, class, and the intersectional experience of oppression is critical to eliminating health and mental health inequities and creating a mental health system in which all people can thrive.

Racial inequities within the system of mental health are well documented. Research indicates that compared with people who are white, those who are Black, Indigenous and People of Color (BIPOC) are:

- Less likely to have access to mental health services
- Less likely to seek out services
- Less likely to receive needed care
- More likely to receive poor quality of care
- More likely to end services prematurely

Black men are four times more likely than white men to be diagnosed with schizophrenia, while also underdiagnosed with posttraumatic stress disorder and mood disorders.

Numerous studies over decades have shown that Black Americans are diagnosed at higher rates of schizophrenia than White Americans. In a 2018 analysis of data from 52 different studies, researchers found that Black Americans are 2.4 times more likely to be diagnosed with schizophrenia. International findings reveal a clear and pervasive pattern wherein African American/Black consumers show a rate of on average three to four times higher than Euro-American/White consumers. Latino American/Hispanic consumers were also disproportionately diagnosed with psychotic disorders on average approximately three times higher compared to Euro-American/White consumers. In addition, a trend among international studies suggests that immigrant racial minority consumers receiving mental health services may be assigned a psychotic disorder diagnosis more frequently than native consumers sharing a majority racial background.

Racial inequities have a profound impact on the lives and experiences of our families and communities in WNY as well. We must apply a racial equity impact lens on all our policies and investments in WNY going forward. We must recognize that in order to reverse course on these long-standing inequities, we must be willing to stop trying to force people into existing services that don't work for them. We must instead work with our communities to be the decision makers about what is offered and best match services with their needs.