## PSYCHOSIS AND COVID-19:

Communities In Need Across The U.S.





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## Acknowledgements

Mental Health America (MHA) was founded in 1909 and is the nation's leading community-based nonprofit dedicated to addressing the needs of those living with mental illness and promoting the overall mental health of all. Our work is driven by our commitment to promote mental health as a critical part of overall wellness, including prevention services for all, early identification and intervention for those at risk, and integrated care, services, and supports for those who need them, with recovery as the goal.

#### **Key Stakeholder Involvement**

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### **Executive Summary**

# As the nation works to mitigate the public health crisis introduced by COVID-19, we have a critical responsibility to ensure a fast and coordinated response to address the growing mental health crisis exacerbated by the pandemic.

The data collected from over 7.1 million users visiting MHA Screening (at www.mhascreening.org) 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.

In 2021, MHA published three briefs, <u>Suicide and COVID-19: Communities in Need Across the U.S.</u>, evaluating data from individuals reporting frequent thoughts of suicide or self-harm on the depression screen (PHQ-9), <u>Severe Depression</u> <u>and COVID-19: Communities in Need Across the U.S.</u>, evaluating data from individuals scoring at risk for severe depression on the depression screen, and <u>Trauma and COVID-19: Communities in Need Across the U.S.</u>, exploring the data from individuals seeking support for post-traumatic stress disorder (PTSD) and individuals seeking mental health supports who self-identify as trauma survivors in the U.S. This brief, *Psychosis and COVID-19: Communities in Need Across the U.S.*, is the final brief in our series and evaluates the data from individuals who scored at risk for psychotic-like experiences on the psychosis screen (PQ-B) in 2020-2021.

As opposed to previous disasters in the U.S. that affected certain specific regions or populations where aid and trauma response could be concentrated, the COVID-19 pandemic has affected the entire population of the country. While the risk of contracting COVID-19 is a population-wide traumatizing event, over the course of 2020 and 2021 it was coupled with traumatic changes to people's social environments, including financial hardship, housing and food insecurity, death of loved ones, dramatic changes to work and schooling environments, and increased household stress that may have led to increases in interpersonal violence. During this time, the U.S. also experienced increasingly visible race-based violence, including the harassment and killing of Black and Asian community members. Each of these experiences alone can cause an acute stress response, and for many individuals in the U.S., these experiences compounded one another. Trauma exposure,<sup>1,2</sup> psychosocial stress, and discrimination<sup>3</sup> are all associated with risk of psychosis. Increased stress affects cortisol production, and for those with a genetic predisposition for psychosis, increases in cortisol can trigger symptoms of psychotic-like experiences or a first episode of psychosis. Increased levels of cortisol have also been found to be associated with greater symptom severity,<sup>4</sup> so for many individuals who were already living with psychosis, the stress of COVID-19 likely exacerbated symptoms.

<sup>&</sup>lt;sup>1</sup> Lecei, A et al. (2019). Evidence that the association of childhood trauma with psychosis and related psychopathology is not explained by gene-environment correlation: A monozygotic twin differences approach. *Schizophrenia Research*, 205:58-62. https://doi.org/10.1016/j.schres.2018.05.025

<sup>&</sup>lt;sup>2</sup> Schäfer, I, & Fisher, HL. (2011). Childhood trauma and psychosis – what is the evidence? *Dialogues in Clinical Neuroscience*, 13(3): 360-365. doi: <u>10.31887/DCNS.2011.13.2/ischaefer</u>

<sup>&</sup>lt;sup>3</sup> Van Winkel, R, Stefanis, NC, & Myin-Germeys, I. (2008). Psychosocial stress and psychosis. A review of the neurobiological mechanisms and the evidence for gene-stress interaction. *Schizophrenia Bulletin*, 34(6): 1095-1105. doi: <u>10.1093/schbul/sbn101</u>

<sup>&</sup>lt;sup>4</sup> Jones, SR & Fernyhough, C. (2007). A new look at the neural diathesis-stress model of schizophrenia: The primacy of social-evaluative and uncontrollable situations. *Schizophrenia Bulletin*, 33(5): 1171-1177. doi: <u>10.1093/schbul/sbl058</u>

The following data provide insight into the prevalence of psychotic-like experiences and opportunities to identify where early intervention and increased awareness could support people at increased risk of psychosis.

#### **State-Level Psychosis Risk**

- States with the highest number of people: The three states with the highest number of people scoring at risk for psychotic-like experiences on the PQ-B screen (a screening tool that assesses clinical high risk for psychosis) from January 2020 to October 2021 were California (N=14,406), Texas (N=11,218), and Florida (N=8,102).
- States with the highest percentage of individuals: West Virginia had the highest percentage of individuals score at risk for psychotic-like experiences of those who took a PQ-B screen (83%, N=1,061), followed by Oklahoma (82%, N=2,065), Wyoming (82%, N=316), Louisiana (82%, N=1,647), and Mississippi (81%, N=1,133). The percentage of individuals scoring at risk for psychotic-like experiences of those who took a PQ-B screen ranged from 69%-83% across all states.
- States with the highest percentage in comparison to overall state population: Alaska had the highest percentage of individuals score at risk for psychotic-like experiences in comparison to the overall state population (0.146%, N=1,069), followed by Alabama (0.068%, N=3,314), Maine (0.061%, N=820), Arkansas (0.060%, N=1,808), and West Virginia (0.059%, N=1,061).
- States with the highest percentage when weighted to match state demographics: When weighted to match state demographics for gender and age, the five states with the highest percentage of the population screening at risk for psychotic-like experiences were the same as with the unweighted screening data. Alaska still had the highest percentage of the population screening at risk for psychotic-like experiences were the same as risk for psychotic-like experiences (N=1,037\*, 0.14172%), followed by Alabama (N=3,240\*, 0.06608%), Maine (N=797\*, 0.05929%), Arkansas (N=1,785\*, 0.05916%), and West Virginia (N=1,044\*, 0.05827%).

#### **County-Level Psychosis Risk**

- Counties with the highest number of people: The three counties in the U.S. with the highest number of individuals scoring at risk for psychotic-like experiences on the PQ-B from January 2020 to October 2021 were Los Angeles County, California (N=2,823), Maricopa County, Arizona (N=1,707), and Harris County, Texas (N=1,334).
- Large County Analysis: Franklin County, Ohio had the highest percentage of the population score at risk for psychotic-like experiences of the most populous counties (0.04116%, N=542), followed by Bexar County, Texas (0.03978%, N=797), Maricopa County, Arizona (0.03788%, N=1,699), Clark County, Nevada (0.03503%, N=794), and Tarrant County, Texas (0.03486%, N=733).
- <u>Small and Mid-Size County Analysis</u>: Bristol City, Virginia had the highest percentage of the population score at risk of psychotic-like experiences (0.11101%, N=19), followed by Whitley County, Kentucky (0.10203%, N=37), Humboldt County, Nevada (0.09506%, N=16), Pendleton County, Kentucky (0.08910%, N=13), and Neosho County, Kansas (0.08746%, N=14).

