July 28, 2023

The Honorable Alex Azar
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Re: Illinois Behavioral Health Transformation Section 1115 Demonstration Project No: 11-W-00316/5 Application for Extension

Dear Secretary Azar:

NAMI appreciates the opportunity to submit comments in support of the Illinois Behavioral Health Transformation Section 1115 Demonstration Project No: 11-W-00316/5 Application requesting a five-year extension and amendment. NAMI, the National Alliance on Mental Illness, is the nation's largest grassroots mental health organization and is dedicated to building better lives for people affected by mental illness.

Access to coverage and care are essential for people with mental illness to successfully manage their condition and get on a path of recovery. Medicaid is lifeline for much of that care as the nation's largest payer of mental health and substance use condition services[i], with nearly 40 percent of Medicaid beneficiaries having some form of mental health or substance use disorder conditions[ii]. Through Medicaid coverage, people with mental health conditions can access critical services like therapy, inpatient treatment, and prescription medications.

Unfortunately, gaps continue to persist. Despite state and federal efforts to improve accessibility and quality, 35 percent of Medicaid-covered individuals with significant mental health concerns report not receiving treatment[iii]. And in Illinois, the number of behavioral health care professionals is lower than the U.S. average[iv]. This prevents people from receiving the right care, at the right time, in the right setting. Amidst a deepening mental health and substance use crisis in Illinois and in the U.S. overall, new, community-based strategies are needed to ensure equitable access to quality care and ultimately improve outcomes for people with mental health conditions.

Through this waiver amendment, NAMI appreciates the state's efforts to strengthen behavioral health care and develop innovative methods to address unmet social needs that are critical to one's health, putting the state on stronger footing toward improving mental health outcomes. NAMI supports the state's waiver amendment and urges its approval by CMS. We focus our attention on several proposed benefits and pilot initiatives and offer the following comments.

Proposed Benefit/Pilot Initiative: Justice-Involved Reentry Pilot

NAMI strongly supports Illinois's proposal to provide Medicaid coverage and pre-release supports for incarcerated individuals, both adults and youth, 90 days prior to release. We urge its approval by CMS. We also encourage CMS to clarify to states that the 30-day supply of prescription medication requirement is a minimum amount.

People with mental illness are overrepresented in our nation's criminal justice system. As a result, NAMI has a unique understanding of the unique health care related needs and challenges of people with mental illness who are justice-involved. Because federal law prohibits the use of Medicaid funds for services provided to an inmate of a public institution, when beneficiaries become incarcerated, they lose access to mental health services provided through Medicaid. Yet prisons, jails, and other penal institutions are often unable to provide adequate care as part of a system that is not built to provide health services. When individuals are released from incarceration and return to the community, it is a crucial period because it is associated with significant stress and high risk of recidivism, relapse, or crisis. Establishing or re-establishing health care often takes the backburner as they deal with more pressing needs like housing and food security, reconnecting with family members, and finding employment[v]. Many do not have appropriate access to coverage and continuity of care and are more likely to lack health insurance[vi]. On release, people with SMI, particularly those with co-occurring SUD, recidivate at higher rates than those without SMI or SUD. This is frequently attributable to lack of timely access to needed services and supports for their condition[vii].

Reentry services and supports are critical for people with mental health and substance use conditions, and research demonstrates that better mental health, both in prison and post-release, is related to a decrease in the likelihood of recidivating[viii]. For these reasons, NAMI strongly supports the state's proposal to provide all individuals transitioning from incarceration with services up to 90 days prior to release. The state is proposing to offer the following services: physical and behavioral health clinical consultation services provided in-person or via telehealth, laboratory and radiology services, medications and medication administration, medication-assisted treatment (MAT) for all types of SUDs with accompanying counseling, and services of community health workers (CHWs) and community navigators with lived experiences. We believe providing these services will help ensure that this high-risk, high-need population receives needed care as they transition back to their communities. In doing so, Illinois will join the swiftly growing list of states providing critical Medicaid-covered services for individuals reentering their communities from settings of incarceration.

Lastly, NAMI appreciates that the state has specified that the 30-day supply of medication provided to justice-involved individuals upon exit is at "minimum," as clinically appropriate and consistent with the approved Medicaid state plan. While CMS guidance specifies 30 days of prescription medication upon release[ix], NAMI believes a 30-day supply does not always provide beneficiaries with sufficient time to reestablish themselves in their communities. Rather, up to 90-day supplies will help ensure beneficiaries are able to remain on needed medications and is supported by research[x]. We encourage CMS to clarify to Illinois and other states that the 30-day supply of prescription medication requirement is a minimum amount.

Proposed Benefit/Pilot Initiative: Violence Prevention and Intervention Services

NAMI strongly supports Illinois's proposal to implement a Violence Prevention and Intervention Pilot and urges its approval by CMS.

