ONLINE MENTAL HEALTH SCREENINGS:

Opportunities for Policy, Programs, and Ongoing Research

MHA
Mental Health America®

MHA Screening: Turning Data into Insights for Flattening the Mental Health Curve

In 2014, Mental Health America (MHA) created the Online Screening Program (www.mhascreening.org), a collection of 10 free, anonymous, confidential, and clinically validated screens that are among the most commonly used mental health screening tools in clinical settings. Tools available for public use includes screening for depression, anxiety, PTSD, psychosis, bipolar, addiction, eating disorders, perinatal depression, and a parent and youth screen.

The data collected from over 7.1 million users visiting MHA Screening in 2020-2021 is the largest dataset collected from a help-seeking population experiencing mental health conditions during COVID-19. Analysis and dissemination of this data will aid a timely and effective response to the increasing rates of anxiety, depression, psychosis, loneliness, and other mental health concerns in our country.

As expansive as this dataset is, it represents the minimum imminent risk in any community. For every person who takes a mental health screen online, there are likely others who struggle silently before turning to the internet for information and help. In making the data publicly available, we aim to provide a public health tool to address the growing mental health needs in our communities.

MHA has compiled guidance for how stakeholders can use these data to make meaningful and systemic changes for individuals struggling with mental illnesses. Applications of the data include:

- Understand the development and progression of mental illnesses;
- Use data to drive earlier intervention;
- Coordinate data and generate a better real-time understanding of mental health needs;
- Identify where individuals are currently in need of mental health supports and target interventions within communities;
- Close resource gaps for individuals most impacted by COVID-19;
- Inform new and existing resources to address systematic barriers and unmet need for mental health supports; and
- Create systemic policy change to prevent future mental health concerns, and move beyond an issues-based approach to create an environment that promotes mental wellness at the population level.

Understand the Development and Progression of Mental Illnesses

Several of the mental health conditions evaluated through MHA Screening have symptomatic overlap. For example, PTSD and complex PTSD consist of changes to mood, threat perception, perceptual abnormalities, changes in cognition, and physiological reactions that are not completely understood and may look like paranoia in psychosis or intrusive thoughts and behaviors of obsessive-compulsive disorder. Comparing symptoms across multiple mental health screening tools can provide insight into the development and progression of mental health conditions that will help individuals gain insight into emotional, cognitive, and perceptual changes. This research can help us understand how clusters of symptoms occur across an entire spectrum of experiences, as opposed to within diagnoses. Evaluation of symptom clusters across diagnoses is more in line with the future of brain research like the National Institute of Mental Health's Research Domain Criteria (RDoC).

Further, evaluating symptoms across age can help integrate a lifespan development understanding of mental illnesses among youth. Past research on the onset and treatment of mental illnesses reveals that half of mental health challenges begin by the time a person is 14 years old,[1] and individuals often experience a long period of untreated mental illness.[2] Several factors contribute to the challenges of diagnosing youth. Because brains experience rapid change and growth during puberty, called pruning,[3] young brains experience a collection of symptoms that change rapidly over time, making diagnosis of any mental illness difficult. It is not uncommon for youth to have changes associated with learning disabilities like ADHD, mood disorders like depression and bipolar disorder, and perceptual changes like those seen in psychosis. The lack of clarity on symptom development and the multiple labels given to youth and families during childhood and adolescence is confusing for youth and families who are seeking support.

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[1] Kessler RC, Angermeyer M, Anthony JC, et al. (2007). Lifetime prevalence and age-of-onset distributions of mental disorders in the World Health Organization's World Mental Health Survey Initiative. *World Psychiatry: official journal of the World Psychiatric Association (WPA),* 6(3): 168–76. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2174588/

[2] Insel TR, Fenton WS. Psychiatric epidemiology: it's not just about counting anymore. *Arch Gen Psychiatry.* 2005 Jun;62(6):590-2. doi: 10.1001/archpsyc.62.6.590. PMID: 15939836; PMCID: PMC1586102

[3] Spear, L.P. (2013). Adolescent Neurodevelopment. *Journal of Adolescent Health,* 52(2 0 2): S7-13. doi: 10.1016/j.jadohealth.2012.05.006

Use Data for Earlier Intervention

The data available through MHA Screening provides insight in real-time and covers the periods of life before individuals enter health care systems. For many youths, early intervention can lead to better outcomes, and for some, it can even prevent progression to severe mental illness. The average duration of untreated psychosis in the U.S. is 21 months.[4] Individuals experiencing psychosis often do not receive mental health care until their first episode of psychosis. Early intervention for psychosis is associated with profound positive outcomes, including reduced hospitalizations, reduced symptom severity, improved treatment response, greater likelihood of continuing work and schooling, and higher quality of life.[5] Sixty-five percent of individuals who took the PQ-B through MHA Screening in 2020-2021 were under age 25, and 89% of youth ages 11-17 scored at risk for psychotic-like episodes, which is higher than any other age group. Screening and early identification of individuals at risk for psychotic-like experiences are critical to connecting individuals to treatment and supports as early as possible.