#### **Opportunities for Policy, Programs, and Research**

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.

The sections below explore how stakeholders can use these data to make the following meaningful and systemic changes for individuals struggling with mental illnesses:

- Understand the development and progression of mental illnesses;
- Evaluate and close the resource gaps on those most impacted by COVID-19;
- 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;
- Identify and provide support to programs and resources that already exist in communities;
- Generate new resources to address unmet need;
- 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.

## Psychosis and COVID-19: Communities in Need Across the U.S

COVID-19 has had a profound negative effect on the mental health of the nation. Throughout the COVID-19 pandemic, Mental Health America (MHA) has witnessed an increasing number<sup>5</sup> of people experiencing anxiety, depression, psychosis, loneliness, and other mental health concerns. As the nation strives to mitigate the public health crisis introduced by COVID-19, we have a critical responsibility to ensure a fast and coordinated response to address these mental health concerns so we are not left with a mental health crisis long after the virus itself is under control.

Since 2014, MHA has provided online mental health screening to roughly 1 million users a year. In 2020, that number expanded to over 2.6 million users, and from January-October 2021 MHA's screening reached over 4.4 million users. Prior to this series of briefs, MHA published multiple reports and research studies<sup>6</sup> using the data collected from the <u>MHA Screening Program</u> but had never released this data at a county level. County-level data are difficult to find, leaving public administrators such as county board members, local health officials, and school administrators with little insight into their communities' specific problems and how best to invest in services like mental health care.

In 2021, MHA released four briefs publishing data from MHA Screening at a state and county level. MHA's <u>first brief</u> covered rates of suicidal ideation across the U.S. in 2020, the <u>second brief</u> covered rates of severe depression across the U.S. in 2020, and the <u>third brief</u> summarized data from both individuals seeking support for post-traumatic stress disorder (PTSD) and individuals seeking mental health supports who self-identified as trauma survivors in the U.S. This brief is the final one in MHA's series and evaluates data from individuals scoring at risk for psychotic-like experiences on the PQ-B from January 2020-October 2021. The research, policy, and program opportunities outlined in this brief were developed from a meeting with key stakeholders, including federal partners, researchers, providers and industry partners, mental health advocacy organizations, and school advocates.

At the beginning of 2022, MHA anticipates the release of a publicly available dashboard where individuals can obtain information about the counts and rates of suicidal ideation, severe depression, psychosis, and trauma in their state and county. For those interested in exploring these data in detail, MHA will release a process where administrators and researchers can request access to the complete dataset to identify and collaborate with MHA on future research, policy, and program opportunities.

<sup>&</sup>lt;sup>5</sup> <u>https://mhanational.org/mental-health-and-covid-19-what-mha-screening-data-tells-us-about-impact-pandemic</u>

<sup>&</sup>lt;sup>6</sup> https://mhanational.org/about-mha-screening#ScreeningReportsandResearch

As opposed to previous disasters in the U.S. that affected certain specific regions or populations where aid and trauma response could be concentrated, the COVID-19 pandemic has affected the entire population of the country. While the risk of contracting COVID-19 is a population-wide traumatizing event, over the course of 2020 and 2021 it was coupled with traumatic changes to people's social environments, including financial hardship, housing and food insecurity, death of loved ones, dramatic changes to work and schooling environments, and increased household stress that may have led to increases in interpersonal violence. During this time, the U.S. also experienced increasingly visible race-based violence, including the harassment and killing of Black and Asian community members. Trauma exposure,<sup>7,8</sup> psychosocial stress, and discrimination<sup>9</sup> are all associated with risk of psychosis. Each of these experiences can cause an acute stress response that may trigger symptoms of psychotic-like experiences or a first episode of psychosis. Increases in stress have also been found to be associated with greater symptom severity,<sup>10</sup> so for many individuals who were already living with psychosis, the stress and trauma of COVID-19 likely exacerbated symptoms.

The psychosis data presented throughout this report represents the minimum number of individuals who are at risk for psychotic-like experiences in 2020-2021. Before initiating care for a new mental health condition or seeking care for a relapse of symptoms from an existing mental health condition, people are likely to turn to the internet to seek information and solutions about their concerns. Understanding the data provided by people during this time offers insight into the kinds of challenges people face and the opportunities that exist to help people at the earliest stages of awareness.

<sup>&</sup>lt;sup>7</sup> Lecei, A et al. (2019). Evidence that the association of childhood trauma with psychosis and related psychopathology is not explained by gene-environment correlation: A monozygotic twin differences approach. *Schizophrenia Research*, 205:58-62. <u>https://doi.org/10.1016/j.schres.2018.05.025</u>

<sup>&</sup>lt;sup>8</sup> Schäfer, I, & Fisher, HL. (2011). Childhood trauma and psychosis – what is the evidence? *Dialogues in Clinical Neuroscience*, 13(3): 360-365. doi: <u>10.31887/DCNS.2011.13.2/ischaefer</u>

<sup>&</sup>lt;sup>9</sup> Van Winkel, R, Stefanis, NC, & Myin-Germeys, I. (2008). Psychosocial stress and psychosis. A review of the neurobiological mechanisms and the evidence for gene-stress interaction. *Schizophrenia Bulletin*, 34(6): 1095-1105. doi: <u>10.1093/schbul/sbn101</u>

<sup>&</sup>lt;sup>10</sup> Jones, SR & Fernyhough,C. (2007). A new look at the neural diathesis-stress model of schizophrenia: The primacy of social-evaluative and uncontrollable situations. *Schizophrenia Bulletin*, 33(5): 1171-1177. doi: <u>10.1093/schbul/sbl058</u>

## **MHA Screening**

In 2014, 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. These include the Prodromal Questionnaire – Brief Version screen (PQ-B) to screen for clinical high risk for psychosis.<sup>11</sup>

Psychosis is a condition that affects an individual's thoughts and perceptions and causes some loss of contact with reality. Psychosis can be a symptom of several mental



health conditions, and in some cases may lead to schizophrenia or other psychotic disorders if left untreated. Clinical high risk refers to the period in which an individual experiences changes in mental health, including changes in perceptions, cognition, and mood, prior to the onset of a psychotic episode.<sup>12</sup> Screening for clinical high risk for psychosis helps to identify individuals who may be at heightened risk of developing psychosis or experiencing a psychotic episode in the future.