Violence is a public health crisis that can shatter families and devastate communities. Trauma due to acts of violence or other adverse events can persist well into adulthood even when experienced at a young age. People with trauma histories are more likely to experience health problems, participate in risky behavior, struggle financially, and have violent relationships or problems making friends[xi]. These factors are further influenced by the intersection of race, identity and mental health.

A public health approach to violence prevention is urgently needed to promote health equity and address the disproportionate burden of this epidemic on communities of color. In Illinois, Violence Prevention Community Support Teams are already a part of this large safety initiative and will provide culturally responsive, trauma-informed therapeutic interventions and supports focused on reducing traumatic stress symptoms and improving community functioning for individuals who have experienced chronic exposure to firearm violence. To support and expand the violence prevention work under way in Illinois, the state is requesting expenditure authority to help these support teams bring additional activities to local communities. The state also is requesting expenditure authority to provide person-centered, trauma-informed services to Medicaid eligible people who need it by implementing and providing violence prevention and intervention services through MCOs that will address the health effects associated with violence.

NAMI is pleased that if approved, this pilot and other waiver components will help generate resources for other exciting innovations, like the expansion of the recently created, Medicaid-billable Community Violence Prevention Peer, which puts frontline street outreach workers directly into the crisis response/behavioral health workforce pipeline.

Pilot Initiative: Community Health Worker Training

NAMI strongly supports Illinois's proposal to implement a Community Health Worker Training Pilot and urges its approval by CMS. Community Health Workers (CHWs) are frontline workers who have close relationships with the communities they serve, allowing them to better connect community members to health care systems[xii]. Many states rely on CHW services to address the health needs of targeted populations, including beneficiaries with complex behavioral health needs. Over half have made CHWs services Medicaid-reimbursable[xiii]. Services provided by CHWs may include culturally appropriate health promotion and education, assistance in accessing medical and non-medical services, translation services, care coordination, and social support. Research indicates that CHW interventions can be effective in reducing health disparities in communities of color and promoting health equity[xiv]. Critically, CHWs can play a role in helping individuals access health care in areas with provider shortages[xv].

Under the proposal, the state is seeking expenditure authority to support recruitment, training, and certification of CHWs to help provide high-quality, culturally and linguistically competent, community-based health care services to Illinois Medicaid beneficiaries and promote the meaningful employment of individuals in search of local career paths that contribute to a community's well-being. This initiative also may inform opportunities for additional traditional healthcare workers in the future, including peer support specialists or other behavioral health counselors. NAMI strongly supports the CSW program, including opportunities to bring in talented individuals with an interest in focusing on behavioral health, as we believe this will increase access across levels of care.

Proposed Benefit/Pilot Initiative: Housing Support Services Pilot

NAMI strongly supports Illinois's proposal to extend the Housing Support Services pilot and urges its approval by CMS. Access to affordable housing is a critical social determinant of health, and a person's access to housing can affect — and is affected by — mental health. Experiencing housing instability may

contribute to stress, anxiety or other mental health symptoms. The symptoms of a serious mental health condition can also lead to housing instability. Collectively, this makes it more challenging for individuals to manage their mental health. As the waiver notes, people experiencing homelessness are less likely to receive treatment for behavioral conditions than individuals who are stably housed[xvi]. People with mental illness are overrepresented in the unhoused population, as about one in five people experiencing homelessness in the U.S. have a serious mental health condition[xvii]. Moreover, it's well-documented that people with mental illness experience housing discrimination throughout the rental process.

Illinois requests to continue its Housing Support Services Pilot with proposed changes, which will authorize pre-tenancy supports and tenancy sustaining services including care coordination, financial support for housing-related fees, and connection to resources. Stable, safe and affordable housing supports recovery, and helps prevent hospitalizations and involvement in the criminal justice system. Moreover, efforts to provide stable housing for people experiencing homelessness can reduce health care costs and improve health outcomes for people with mental illness[xviii]. NAMI appreciates that the eligibility criteria includes those who are experiencing/at risk of homelessness with a behavioral health condition, highlighting the outsized role that mental health plays in housing. We believe that the Housing Services Pilot will continue playing a key role in the state's efforts to improve social determinants of health, ensuring stable, safe, affordable, and supportive housing options for people with mental health conditions. We urge CMS to approve this request to extend this supportive housing pilot.

Proposed Benefit/Pilot Initiative: Supported Employment Services Pilot

NAMI strongly supports Illinois's proposal to extend the Supported Employment Services Pilot and urges its approval by CMS. Employment is a critical social determinant of health, whether it provides a source of income, health insurance coverage, social connections or sense of pride. However, a variety of barriers can make finding and maintaining a job more difficult for people with mental illness[xix], which may be further compounded by aspects of race, gender, and age[xx]. Symptoms of mental illness may put certain kinds of jobs or minimum work hours out of reach, and people with mental illness have an increased risk of employment termination and both voluntary and involuntary job loss[xxi]. Employment opportunities may be even more limited for people with mental illness who are justice-involved or who enter the workforce without necessary supports. Yet like anyone else, people with mental health conditions value paid employment opportunities for reasons like income, financial security, socializing and sense of achievement[xxii]. What's needed policies that support both the health and employment needs of people with mental illness.