Mapping the real-time data from the MHA Screening Program also identifies where the current need is at a pace and scale that was not possible before. Most national-level data that are available generally have a two-year delay for release[6] or are only available from health care systems when an individual initiates care, significantly weakening prevention efforts.[7] At the county level, data can be even more difficult to obtain, as many counties lack the capacity to consistently collect, analyze, and release data on the prevalence of mental illnesses. Even when these data are available, most counties do not have access to data before individuals enter treatment. This lack of data makes comparison across counties in the country nearly impossible, resulting in a substantial barrier to investing in meaningful prevention and early intervention response.

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[4] Maximo, JO, Nelson, EA, Armstrong, WP, Kraguljac, NV, & Lahti, AC. (2020). Duration of untreated psychosis correlates with brain connectivity and morphology in medication-naïve patients with first-episode psychosis. *Biological Psychiatry: Cognitive Neuroscience and Neuroimaging,* 5(2):231-238. Doi: 10.1016/j.bpsc.2019.10.014

[5] Correll, CU, Galling, B, Pawar, A et al. (2018). Comparison of early intervention services vs. treatment as usual for early-phase psychosis: A systematic review, meta-analysis, and meta-regression. *JAMA Psychiatry,* 75(6): 555-565. Doi: 10.1001/jamapsychiatry.2018.0623

[6] Choi, D. Sumner, S.A., Holland K.M. et al. (2020). Development of a machine learning model using multiple, heterogeneous data sources to estimate weekly U.S. suicide fatalities. *JAMA Network Open*, 3(12): e2030932. doi:10.1001/jamanetworkopen.2020.30932

[7] Choi, D. Sumner, S.A., Holland K.M. et al. (2020). Development of a machine learning model using multiple, heterogeneous data sources to estimate weekly U.S. suicide fatalities. *JAMA Network Open,* 3(12): e2030932. doi:10.1001/jamanetworkopen.2020.30932

Identify Where Individuals Are Currently in Need of Mental Health Supports and Target Interventions Within Communities

Our data also offers opportunities to research motivation and engagement challenges for initiating care among subpopulations. Along with the questions collected through each screening tool, MHA collects voluntary data from individuals about age, race/ethnicity, gender, household income, state/country, ZIP Code data, treatment history, identification as a special population (student, LGBTQ+, trauma survivor, caregiver, veteran or active-duty military, new or expecting mothers, or health care worker), and comorbid health conditions. Analysis of subpopulation data can support targeted intervention for undertreated communities. Location-based data provides an opportunity to explore needs in local communities as well as to implement and test local-level interventions to reduce the impact of mental illness. As this data continues to be collected and released, local leaders, policymakers, public health officials, and other stakeholders can have greater real-time information on imminent need within their communities that improves targeted treatment, support, and coordinated efforts across communities with diverse needs. Making the data publicly available allows local health providers and advocates to work with health administrators and government agencies to interpret and inform more effective and targeted interventions, programming, and policy change.

Examples of immediate program opportunities using MHA Screening data include modeling our work from the National Drug Early Warning System (NDEWS) and implementation of the new 988 legislation. The (NDEWS) was developed by the National Institute on Drug Abuse (NIDA) in 2014 to track early signs of potential drug epidemics across the country. MHA Screening data can be used in the same way the NDEWS uses real-time data to identify geographic regions across the U.S. with a higher risk of substance use in their HotSpot Reports and long-term local development through their Site Reports. Collaborating with researchers, MHA can track changes occurring at a local level and advocate or search for funding announcements that can reduce disparities quickly.

Another example of immediate utilization of MHA Screening data is to support 988 implementation. In October 2020, Congress passed the National Suicide Hotline Designation Act, which established a three-digit phone number (988) for users to call during a mental health crisis. By calling 988, users will be linked to a network of crisis supports for mental health emergencies, as opposed to utilizing 911. Implementation of 988 requires each state to submit its own legislation to fund and implement 988 infrastructure. MHA data can be used to identify which states have the highest risk for crisis, including trauma, severe depression, suicide, and psychosis. Our data can help prioritize which states should immediately pass legislation funding 988 implementations to ensure local crisis response teams have the capacity to meet the demand.