The PQ-B screening tool consists of 21 scored items to assess risk for clinical high risk for psychosis. For each item, respondents are asked, "In the past month, have you had the following thoughts, feelings, or experiences?" Respondents can select either "Yes" or "No" in response to each of these questions. If an individual answers "Yes" to an item, they are asked to respond to the statement, "When this happens, I feel frightened, concerned, or it causes problems for me," on a Likert scale with five options ranging from "Strongly Disagree" to "Strongly Agree." The Likert scale responses are scored from one (Strongly Disagree) to five (Strongly Agree). Item scores are summed, with a possible range of scores from 0-105. An individual is considered at heightened risk of developing psychosis on the PQ-B screen if they score 24 or higher on the distress questions. The PQ-B is designed to test for clinical high risk for psychosis and is considered the first step in a two-stage screening process. A positive score on the PQ-B suggests the need for further evaluation by a qualified health or mental health professional who is trained in recognizing the early signs of psychosis.<sup>13</sup>

From January 2020 to October 2021, 420,630 individuals took the PQ-B screen to check on their mental health. The analysis of 175,795 people in this brief represents a subset of our data pulled from individuals within the U.S. who found MHA Screening <u>organically</u>. In 2020, the MHA psychosis screen was one of the top results on Google for the search terms "psychosis test" and "schizophrenia test."

<sup>&</sup>lt;sup>11</sup>Loewy, R. L., Pearson, R., Vinogradov, S., Bearden, C. E., & Cannon, T. D. (2011). Psychosis risk screening with the Prodromal Questionnaire—brief version (PQ-B). *Schizophrenia research*, 129(1), 42-46. http://www.sciencedirect.com/science/article/pii/S0920996411001770

<sup>&</sup>lt;sup>12</sup> Addington, J. (2003). The prodromal stage of psychotic illness: Observation, detection or intervention? *Journal of Psychiatry & Neuroscience*, 28(2):93-97. <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC161730/</u>

<sup>&</sup>lt;sup>13</sup> Loewy, R. L., Pearson, R., Vinogradov, S., Bearden, C. E., & Cannon, T. D. (2011). Psychosis risk screening with the Prodromal Questionnaire—brief version (PQ-B). *Schizophrenia research*, 129(1), 42-46. http://www.sciencedirect.com/science/article/pii/S0920996411001770

The MHA Screening dataset collects information from a help-seeking population, meaning individuals access the mental health screening tools while searching for mental health resources and support online. As a result, users are more likely to screen at risk or with moderate-to-severe symptoms of mental health conditions than the general population. Thus, the population represented within this dataset differs from other national mental health datasets collected by federal agencies such as the Centers for Disease Control and Prevention (CDC) and the U.S. Census Bureau Household Pulse Survey, both of which survey a sample of the general U.S. population. This convenience sample allows MHA to understand the experiences of individuals with the highest need who were actively seeking help for early psychotic-like experiences, and therefore can be interpreted as a minimum unmet need for immediate resources and support across the U.S.

The results from MHA Screening constitute one of the largest datasets collecting and distributing national mental health information in real-time, allowing us to recognize and react to changes in the mental health of the nation as they occur, including the mental health effects of COVID-19. MHA Screening also captures information about an individual's mental health needs earlier than other datasets. When people first begin experiencing symptoms of a mental health condition or begin to experience a relapse of symptoms from an existing mental health condition, they often look for answers and resources online, long before speaking to a provider. As such, the data can be an indicator of imminent mental health need, which allows for it to be used for earlier intervention and detection of mental health concerns before they become crises.

The following analysis is of the data collected from individuals who took the PQ-B screen in the U.S. from January 2020 to October 2021. For detailed information on data cleaning and methodology, see the Appendix.

175,795 <u>Organic</u> U.S. Users from 2020-2021

#### Screening At Risk for Psychotic-Like Experiences

Of the 175,795 individuals who took a PQ-B screen from January 2020-October 2021, 79% (N=138,078) scored at risk for psychotic-like experiences.

Psychosis Screen Result	Count	Percentage
Low/No Risk for Psychotic-Like Experiences	37,717	21.46%
At Risk for Psychotic-Like Experiences	138,078	78.54%
Grand Total	175,795	100.00%

When examined by year, the *percentage* of people screening at risk for psychotic-like experiences was highest in 2020, at 79% (N=60,205). However, the greatest *number* of people took a PQ-B screen and scored at risk for psychotic-like experiences from January to October 2021 (N=77,873). The number of people who screened at risk for psychotic-like experiences from January-October 2021 was 29% higher than the total number of individuals who screened at risk for psychotic-like experiences in 2020.

Psychosis Screen Result	2020 Count	2020 Percentage	Jan- October	Jan-October 2021
			2021 Count	Percentage
Low/No Risk for Psychotic-Like	15,797	20.78%	21,920	21.97%
Experiences				
At Risk for Psychotic-Like	60,205	79.22%	77,873	78.03%
Experiences				
Grand Total	76,002	100.00%	99,793	100.00%

The PQ-B screening tool consists of 21 scored items to assess risk for clinical high risk for psychosis. For each item, respondents are asked, "In the past month, have you had the following thoughts, feelings, or experiences?" Respondents can select either "Yes" or "No" in response to each of these questions. The median number of items endorsed by individuals on the PQ-B from January 2020-October 2021 was 12.



#### Number of Items Answered "Yes" on the PQ-B 2020-2021

If an individual answers "Yes" to an item, they are asked to respond to the statement, "When this happens, I feel frightened, concerned, or it causes problems for me," on a Likert scale with five options ranging from "Strongly Disagree" to "Strongly Agree." The Likert scale responses are scored from one (Strongly Disagree) to five (Strongly Agree). Item scores are summed, with a possible range of scores from 0-105. An individual is considered at heightened risk of developing psychosis on the PQ-B screen if they score 24 or higher on the distress questions. The median score among all individuals who took the PQ-B from January 2020-October 2021 was 43. Among youth ages 11-17, the median score was 52, and among adults over age 18 the median score was 39.



#### Gender

Sixty percent (N=103,969) of respondents identified as female, 35% identified as male, and 5% identified as another gender. Among the entire sample, 8% (N=12,757) identified as transgender.

Gender	Count	Percentage
Male	59,640	34.54%
Female	103,969	60.21%
Another gender	9,064	5.25%
Grand Total	172,673	100.00%

#### **Psychosis by Gender**

Respondents who identified as another gender were most likely to score at risk for psychotic-like experiences (95%, N=8,576).

Psychosis Screen Result by Gender	Female Count	Female Percentage	Male Count	Male Percentage	Another Gender Count	Another Gender Percentage
Low/No Risk for Psychotic- Like Experiences	15,583	26.13%	20,795	20.00%	488	5.38%
At Risk for Psychotic-Like Experiences	44,057	73.87%	83,174	80.00%	8,576	94.62%
Grand Total	59,640	100.00%	103,969	100.00%	9,064	100.00%

#### **Race/Ethnicity**

Sixty-two percent (N=106,216) of respondents identified as white. Fourteen percent of respondents identified as Hispanic or Latino, 9% were Black or African American, and 7% identified as more than one race. Middle Eastern or North African was not included as an option under Race/Ethnicity until May 2021.