Illinois requests to continue its Supported Employment Services Pilot with proposed changes, that will authorize supported employment services to eligible beneficiaries through a person-centered planning process when eligible services are identified in the individuals' plan of care. Services may include placement assistance, job coaching, and follow-along supports. Supported employment programs have proven benefits for people with mental illness, and research shows that supported employment programs can help people with mental illness find competitive employment, put in more time on the job and earn higher wages[xxiii]. NAMI appreciates that the eligibility criteria includes those who are identified as needing employment assistance and a behavioral health condition, highlighting the outsized role that mental health plays in employment. We believe that the Supported Employment Services Pilot will continue playing a key role in the state's efforts to improve social determinants of health, ensuring meaningful employment options that support success and recovery. We urge CMS to approve this request to extend this pilot program.

Proposed Benefit: Non-Medical Transportation

NAMI strongly supports Illinois's proposal to provide non-medical transportation to Medicaid beneficiaries and urges its approval by CMS. Access to mental health treatment, services and supports is vital for people with mental illness to get well and stay well. Yet without transportation options to get receive medical care and manage social needs, treatable conditions can worsen and become more serious — and may lead to worse health outcomes.

Currently, all state Medicaid programs must cover non-emergency medical transportation (NEMT), which helps people get transportation to necessary medical care, including mental health care. Beneficiaries are significantly more likely to receive care through recommended medical appointments when using NEMT[xxiv], and most individuals on Medicaid agree that they would not be able to keep medical appointments without it[xxv]. NEMT is particularly important for people with mental illness, since behavioral health services are the most frequently cited reason for using NEMT[xxvi].

For these reasons, NAMI is strongly supportive of Illinois's initiative to expand current services and offer transportation to needed, non-medically related services, supports or locations for beneficiaries in need. Such places include grocery stores, food pantries, pharmacies, social services agencies and other support services. We believe this is an innovative and exciting approach to addressing the whole-person needs of beneficiaries, and we urge CMS to approval this proposed benefit.

Proposed Benefit: Food and Nutrition Services

NAMI strongly supports Illinois's proposal to provide food and nutrition services to Medicaid beneficiaries and urges its approval by CMS. A person's access to healthy food can affect — and is affected by — mental health. Just as being food-insecure may contribute to stress or anxiety, having a serious mental health condition may hinder a person's ability to work or limit the kind of work they can do, making it more difficult to afford groceries. Research by the U.S. Department of Agriculture found that adults with a mental health disability are up to five times more likely to live in a household that is food insecure[xxvii]. And when adults with serious mental illness (SMI) experience very low food security, they are less likely to be able to afford mental health care and use mental health services[xxviii]. Even for people who do not have a diagnosed mental illness, dealing with food insecurity may contribute to anxiety and depression in adults[xxix], and emotional problems among adolescents[xxx].

For these reasons, NAMI is strongly supportive of Illinois's initiative to offer a food and nutrition services benefit within the demonstration, and the expansive list of services within. Thoughtful, needed benefits like medically tailored meals and groceries, fruit and vegetable prescriptions, and cooking supplies will greatly help support the health needs of beneficiaries. NAMI appreciates that the eligibility criteria includes those who are considered food insecure and have a behavioral health condition, highlighting the outsized role that mental health plays in food security. We also appreciate that the state made substantial changes to the demonstration renewal application in response to public comments "to be as expansive as CMS has approved across the spectrum of other state section 1115 programs implementing health-related social needs services." We believe this is an innovative and exciting approach to addressing the whole-person needs of beneficiaries, and we urge CMS to approval this proposed benefit.

Additional Considerations

In addition to our comments above, we also share the following recommendation:

- NAMI believes this waiver demonstration will help transform the care and support that state Medicaid beneficiaries will receive; at the same time, we understand this waiver will only be applicable to those in managed care. Given that nearly 20 percent of Illinois Medicaid beneficiaries are covered by fee-for-service Medicaid[xxxi], we encourage the state with the support of CMS to review and assess the ability to provide these health-related social needs services equally under the state's fee-for-service Medicaid program.

Thank you for the opportunity to provide comments on this important issue. We strongly believe that the substantial steps outlined in this waiver demonstration renewal and amendment will enhance the mental health of Illinois Medicaid beneficiaries by supporting their health and social needs within their communities. If you have any questions or would like to discuss this issue, please do not hesitate to contact Jennifer Snow, NAMI National Director of Government Relations and Policy at jsnow@nami.org or Andrew Wade, NAMI Illinois Executive Director at AndyWade@namiillinois.org.

Sincerely,

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