Coordinate Data to Improve Interventions and Target Supports Within Communities

Aligning the MHA Screening dataset with existing national surveys or healthcare data can also create opportunities for data coordination to generate deeper and more responsive learning and collaboration to prevent and address mental illness throughout the country. For example, studies have shown that including multiple current data sources to estimate trends in suicide is more effective than current modeling based on historical data. Researchers can include data from MHA Screening as an additional measure within models using multiple sources to predict true rates of mental health conditions in the community so that health officials, policymakers, and other stakeholders are able to make decisions to provide comprehensive care, which includes timely responses to risks of suicide in their communities.

Several national surveys, such as SAMHSA's National Survey on Drug Use and Health (NSDUH), and the CDC's Youth Risk Behavior Surveillance System (YRBSS) and Behavioral Risk Factor Surveillance System (BRFSS), collect data on rates of mental health conditions among different samples. The Healthcare Cost and Utilization Project (HCUP) includes longitudinal hospital care data in the U.S. Combining the location-based data from MHA Screening with these other existing national datasets can deepen understanding of both the risks of various mental health conditions among different populations (e.g., between individuals who are searching for mental health resources and supports online, and those who are surveyed through a general population sample), as well as how individuals are seeking and utilizing mental health-related treatment. Using this data, researchers can better understand the factors that may lead individuals at highest risk for mental illness to seek help and how they may compare to the general population.

The MHA dataset can also provide insight on the gap between individuals seeking information and resources online and their connection to services and supports. MHA Screening data can be combined with datasets from providers such as the National Suicide Prevention Lifeline (NSPL) and Crisis Text Line, or data that are collected through large health care research networks, like those in the Mental Health Research Network, to better understand who is being served, what gaps exist between help-seeking and connection to services, and where we may be missing individuals who are searching for help with initial mental health concerns and may later reach levels of severity that need immediate support.

Close Resource Gaps for Individuals Most Impacted by COVID-19

When a traumatic event like COVID-19 occurs in a community, the mental health consequences are hard to quantify, resulting in challenges in developing appropriate responses for care. Having timely data available can allow local communities the ability to evaluate baseline rates of various mental health conditions before and after traumatic events. The changes in rates of number and severity of various mental health challenges provide insight into the kinds of resources that need to be developed for each community. Looking at geographical areas surrounding communities can allow policymakers, health officials, and community leaders to better evaluate how much the impact of an event affects people's mental health over time.

MHA Screening collects voluntary demographic data, including age, income, and identification as a special population, such as students and health care workers. Evaluating responses based on these voluntary demographics can provide insight into how mental health problems are experienced across different members of a community. Analysis of how local data compares to data from neighboring communities or compares to national data can highlight hotspots for trauma, grief, or new mental health challenges related to COVID-19, especially among populations that were affected most severely, such as health care workers and individuals in areas that experienced more severe coronavirus outbreaks.

Data analysis from our population is best suited to identify need in early identification and intervention of mental health conditions. Over half of screeners screening for severe depression, frequent suicidal ideation, trauma, PTSD, and psychosis through MHA Screening are under 25 years of age, and many are not currently in treatment. Allocation of resources should include whole-family care, including support to new and expecting parents and school-based supports. Generating additional mental health resources directed toward children and adolescents in sites where they can access them, like in schools, is especially important following a nationwide traumatic event like COVID-19. Even prior to the COVID-19 pandemic, unexpected death was identified as a public health concern. U.S. population-based studies have shown that unexpected deaths are associated with increased incidence of several mental health conditions across the lifespan, including PTSD and depression.[8] One in 500 Americans have died from COVID-19,[9,10] and over 130,000 children in the U.S. lost a primary or secondary caregiver to COVID-19 in the first 14 months of the pandemic.[11] Further, American Indian or Alaska Native, Hispanic or Latino, and Black individuals are all more than two times more likely to die from COVID-19 than white individuals.[12] As the COVID-19 pandemic continues, there is an ever-increasing need for additional supports to prevent the development of future mental health conditions following the experience of trauma, especially for BIPOC individuals and families who have been disproportionately impacted.