Race/Ethnicity	Count	Percentage
Asian or Pacific Islander	7,513	4.38%
Black or African American (non-Hispanic)	15,043	8.77%
Hispanic or Latino	23,248	13.55%
Middle Eastern or North African	589	0.34%
More than one of the above	11,824	6.89%
American Indian or Alaska Native	3,078	1.79%
Other	4,022	2.34%
White (non-Hispanic)	106,216	61.92%
Grand Total	171533	100.00%

#### Psychosis by Race/Ethnicity

Individuals who identified as more than one race were most likely to screen at risk for psychotic-like experiences (85%, N=10,103), followed by individuals who identified as Native American or American Indian (83%, N=2,555).

Psychosis Screen Result by Race/Ethnicity	Count Scoring At Risk for Psychotic-Like Experiences	Percentage Scoring At Risk for Psychotic-Like Experiences
More than one race/ethnicity	10,103	85.44%
Native American or American Indian	2,555	83.01%
Hispanic or Latino	18,366	79.00%
White (non-Hispanic)	83,343	78.47%
Black or African American (non- Hispanic)	11,626	77.29%
Other	3,093	76.90%
Middle Eastern or North African	432	73.34%
Asian or Pacific Islander	5,398	71.85%
Grand Total	134,916	

#### Age

Most individuals who took a psychosis screen from 2020-2021 were young adults ages 18-24 (35%, N=60,646), which is consistent with the age of onset of psychosis. Young adults were followed by youth ages 11-17 (30%, N=52,435), and adults ages 25-34 (20%, N=34,444).

Age	Count	Percentage
11-17	52,435	30.24%
18-24	60,646	34.97%
25-34	34,444	19.86%
35-44	15,140	8.73%
45-54	6,637	3.83%
55-64	2,921	1.68%
65+	1,185	0.68%
Grand Total	173,408	100.00%

#### Psychosis by Age

While young adults ages 18-24 were the largest group of respondents to the psychosis screen, youth ages 11-17 were the most likely to score at risk of psychotic-like experiences on the PQ-B screen (89%, N=46,862).

Psychosis Screen Result by Age	11-17	18-24	25-34	35-44	45-54	55-64	65+
Low/No Risk for	10.63%	19.67%	28.92%	33.88%	37.65%	46.18%	52.07%
Psychotic-Like	(N=5,573)	(N=11,927)	(N=9,962)	(N=5,130)	(N=2,499)	(N=1,349)	(N=617)
Experiences							
At Risk for	89.37%	80.33%	71.08%	66.12%	62.35%	53.82%	47.93%
Psychotic-Like	(N=46,862)	(N=48,719)	(N=24,482)	(N=10,010)	(N=4,138)	(N=1,572)	(N=568)
Experiences							
Grand Total	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%
	(N=52,435)	(N=60,646)	(N=34,444)	(N=15,140)	(N=6,637)	(N=2,921)	(N=1,185)

#### **Household Income**

Fifty-four percent (N=76,385) of respondents to the psychosis screen reported a household income under 40,000. Thirty-one percent (N=43,415) had a household income under 20,000.

Household Income	Count	Percentage
Less than \$20,000	43,415	30.50%
\$20,000 - \$39,999	32,970	23.16%
\$40,000 - \$59,999	21,619	15.19%
\$60,000 - \$79,999	14,750	10.36%
\$80,000 - \$99,999	9,653	6.78%
\$100,000 - \$149,999	11,372	7.99%
\$150,000+	8,563	6.02%
Grand Total	142,342	100.00%

#### **Psychosis by Household Income**

Individuals who reported lower household incomes were more likely to screen at risk for psychotic-like experiences than those who reported higher household incomes. Among individuals who reported a household income of less than \$20,000, 82% (N=35,744) screened at risk for psychotic-like experiences.

Household Income	Count Scoring At Risk for Psychotic-Like Experiences	Percentage Scoring At Risk for Psychotic-Like Experiences
Less than \$20,000	35,744	82.33%
\$20,000 - \$39,999	26,053	79.02%
\$40,000 - \$59,999	16,386	75.79%
\$60,000 - \$79,999	10,986	74.48%
\$80,000 - \$99,999	7,156	74.13%
\$100,000 - \$149,999	8,106	71.28%
\$150,000+	5,956	69.56%
Grand Total	110,387	

#### **Mental Health Care**

Over half of individuals who took a psychosis screen from 2020-2021 and scored at risk for psychotic-like experiences had received a prior mental health diagnosis and care. Of those who scored at risk, 57% (N=75,812) had been diagnosed with a mental health condition in the past, and 58% (N=79,004) had received mental health treatment or supports.

Among screeners at risk of psychotic-like experiences: Are you currently, or have you ever been, diagnosed with a mental health condition by a professional?	Count	Percentage
No	56,462	42.69%
Yes	75,812	57.31%
Grand Total	132,274	100.00%

Among screeners at risk of psychotic-like experiences: Have you ever received treatment/support for a mental health problem?	Count	Percentage
No	58,125	42.39%
Yes	79,004	57.61%
Grand Total	137,129	100.00%

#### **Special Populations**

Individuals who took a psychosis screen from 2020-2021 were most likely to identify as students (62%, N=87,702), followed by trauma survivors (40%, N=56,361), and LGBTQ+ (39%, N=55,386).

Which of the following populations describes you?	Count	Percentage
Student	87,702	61.73%
Trauma Survivor	56,361	39.67%
LGBTQ+	55,386	38.98%
Health care worker	8,449	5.95%
Caregiver of someone living with	6,471	4.55%
an emotional or physical illness		
Veteran or active duty military	4,627	3.26%
New or expecting mother	3,996	2.81%
Grand Total	142,074	

#### **Psychosis by Special Population**

People who identified as LGBTQ+ were more likely than any other special population to score at risk for psychotic-like experiences (90%, N=49,763), followed by trauma survivors (86%, N=48,587).

Psychosis Screen Result by Special Population	Student	Trauma Survivor	LGBTQ+	Caregiver of someone living with emotional or physical illness	New or expecting mother	Veteran or active duty military	Health care worker
At Risk for	83.09%	86.21%	89.85%	78.04%	76.63%	70.61%	65.98%
Psychotic-	(N=72,871)	(N=48,587)	(N=49,763)	(N=5,050)	(N=3,062)	(N=3,267)	(N=5,575)
Like							
Experiences							
Low/No Risk	16.91%	13.79%	10.15%	21.96%	23.37%	29.39%	34.02%
for Psychotic-	(N=14,831)	(N=7,774)	(N=5,623)	(N=1,421)	(N=934)	(N=1,360)	(N=2,874)
Like							
Experiences							

#### **Main Concerns**

In April 2020, MHA added the demographic question, "Think about your mental health test. What are the main things contributing to your mental health problems right now? Choose up to three," to each of the MHA Screening tools. Individuals who scored at risk for psychotic-like experiences were 20% more likely to report past trauma and 16% more likely to report loneliness or isolation as contributing to their mental health problems than individuals who scored with little or no risk for psychotic-like experiences.

