

May 31, 2024

National Institutes of Health Comments submitted via nih.gov

Re: Request for Information (RFI): Moving beyond individual-level determinants of mental health to address mental health disparities

Please discuss your views on one or more of the following:

- Gaps in our understanding of determinants of mental health disparities beyond the individual level.
- Barriers to studying determinants of mental health disparities beyond the individual level.
- Methodological and measurement considerations for examining and integrating SDoMH in mental health disparities research, including the use of common data elements (e.g., <u>PhenX</u> Toolkit).
- How to engage community members (e.g., leaders of community-based organizations, those with lived experience) to identify social (e.g., discrimination, isolation), systemic (e.g., health care system, school system), and structural (e.g., structural racism, policy) drivers of mental health disparities within their communities.

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. We have heard repeatedly about the major social drivers of mental health disparities: lack of employment, food security, and housing. NAMI urges NIMH to fund research that moves beyond identifying social determinants of mental health disparities, and instead identifies state/community level solutions that have successfully addressed these drivers and strategies for scaling up these solutions at the federal level.

Employment is a critical <u>social determinant of health</u> by providing a source of income, health insurance coverage, social connections and sense of pride. However, a variety of <u>barriers</u> can make finding and maintaining a job more difficult for people with mental illness, and these may be <u>further</u> <u>compounded</u> by race, gender, age, and involvement with the criminal justice system. Supported employment programs have proven benefits for people with mental illness. However, limited expansion or lack of funding means they serve just a fraction of individuals with mental illness who are willing and able to work. NAMI supports public policies that implement effective supported employment programs to provide employment options for people with mental health needs.

A person's access to healthy food can affect — and is affected by — mental health. Just as being foodinsecure 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. Neighborhood characteristics and transportation options also impact access to food. For example, people living in certain urban areas, rural areas, low-income, and predominantly Black and Latino neighborhoods may have limited access to full-service supermarkets or grocery stores. NAMI supports public policies that help address increasing food security for individuals with mental health conditions.

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. Moreover, it's well-documented that people with mental illness experience housing discrimination throughout the rental process. People with mental illness are overrepresented in the unhoused population, as about <u>1 in</u> <u>5</u> people experiencing homelessness in the U.S. have a serious mental health condition. Additionally, certain demographic groups experience higher rates of homelessness, such as Black Americans who represent 13 percent of the U.S. population, but 37 percent of the unhoused population.

The major social drivers of mental health disparities are known; however, less is known about how to address social needs on a broad scale. NAMI urges NIMH to prioritize research that identifies 1) successful interventions for addressing SDoMH, and 2) ways to scale up existing solutions at the federal level. Research should include how to incorporate solutions that address social drivers in settings where individuals are already seeking care/social services, facilitate data sharing about social needs between medical and social service settings, and develop financing and payment models that pay for upstream social services.

Please discuss your views on one or more of the following:

- Integrating individual, interpersonal, social, systemic, and structural targets into multilevel intervention development to address mental health disparities.
- Recommended approaches (e.g., study design, methods, measurement) for developing multilevel interventions to address mental health disparities.
- Barriers and facilitators to engaging in multilevel intervention design and implementation.
- Considerations for developing culturally responsive multilevel interventions to address mental health disparities.
- Integrating intersectionality into multilevel interventions to address mental health disparities.
- Strategies for engagement with community members, providers, and other important representatives in the development and implementation of multilevel interventions to address mental health disparities.
- Bi-directional relationships among multilevel intervention research, practice and policy.

NAMI can serve as a valuable resource to connect NIMH and researchers to individuals with lived experience and their families. NAMI has 49 state organizations and over 600 local affiliate groups. NAMI reaches millions of consumers each year. Our website serves as the preeminent resource for people searching for guidance, information, and support as they navigate mental health conditions, and it serves more than 12 million unique visitors annually. Our no-cost education courses, presentations, and support groups serve hundreds of thousands of families, individuals, professionals, and the public each year.

NAMI can work with NIMH to share opportunities for researchers to consult with or recruit individuals with lived experience and their families. NAMI regularly shares Research Opportunity Announcements (ROAs) with our grassroots leaders to make them aware of both clinical trials and social sciences research relevant to the mental health community. Promoted research may be conducted by government, academic or private industry partners, or any other entity that has secured IRB approval/exemption for their study. After initial distribution by NAMI National (intranet post and leadership newsletter), state and local NAMI leaders may share the announcement with their networks as appropriate. The amount of lead time to develop an ROA for a particular engagement may vary, however we are typically able to distribute ROAs within two weeks of a request. NAMI does not accept compensation for recruiting research participants; there is no financial component to requesting an ROA.

We encourage NIMH to include individuals with lived experience early in the study design process by requiring consultation with such individuals in grant applications, and subsequent grant progress reports. This requirement could include forming advisory groups of individuals with lived experience and their families or engaging with mental health nonprofit organizations, such as NAMI. Such a requirement would ensure that people with lived experience have an opportunity to shape the research early on, and provide first-hand accounts of the social drivers that contribute to mental health disparities.

As a final consideration, NAMI recommends that study design and multilevel interventions take language access into account. Language barriers, such as a limited English proficiency, can make it harder to navigate social and health systems and contribute to mental health disparities. Access to translation services, and a linguistically diverse workforce, including non-clinical community workers, can help mitigate some of these language challenges.