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[8] Keyes, KM, Pratt, C, Galea, S, McLaughlin, KA, Koenen, KC & Shear, MK. (2014). The burden of loss: Unexpected death of a loved one and psychiatric disorders across the life course in a national study. *American Journal of Psychiatry,* 2014; 171(8):864-871. Doi: https://dx.doi.org/10.1176%2Fappi.ajp.2014.13081132

[9] Keating, D, Johnson, A & Ulmanu, M. (September 15, 2021). The pandemic marks another grim milestone: 1 in 500 Americans have died of COVID-19. *The Washington Post,* 15, Sep. 2021, *https://www.washingtonpost.com/health/interactive/2021/1-in-500-covid-deaths/?itid=hp-top-table-main*

[10] Centers for Disease Control and Prevention (CDC). COVID-19 Mortality Overview. *National Center for Health Statistics.* Retrieved September 16, 2021 from https://www.cdc.gov/nchs/covid19/mortality-overview.htm

[11] Hillis,SD, Unwin,HJT, Chen, Y, Cluver, L, Sherr, L, Goldman, PS et al. Global minimum estimates of children affected by COVID-19-associated orphanhood and deaths of caregivers: a modelling study. *The Lancet,* July 2021; 398(10298):391-402. https://doi.org/10.1016/S0140-6736(21)01253-8

[12] Centers for Disease Control and Prevention (CDC) (September 2021). Risk for COVID-19 infection, hospitalization, and death by race/ethnicity. *CDC COVID-19 Data and Surveillance.* Retrieved September 16, 2021 from https://www.cdc.gov/coronavirus/2019-ncov/covid-data/investigations-discovery/hospitalization-death-by-race-ethnicity.html

Support Schools in Crisis

Over half of individuals screening at risk for severe depression, frequent suicidal ideation, trauma, PTSD and psychosis through MHA Screening in 2020-2021 were youth and young adults ages 11-24. The data findings are consistent with research on the onset of mental health conditions. Fifty percent of individuals will develop a diagnosable mental health condition in their lifetime. Fifty percent of those with a diagnosable mental health condition will develop symptoms during puberty.[13] Increasing school mental health funding and programs is the best way to catch children where they are and ensure families have the support they need to address mental health concerns before problems worsen.

The COVID-19 pandemic is exacerbating the need to respond to student mental health. The amount of stress students face, the reduced face-to-face contact in schools, the loss of family members and caregivers, and risk factors associated with home conflict (especially for LGBTQ+ youth or youth in poverty), are examples of compounding problems that may result in mental health problems for students due to COVID-19 alone.

School districts throughout the U.S. are severely underfunded and lack the resources and capacity to screen their students for mental health conditions or track mental health data over time. The available data from MHA Screening will help identify hotspots of minimum risk in school districts throughout the country and disseminate targeted interventions to promote student mental health. There is not sufficient federal funding for local education agencies to meet the mental health needs of students. Stakeholders can use these data to triage care to the communities with the most severe risk. Triaging care in this way is only a first step. To create healthier communities, schools need long-term financial support to build up sustained and sufficient school infrastructure. This infrastructure should include, at minimum, implementing comprehensive mental health education, increasing the number of mental health providers in schools, identifying processes and supports for screening and treating students, and reducing the gap in care when students transition from school to college and college to the workforce.

MHA Screening data serves to support more robust targeted funding to implement mental health supports within schools, create and maintain additional partnerships between schools and community organizations, and tailor programming and support based on the needs indicated by the data. MHA provides additional support for schools to increase mental health screening and education as a holistic approach to improving youth mental health.

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[13] Kessler RC, Angermeyer M, Anthony JC, et al. (2007). Lifetime prevalence and age-of-onset distributions of mental disorders in the World Health Organization's World Mental Health Survey Initiative. *World Psychiatry*, 6(3): 168–76. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2174588/

Address Systematic Barriers and Unmet Need for Mental Health Supports

Data on communities with higher numbers of individuals at risk of experiencing severe depression, suicide, trauma, or psychosis can also be used to identify hotspots in the U.S with the greatest unmet need, for example, where mental health infrastructure does not currently exist or is not sufficient. The data presented in this series of briefs represent individuals with the highest need who were actively seeking help for their mental health in 2020-2021 and therefore indicate the minimum risk at any given time. By combining this data on imminent need with information on the availability of mental health providers within communities, we can identify areas in the country with the greatest need and lowest access to mental health care. For example, this data can be combined with the Substance Use and Mental Health Services Administration (SAMHSA) Treatment Locator or provider data through the Health Resources and Services Administration (HRSA) to uncover areas with the largest gaps in care. Although the presence of mental health providers and facilities are not entirely indicative of access to care, overlaying mental health infrastructure with data on individuals in need can give a baseline view into which areas of the country are in greatest need of immediate resources and investment. Even where some mental health infrastructure exists, these data can help reveal where greater investment is needed or where opportunities exist for greater collaboration at the federal, state, and local levels to fill gaps in programming or mental health supports.