Think about your mental health test. What are the main things contributing to your mental health problems right now? Choose up to three.	Count of Low/No Risk for Psychotic- Like	Percentage of Low/No Risk for Psychotic- Like	Count of At Risk for Psychotic- Like Experiences	Percentage Scoring At Risk for Psychotic- Like
	Experiences	Experiences		Experiences
Loneliness or Isolation	17,153	52.05%	87,295	68.02%
Past Trauma	15,749	47.79%	86,517	67.41%
Relationship problems	12,183	36.97%	50,605	39.43%
Grief or loss of someone or something	7,088	21.51%	34,911	27.20%
Financial problems	8,031	24.37%	28,945	22.55%
Current events	6,786	20.59%	27,525	21.45%
Coronavirus	7,396	22.44%	20,152	15.70%
Racism	1,618	4.91%	6,947	5.41%
Grand Total	32,957		128,341	

## State-Level Psychosis Risk

The three states with the highest number of people scoring at risk for psychotic-like experiences on the PQ-B screen from January 2020 to October 2021 were California (N=14,406), Texas (N=11,218), and Florida (N=8,102). Each of the below state counts represents the number of individuals in each state who took the PQ-B screen and scored at risk for psychotic-like experiences through the MHA Online Screening Program from January 2020 to October 2021. These findings indicate the number of individuals who may need support for clinical high risk or early-onset psychosis at this point in time. About 100,000 adolescents and young adults experience first-episode psychosis each year, and about 3% of individuals in the U.S. will experience psychosis during their lifetime. <sup>14</sup>

The percentage of individuals at risk for psychotic-like experiences is calculated as the percentage of individuals with a score indicating risk of psychotic-like experiences of those who took a PQ-B screen from 2020-2021. The percent of state population is the percentage of the overall state population that took a psychosis screen on MHA Screening from 2020-2021 and scored at risk for psychotic-like experiences. West Virginia had the highest percentage of individuals score at risk for psychotic-like experiences of those who took a PQ-B screen (83%, N=1,061), followed by Oklahoma (82%, N=2,065), Wyoming (82%, N=316), Louisiana (82%, N=1,647), and Mississippi (81%, N=1,133). The percentage of individuals scoring at risk for psychotic-like experiences of those who took a PQ-B screen ranged from 69%-83% across states. Alaska had the highest percentage of individuals score at risk for psychotic-like experiences of individuals score at risk for psychotic-like experiences of individuals score at risk for psychotic-like experiences of those who took a PQ-B screen ranged from 69%-83% across states. Alaska had the highest percentage of individuals score at risk for psychotic-like experiences in comparison to the overall state population (0.146%, N=1,069), followed by Alabama (0.068%, N=3,314), Maine (0.061%, N=820), Arkansas (0.060%, N=1,808), and West Virginia (0.059%, N=1,061).

State	Count of At Risk for Psychotic- Like Experiences	Count of Low/No Risk for Psychotic- Like Experiences	Total Count PQ-B Screens	Percentage of At Risk for Psychotic- Like Experiences	State Population Count	Percent of State Population Scoring At Risk for Psychotic- Like Experiences
Alabama	3,314	1,048	4,362	75.97%	4,903,185	0.06759%
Alaska	1,069	408	1,477	72.38%	731,545	0.14613%
Arizona	3,911	1,089	5,000	78.22%	7,278,717	0.05373%
Arkansas	1,808	460	2,268	79.72%	3,017,804	0.05991%
California	14,406	4,575	18,981	75.90%	39,512,223	0.03646%
Colorado	3,074	863	3,937	78.08%	5,758,736	0.05338%
Connecticut	1,451	444	1,895	76.57%	3,565,287	0.04070%
Delaware	531	198	729	72.84%	973,764	0.05453%
<b>District of Columbia</b>	257	114	371	69.27%	705,749	0.03642%
Florida	8,102	2,125	10,227	79.22%	21,477,737	0.03772%

#### Psychosis Risk by State in Alphabetical Order

<sup>14</sup> National Institute of Mental Health. (2021, November). *RAISE Questions and Answers*. <u>https://www.nimh.nih.gov/health/topics/schizophrenia/raise/raise-guestions-and-answers</u>

State	Count of At	Count of	Total	Percentage	State	Percent of State
	Risk for	Low/No Risk	Count	of At Risk	Population	Population
	Psychotic-	for	PQ-B	for	Count	Scoring At Risk
	Like	Psychotic-	Screens	Psychotic-		for Psychotic-
	Experiences	Like		Like		Like Experiences
		Experiences		Experiences		
Georgia	4,481	1,170	5,651	79.30%	10,617,423	0.04220%
Hawaii	515	169	684	75.29%	1,415,872	0.03637%
Idaho	948	229	1,177	80.54%	1,787,065	0.05305%
Illinois	4,519	1,280	5,799	77.93%	12,671,821	0.03566%
Indiana	3,809	967	4,776	79.75%	6,732,219	0.05658%
lowa	1,520	395	1,915	79.37%	3,155,070	0.04818%
Kansas	1,406	371	1,777	79.12%	2,913,314	0.04826%
Kentucky	2,421	581	3,002	80.65%	4,467,673	0.05419%
Louisiana	1,647	366	2,013	81.82%	4,648,794	0.03543%
Mamland	820	223	1,043	78.62%	1,344,212	0.06100%
Massachusatta	2,108	63U	2,/38	76.99%	6,045,680	0.03487%
Michigan	2,575	1 1 1 1 0	5,147	75.41%	0,092,505	0.03443%
Minnesota	2 229	575	2 80/	79.09%	5,639,632	0.04300%
Mississinni	1 133	258	1 391	81 45%	2 976 149	0.03552%
Missouri	2.743	686	3.429	79,99%	6,137,428	0.04469%
Montana	548	148	696	78.74%	1.068.778	0.05127%
Nebraska	808	239	1,047	77.17%	1,934,408	0.04177%
Nevada	1,372	365	1,737	78.99%	3,080,156	0.04454%
New Hampshire	659	171	830	79.40%	1,359,711	0.04847%
New Jersey	2,802	853	3,655	76.66%	8,882,190	0.03155%
New Mexico	863	242	1,105	78.10%	2,096,829	0.04116%
New York	6,534	2,177	8,711	75.01%	19,453,561	0.03359%
North Carolina	4,024	963	4,987	80.69%	10,488,084	0.03837%
North Dakota	326	88	414	78.74%	762,062	0.04278%
Ohio	5,504	1,424	6,928	79.45%	11,689,100	0.04709%
Oklahoma	2,065	454	2,519	81.98%	3,956,971	0.05219%
Oregon	2,171	546	2,/1/	79.90%	4,217,737	0.05147%
Pennsylvania	5,051	1,364	6,415	78.74%	12,801,989	0.03945%
Rhode Island	392	I20	2 5 1 2	76.56%	1,059,361	0.03700%
South Carolina	2,080	513 105	2,595	80.22%	5, 146, 7 14	0.04040%
	3 297	766	470	81 15%	6 829 174	0.04134%
Texas	11 218	2 720	13 938	80.49%	28 995 881	0.03869%
Utah	1.639	411	2.050	79,95%	3.205.958	0.05112%
Vermont	299	77	376	79.52%	623.989	0.04792%
Virginia	3,633	963	4,596	79.05%	8,535,519	0.04256%
Washington	3,670	991	4,661	78.74%	7,614,893	0.04820%
West Virginia	1,061	211	1,272	83.41%	1,792,147	0.05920%
Wisconsin	2,426	628	3,054	79.44%	5,822,434	0.04167%
Wyoming	316	70	386	81.87%	578,759	0.05460%