Population-level demographic information collected through the MHA Screening Program can help identify systematic barriers and disparities in access to mental health care across communities in the U.S., especially among traditionally underserved populations, including LGBTQ+ individuals and Black, Indigenous, and People of Color (BIPOC). Two examples of utilizing MHA Screening data to address disparities in mental health care are prevention of adverse childhood experiences (ACEs) and addressing rates of suicide among Black youth.

A trauma-informed approach to mental health care requires evaluation of how social determinants of health and adverse childhood experiences (ACEs) impact mental health. Childhood trauma and multiple ACEs are strong predictors of both early onset of mental illness, including psychosis, and additional barriers to recovery from mental illness. Individuals who experience several ACEs are more likely to have poor outcomes in adulthood and are at increased risk of mental health problems, including depression, PTSD, and psychosis. Poor outcomes are worse for communities who have experienced historical discrimination, such as Native American or LGBTQ+ community members. Individuals experiencing mental health disparities because of systemic racism or intergenerational poverty are also more likely to be exposed to serious traumatic events, including losing a parent (to death or incarceration); experiencing child abuse; community violence; early exposure to substance use; or witnessing a murder. Future research with MHA data includes comparing mental health screening data with other available data on social determinants of health and social needs, such as incarceration rates; low income; food deserts; community violence; under-resourced schools; underfunded neighborhoods; and other intersecting determinants to identify which communities are at highest risk and highest need for mental health resources.

In 2019, the Congressional Black Caucus released a report to Congress noting that the suicide death rate for Black youth is rising faster than any other racial group, and Black adolescents are significantly less likely to receive care for depression, a risk factor for suicide. Data on race and ethnicity from MHA Screening can help identify areas in the country with greater numbers of Black youth reporting thoughts of suicide or self-harm. Combining the data on social determinants of mental health, risk as measured by MHA Screening, and service utilization can allow stakeholders to explore systemic barriers to care and direct federal, state, and local investments toward more culturally appropriate, representative, and responsive care and support. Understanding where the greatest needs are in a community, or who is currently being served and who is not, can help community leaders identify where more resources need to be generated or where resources need to be allocated more equitably. It can also help leaders identify informal or previously underfunded providers, organizations, or other assets that already exist in their communities and scale them to serve the need that exists. At a minimum, evaluation and advocacy to implement evidence-based practices – such as integrated mental health and substance use treatment, peer support services, telehealth, and collaborative care within the private mental health system – will support increasing severely needed access to mental health care for all.

Create Systemic Policy Change

The mental health care infrastructure has been chronically underfunded for centuries. Lack of funding and lack of coordinated responses result in a system that does not meet the needs of individuals and families who have mental illnesses. Families in our system are left without supports for mental health problems that result in the increased use of crisis services, interaction with the criminal legal system, homelessness, disruptions or termination in education, loss of employment, and – in the case of suicide – loss of lives.

The COVID-19 pandemic highlighted the disparity in funding for mental health care, and at the same time it exacerbated the need for increased support. The American Rescue Plan Act Funds provided much-needed funding for the mental health system to respond to increased demand for treatment and trauma response. In order to implement an adequate response to COVID-19, our system must ensure that funding granted as a result of the COVID-19 pandemic is ongoing and sustained to ensure long-term care following this health crisis, rather than a one-time infusion of resources. Additionally, the allocation of funding should be focused not just on treatment but also on prevention and early intervention supports known to identify and treat mental illnesses early, including early childhood development programs, childcare and school-based mental health care, mental health education and screening in schools, and workforce development funding.

Although one in five individuals struggles with a diagnosable mental health condition, mental health impacts all individuals in their personal lives and in their communities. Data has the power to support early intervention, increase learning in research and practice, and coordinate care in communities and schools. But we cannot accomplish these aims without systemic and material policy change. **For our data to be meaningful, it must result in legislation, regulation, and policy implementation that funnels federal, state, and local funding and guidance to increase quality and responsive mental health care for youth, adults, and families.**

This policy agenda can be accomplished by arming researchers, advocates, providers, administrators, and policymakers with data for meaningful, targeted policy. Furthermore, additional data on demographics and location provides the opportunity and responsibility to explore the intersectional impact of mental health and poverty, trauma, environmental inequities, community development and connectedness, discrimination, racism, and other social determinants of health. With this greater understanding, stakeholders can better invest in working with communities to eliminate harm, promote wellness, and create environments that allow people to thrive.