#### Psychosis Risk by State Weighted by Age and Gender in Ranked Order

The MHA Screening population is more likely to be young (ages 11-17) and to identify as female than the general population. Post-stratification weights were calculated and applied to the dataset for both gender and age to normalize the data to match the demographics of each state population.<sup>15</sup>

The below tables on the next two pages show the states ranked by the percentage of the state population screening at risk for psychotic-like experiences through the MHA Screening Program. Alaska had the highest percentage of the population screening at risk for psychotic-like experiences (N=1,037\*, 0.14172%), followed by Alabama (N=3,240\*, 0.06608%), Maine (N=797\*, 0.05929%), Arkansas (N=1,785\*, 0.05916%), and West Virginia (N=1,044\*, 0.05827%).

Rank	State	Weighted	Weighted	Weighted	State	Weighted
		Count* of At	Count* of	Total*	Population	Percent of State
		Risk for	Low/No Risk	Count PQ-B	Count	Population
		Psychotic-	for Psychotic-	Screens		Scoring At Risk
		Like	Like			for Psychotic-
		Experiences	Experiences			Like Experiences
1	Alaska	1,036.73	440.27	1,477	731,545	0.14172%
2	Alabama	3,240.27	1,121.73	4,362	4,903,185	0.06608%
3	Maine	796.94	246.06	1,043	1,344,212	0.05929%
4	Arkansas	1,785.20	482.80	2,268	3,017,804	0.05916%
5	West Virginia	1,044.25	227.75	1,272	1,792,147	0.05827%
6	Indiana	3,754.89	1,021.11	4,776	6,732,219	0.05577%
7	Wyoming	308.94	77.06	386	578,759	0.05338%
8	Kentucky	2,381.77	620.23	3,002	4,467,673	0.05331%
9	Arizona	3,815.34	1,184.66	5,000	7,278,717	0.05242%
10	Delaware	510.37	218.63	729	973,764	0.05241%
11	Idaho	932.16	244.84	1,177	1,787,065	0.05216%
12	Colorado	3,000.27	936.73	3,937	5,758,736	0.05210%
13	Oklahoma	2,058.22	460.78	2,519	3,956,971	0.05202%
14	Utah	1,631.85	418.15	2,050	3,205,958	0.05090%
15	Oregon	2,137.60	579.40	2,717	4,217,737	0.05068%
16	Montana	540.02	155.98	696	1,068,778	0.05053%
17	Tennessee	3,265.07	797.93	4,063	6,829,174	0.04781%
18	New Hampshire	647.82	182.18	830	1,359,711	0.04764%
19	lowa	1,497.87	417.13	1,915	3,155,070	0.04748%
20	Kansas	1,380.75	396.25	1,777	2,913,314	0.04739%
21	Washington	3,599.70	1,061.30	4,661	7,614,893	0.04727%
22	Ohio	5,396.21	1,531.79	6,928	11,689,100	0.04616%
23	Vermont	287.51	88.49	376	623,989	0.04608%

<sup>&</sup>lt;sup>15</sup>U.S. Census Bureau (2019). Population Estimates 2019. U.S. Census Bureau QuickFacts,

https://www.census.gov/quickfacts/fact/table/US/PST045219

<sup>\*</sup>Weights were determined for both gender and age using 2019 state population demographic data from the U.S. Census. One of the limitations of the U.S. Census demographic dataset is that it only provides "Male" and "Female" as options for individuals to identify their gender. Therefore, applying weights based on that data undercounts the percentage of the Screening population who identify with another gender. All individuals who identified as another gender in the MHA Screening data were assigned a weight of 1.

Rank	State	Weighted	Weighted	Weighted	State	Weighted
		Count* of	Count* of	Total*	Population	Percent of State
		At Risk for	Low/No Risk	Count PQ-B	Count	Population
		Psychotic-	for Psychotic-	Screens		Scoring At Risk
		LIKE	LIKE			tor Psychotic-
24	Misser	Experiences	Experiences	2,420	C 127 420	Like Experiences
24	Missouri	2,709.60	/ 19.40	3,429	6,137,428	0.04415%
25	Nevaua North Dakota	325.13	407.21	1,757	762 062	0.04317%
20	Michigan	4 251 78	1 212 22	5 464	9 986 857	0.04200%
28	Virginia	3,555,29	1.040.71	4,596	8.535.519	0.04165%
29	South Dakota	367.75	108.25	476	884,659	0.04157%
30	Nebraska	796.51	250.49	1,047	1,934,408	0.04118%
31	Georgia	4,363.20	1,287.80	5,651	10,617,423	0.04109%
32	Wisconsin	2,377.15	676.85	3,054	5,822,434	0.04083%
33	New Mexico	849.74	255.26	1,105	2,096,829	0.04052%
34	South Carolina	2,035.68	557.32	2,593	5,148,714	0.03954%
35	Connecticut	1,399.09	495.91	1,895	3,565,287	0.03924%
36	Minnesota	2,175.16	628.84	2,804	5,639,632	0.03857%
37	Pennsylvania	4,935.93	1,479.07	6,415	12,801,989	0.03856%
38	Texas	11,043.28	2,894.72	13,938	28,995,881	0.03809%
39	Mississippi	1,118.44	272.56	1,391	2,976,149	0.03758%
40	North Carolina	3,936.08	1,050.92	4,987	10,488,084	0.03753%
41	Florida	7,798.94	2,428.06	10,227	21,477,737	0.03631%
42	Rhode Island	383.40	128.60	512	1,059,361	0.03619%
43	California	14,003.06	4,977.94	18,981	39,512,223	0.03544%
44	District of	249.16	121.84	371	705,749	0.03530%
45	Hawaii	497.64	186.36	684	1.415.872	0.03515%
46	Illinois	4.403.97	1,395.03	5.799	12,671.821	0.03475%
47	Louisiana	1,610.06	402.94	2,013	4,648,794	0.03463%
48	Marvland	2,031.66	706.34	2,738	6,045,680	0.03361%
49					. ,	
1 C C C C C C C C C C C C C C C C C C C	Massachusetts	2,301.50	845.50	3,147	6,892,503	0.03339%
50	Massachusetts New York	2,301.50 6,308.05	845.50 2,402.95	3,147 8,711	6,892,503 19,453,561	0.03339%

\*Weighted counts based on 2019 U.S. Census Gender and Age Demographics for each state.

## **County-Level Psychosis Risk**

The three counties in the U.S. with the highest number of individuals scoring at risk for psychotic-like experiences on the PQ-B from January 2020 to October 2021 were Los Angeles County, California (N=2,823), Maricopa County, Arizona (N=1,707), and Harris County, Texas (N=1,334).

Counties were sorted based on the number of individuals scoring at risk for psychotic-like experiences. Most of the top 20 counties matched the 20 largest counties in the U.S. based on population size. However, Franklin County, Ohio; Sacramento County, California; Hillsborough County, Florida; and New York County, New York ranked among the top counties with the most individuals screening at risk of psychotic-like experiences, but are not among the 20 most populous counties in the U.S.

Among this list of large counties, we calculated population percentage as the percentage of individuals who scored at risk for psychotic-like experiences on MHA Screening from 2020-2021 out of the overall county population. Of the most populous counties, Franklin County, Ohio had the highest percentage of the population score at risk for psychotic-like experiences (0.04116%, N=542), followed by Bexar County, Texas (0.03978%, N=797), Maricopa County, Arizona (0.03788%, N=1,699), Clark County, Nevada (0.03503%, N=794), and Tarrant County, Texas (0.03486%, N=733).

County Name	State Name	Count of At Risk for Psychotic-Like Experiences	County Population Count	Percent of County Population Scoring At Risk for Psychotic-Like Experiences
Franklin	Ohio	542	1,316,756	0.04116%
Bexar	Texas	797	2,003,554	0.03978%
Maricopa	Arizona	1,699	4,485,414	0.03788%
Clark	Nevada	794	2,266,715	0.03503%
Tarrant	Texas	733	2,102,515	0.03486%
Hillsborough	Florida	502	1,471,968	0.03410%
Sacramento	California	518	1,552,058	0.03338%
Wayne	Michigan	556	1,749,343	0.03178%
King	Washington	709	2,252,782	0.03147%
New York	New York	503	1,628,706	0.03088%
Riverside	California	738	2,470,546	0.02987%
San Bernardino	California	642	2,180,085	0.02945%
San Diego	California	978	3,338,330	0.02930%
Harris	Texas	1,334	4,713,325	0.02830%
Los Angeles	California	2,823	10,039,107	0.02812%
Dallas	Texas	698	2,635,516	0.02648%
Orange	California	742	3,175,692	0.02336%
Cook	Illinois	1,201	5,150,233	0.02332%
Miami-Dade	Florida	563	2,716,940	0.02072%
Kings	New York	510	2,559,903	0.01992%

#### **Top 20 Large Counties with Psychosis Risk**

#### **Top 20 Small and Mid-Size Counties with Psychosis Risk**

In addition to evaluating rates of psychosis among more populous counties in the U.S., MHA identified areas with the highest need for psychosis supports within small and mid-sized counties. The 20 small and mid-sized counties with the highest percentages of their populations scoring at risk for psychotic-like experiences on the PQ-B screen through MHA Screening from 2020-2021 are identified below. To ensure that the analyses were not biased toward the smallest counties, we excluded all counties with a sample of individuals scoring at risk for psychotic-like experiences that were lower than the median.<sup>\*</sup>

Bristol City, Virginia had the highest percentage of the population score at risk for psychotic-like experiences (0.11101%, N=19), followed by Whitley County, Kentucky (0.10203%, N=37), Humboldt County, Nevada (0.09506%, N=16), Pendleton County, Kentucky (0.08910%, N=13), and Neosho County, Kansas (0.08746%, N=14).

County Name	State Name	Count of At Risk for Psychotic- Like Experiences	Count of Low/No Risk for Psychotic- Like Experiences	Total Count PQ-B Screens	Percentage of At Risk for Psychotic- Like Experiences	County Population Count	Percent of County Population Scoring At Risk for Psychotic- Like Experiences
Bristol City*	Virginia	19	2	21	90.48%	17116	0.11101%
Whitley	Kentucky	37	9	46	80.43%	36264	0.10203%
Humboldt	Nevada	16	2	18	88.89%	16831	0.09506%
Pendleton	Kentucky	13	1	14	92.86%	14590	0.08910%
Neosho	Kansas	14	3	17	82.35%	16007	0.08746%
Cass	lowa	11	2	13	84.62%	12836	0.08570%
Winchester City*	Virginia	24	6	30	80.00%	28078	0.08548%
Jasper	Indiana	29	4	33	87.88%	35403	0.08191%
Fentress	Tennessee	15	3	18	83.33%	18523	0.08098%
Grant	Kentucky	22	3	25	88.00%	28035	0.07847%
Lawrence	Kentucky	12	1	13	92.31%	15317	0.07834%
Unicoi	Tennessee	14	3	17	82.35%	17883	0.07829%
Craig	Oklahoma	11	1	12	91.67%	14142	0.07778%
Cocke	Tennessee	28	1	29	96.55%	36004	0.07777%
Richland	Illinois	12	3	15	80.00%	15513	0.07735%
Ashland	Wisconsin	12	1	13	92.31%	15562	0.07711%
McIntosh	Georgia	11	1	12	91.67%	14378	0.07651%
Liberty	Georgia	47	7	54	87.04%	61435	0.07650%
Howard	Indiana	61	11	72	84.72%	82544	0.07390%
Rowan	Kentucky	18	6	24	75.00%	24460	0.07359%

\*Bristol City, Virginia and Winchester City, Virginia are included in county-level analyses because they are independent cities.

<sup>\*</sup> The median count of individuals scoring at possible risk of psychosis at the county level was 11.

## Flattening the Curve: Policy, Programs, and Research Implications Using Real-Time MHA Screening Data

In 2014, MHA created the Online Screening Program (<u>www.mhascreening.org</u>), 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 include screenings 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. The data from MHA Screening also represents the minimum imminent risk in any community. For any one person who takes a mental health screen online, there are likely others who struggle silently before turning to the internet for information and help. Because we know that individuals often turn to the internet to find health-related information, publishing our data will meet the goal of providing a public health tool to address the growing mental health needs in our communities.

#### To accompany the release of MHA Screening data in a mapping dashboard, MHA has compiled guidance for how stakeholders can use these data to make the following meaningful and systemic changes for individuals struggling with mental illnesses:

- Understand the development and progression of mental illnesses;
- Coordinate data and generate a better real-time understanding of mental health needs;
- Evaluate and close the resource gaps on those most impacted by COVID-19;
- Identify where individuals are currently in need of mental health supports and target interventions within communities;
- Identify and provide support to programs and resources that already exist in communities;
- Generate new resources to address unmet need;
- Create systemic policy change to prevent future mental health concerns; and
- Create an environment that promotes mental wellness at the population level.

#### **Understanding the Development and Progression of Mental Illnesses**

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,<sup>16</sup> and individuals often experience a long period of untreated mental illness.<sup>17</sup> Several factors contribute to the challenges of diagnosing youth. Because brains experience rapid change and growth during puberty, called pruning,<sup>18</sup> 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.

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.

#### **Publicly Available 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 youth, early intervention can mean preventing that young person from receiving a diagnosis like schizophrenia. The average duration of untreated psychosis in the U.S. is 21 months.<sup>19</sup> 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.<sup>20</sup> 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 connect individuals to treatment and supports as early as possible.

<sup>&</sup>lt;sup>16</sup> 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. <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2174588/</u>

<sup>&</sup>lt;sup>17</sup> 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

 <sup>&</sup>lt;sup>18</sup> Spear, L.P. (2013). Adolescent Neurodevelopment. *Journal of Adolescent Health*, 52(2 0 2): S7-13. doi: <u>10.1016/j.jadohealth.2012.05.006</u>
<sup>19</sup> 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

<sup>&</sup>lt;sup>20</sup> 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

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<sup>21</sup> or are only available from health care systems when an individual initiates care, significantly weakening prevention efforts.<sup>22</sup> 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.

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 <u>National Drug Early Warning System</u> (NDEWS) and implementation of the <u>new 988 legislation</u>. 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 higher risk of substance use in their <u>HotSpot Reports</u> and long-term local development through their <u>Site Reports</u>. 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.

 <sup>&</sup>lt;sup>21</sup> 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
<sup>22</sup> 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

#### **Closing Resource Gaps for Individuals Most Impacted Following 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.<sup>23</sup> One in 500 Americans have died from COVID-19,<sup>24,25</sup> 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.<sup>26</sup> 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.<sup>27</sup> 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.

<sup>&</sup>lt;sup>23</sup> 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: <a href="https://dx.doi.org/10.1176%2Fappi.ajp.2014.13081132">https://dx.doi.org/10.1176%2Fappi.ajp.2014.13081132</a>

<sup>&</sup>lt;sup>24</sup> 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, <u>https://www.washingtonpost.com/health/interactive/2021/1-in-500-covid-deaths/?itid=hp-top-table-main</u>

<sup>&</sup>lt;sup>25</sup> Centers for Disease Control and Prevention (CDC). COVID-19 Mortality Overview. *National Center for Health Statistics*. Retrieved September 16, 2021 from <a href="https://www.cdc.gov/nchs/covid19/mortality-overview.htm">https://www.cdc.gov/nchs/covid19/mortality-overview.htm</a>

<sup>&</sup>lt;sup>26</sup> 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. <u>https://doi.org/10.1016/S0140-6736(21)01253-8</u>

<sup>&</sup>lt;sup>27</sup> 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 <u>https://www.cdc.gov/coronavirus/2019-ncov/covid-</u> <u>data/investigations-discovery/hospitalization-death-by-race-ethnicity.html</u>

#### **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.<sup>12</sup> 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 <u>additional support for schools</u> to increase mental health screening and education as a holistic approach to improving youth mental health.

#### **Coordinated Intervention and Learning**

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 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.

#### Addressing 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.

#### **Responsibility for 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 harms, promote wellness, and create environments that allow people to thrive.

## Appendix

#### Methodology

MHA did not ask for any identifiable personal information as part of MHA Screening. All identifiable information provided by screeners in question responses, including email addresses, phone numbers, home addresses, and names, were immediately removed from the dataset. To ensure that duplicate users were not included in the analyses, only the first recorded screening result from each user's IP address was included in the dataset, and all additional results were removed. As a result, each count in these analyses represents one individual person who took a psychosis screen. While most individuals access MHA Screening organically, MHA has 200 affiliate organizations and multiple partner organizations that often refer users to the MHA Screening Program. To reduce oversampling in areas where these organizations are located, data referred from affiliates and partners were removed from the dataset. Data were only included in the final set if it was referred from search engines (including Google, Bing, and Yahoo, among others), from the MHA National main website, or from national social media platforms (including Instagram, Twitter, Reddit, and YouTube). The final dataset for psychosis after cleaning contained PQ-B screening results from 420,630 individuals.

We conducted demographic analyses and state-level analyses using only results from individuals who had reported living in the U.S. on the state demographic question. In response to that question, users either select the state they live in, "I live outside the U.S.," or "I live in a U.S. territory." The sample size of users who took a PQ-B screen from 2020-2021 and reported their state on this question was 175,795. U.S. Census 2019 state resident population totals<sup>28</sup> were used to calculate the percentage of each state's population screening at risk for psychotic-like experiences. We conducted county-level analyses using results from the ZIP Code demographic question, in which users can type in their ZIP Code. ZIP Codes were then consolidated into counties on Tableau, using an online U.S. ZIP Code database.<sup>29</sup> For county-level analyses, additional data cleaning was performed to ensure accurate counts. In some cases, users will enter their ZIP Code but will not report their state or will report a state that does not match the ZIP Code they entered. Where a user's response for state did not match the ZIP Code they provided in the demographic questions, or they did not answer the state demographic question, we verified the user's location at the time of taking a screen with their IP address. U.S. Census 2019 county resident population totals<sup>30</sup> or a sum of the 2019 American Community Survey population totals by ZIP Code<sup>31</sup> were used to calculate the percentage of each county's population screening at risk for psychotic-like experiences. For a conservative estimate, if the U.S. Census county population total differed from the sum of American Community Survey population totals by each ZIP Code within the county, we used the larger of the two figures for county population.

<sup>&</sup>lt;sup>28</sup> U.S. Census Bureau (2019). Annual estimates of the resident population for the United States, regions, states, and Puerto Rico: April 1, 2010, to July 1, 2019. U.S. Census Bureau. Retrieved from <u>https://www.census.gov/data/tables/time-series/demo/popest/2010s-state-total.html</u>

<sup>\*</sup>The median count of individuals reporting frequent thoughts of suicide and self-harm of all counties within the U.S. was seven. <sup>29</sup> SimpleMaps (2021). U.S. zip codes database. Retrieved from <u>https://simplemaps.com/data/us-zips</u>

<sup>&</sup>lt;sup>30</sup>U.S. Census Bureau (2019). Annual estimates of the resident population for counties: April 1, 2010 to July 1, 2019. U.S. Census Bureau. Retrieved from <u>https://www.census.gov/data/datasets/time-series/demo/popest/2010s-counties-total.html#par\_textimage\_70769902</u>

<sup>&</sup>lt;sup>31</sup> U.S. Census Bureau; American Community Survey, 2019 American Community Survey 5-Year Estimates Detailed Tables, Table B01003. Retrieved from www.data.census.gov.

#### **Post-stratification weights**

At the state level, we calculated post-stratification weights to normalize the gender and age demographics based on 2019 state population demographics. Weights were applied to the data using a manual iterative process, beginning with age. Due to limited sample sizes at the county level, we did not apply post-stratification weights to the county-level data.

#### **User Privacy**

MHA works to ensure that no one individual is identifiable from information within this dataset. These analyses did not include any demographic or other potentially identifiable information. As noted above, the final dataset only included counties if there were more than 11 individuals (the median count of the sample) in the county scoring at risk for psychotic-like experiences on the PQ-B screen.