



**STATEMENT ON INCLUSION OF CALIFORNIA'S MENTAL HEALTH COMMUNITY IN THE 2020 CENSUS COUNT
APRIL 30, 2019**

I. ABOUT NORCAL MHA

Mental Health America of Northern California (NorCal MHA) is a 501(c)(3) public benefit organization dedicated to improving the lives of residents in the diverse communities of California through advocacy, education, research, and culturally relevant peer support services. In all its programs, NorCal MHA works with individuals and families with mental health challenges to promote wellness and recovery, prevention, and improved access to services and supports. While our agency still has "NorCal" in our name, we are actually a statewide organization with advocacy and education programs operating throughout California for the better part of a decade.

About ACCESS California

ACCESS California is a statewide consumer-led stakeholder advocacy program of NorCal MHA funded by the California Mental Health Services Act (MHSA/Prop. 63) and the Mental Health Services Oversight and Accountability Commission (MHSOAC). ACCESS's mission is to strengthen and expand local and statewide client stakeholder advocacy in California's Public Mental Health System (PMHS) through individual and community empowerment. Through our ongoing research, data collection and evaluation, legislative and policy analysis, advocacy, education, training, outreach, and engagement activities, ACCESS implements strategies to elevate the voices, identify the needs, and increase genuine public participation of client stakeholders to drive truly transformative change in California's PMHS.

ACCESS Ambassadors are a major component of this program. Ambassadors identify as mental health clients and are highly familiar with the structure and function of California's PMHS. Most are receiving or have previously received services in the PMHS. Ambassadors attend public meetings to represent the interests of local PMHS consumers and develop regional networks of advocates to expand public participation in mental health policy planning and discussions. We presently have more than 20 ACCESS Ambassadors advocating and networking on the ground throughout California.

II. STATISTICS: A SNAPSHOT OF PREVALENCE IN CALIFORNIA

According to the Substance Abuse and Mental Health Services Administration (SAMHSA), in FY 2016-2017, nearly one in five adults in California reported experiencing **any mental illness (AMI)**, a diagnosable mental, behavioral, or emotional disorder, other than a developmental or substance use disorder. During that same year, nearly four percent of adults in the state experienced a **serious mental illness (SMI)**, which is defined as any mental health disorder resulting in a serious functional impairment.¹

All evidence indicates the prevalence of both AMI and SMI in California have continued to rise for at least a decade.

A comparison of SAMHSA's mental health data for California collected in FYs 2008-2009 and 2016-2017 also support this upward trend. This information reveals that prevalence of **SMI** among all adults rose from 3.2% in FY08-09 to 3.94% in FY16-17, with the greatest increase in young adults ages 18-25, whose percentages jumped from **3.62% to 6.61%** in just under a decade.

Likewise, incidence of **AMI** for California adults also rose during this period, from 17.44% in FY08-09 to 18.18% in FY16-17, again with the greatest increase in young adults ages 18-25, which grew from **18.49% to 24.75%**.

¹ [SAMHSA, National Survey on Drug Use and Health: Comparison of 2015-2016 and 2016-2017 Populations Percentages, Tables 27 and 28, pp. 54-57.](#)

California’s PMHS primarily serves non-ACA Medi-Cal enrollees and indigent populations who lack any form of health insurance. In the 2016-2017 state fiscal year, 6,313,485 California children and 8,220,974 adults were deemed Medi-Cal eligibles, meaning at least 14,534,459 residents of this state were eligible for public mental health services in that year.²

According to California’s Department of Health Care Services (DHCS), 339,992 adults and 264,882 children (nearly 605,000 people) in California received specialty mental health services in the PMHS in FY 2016-2017.³ This does not include clients who are insured under the ACA’s Medicaid Expansion or those paying on fee-for-service basis that receive services in the PMHS.

DHCS predicts the number of individuals served in the PMHS will continue to increase in the immediate future:

- **Forecast FY 2018-2019: over 686,000**
- **Forecast FY 2019-2020: over 720,000**

III. CORRELATED CONDITIONS

Chronic mental illness is highly correlated with poverty, unemployment, and homelessness, not to mention comorbidity with physical health conditions, developmental/intellectual disabilities, and co-occurring disorders.

Poverty

According to SAMHSA’s 2015 National Survey of Drug Use and Health, an estimated 9.8 million adults aged 18 or older in the U.S. had a SMI, including 2.5 million adults (a little more than 25%) living below the poverty line. The relationship between mental illness and poverty is complicated. Poverty may intensify the experience of mental illness. Poverty may also increase the likelihood of the onset of mental illness. At the same time, experiencing mental illness may also increase the chances of living below the poverty line.

Unemployment

According to SAMHSA, among adults served in California’s PMHS in 2012, only **10%** reported being employed, with **15%** unemployed, and **75%** not participating in the labor force.⁴ These statistics are getting worse, not better. Fast forward to three years later, and among adults served in California’s public mental health system in 2015, only **8.3%** reported being employed, with **12.3%** unemployed, and **79.4%** not participating in the labor force.⁵

Homelessness

Homelessness affects a sizable portion of persons with serious mental illness, and persons with serious mental illness are at greater risk for homelessness than the general population.

Prevalence of SMI in Homeless Populations

Since 2016, California experienced a larger increase in homelessness than any other state.⁶ Nearly 70 percent of the state’s homeless population is “unsheltered” – individuals falling into this category do not utilize temporary living

² [DHCS, Statewide Aggregate Specialty Mental Health Services Performance Dashboard 2018, pp. 6, 21.](#)

³ [DHCS, Medi-Cal Specialty Mental Health Services November 2018 Estimate Policy Change Supplement for Fiscal Years 2018-19 and 2019-20, pp. 17, 27.](#)

⁴ [SAMHSA, Behavioral Health Barometer California, 2013, p. 10.](#)

⁵ [SAMHSA, Behavioral Health Barometer California, Volume 4, 2015, p. 10.](#)

⁶ [CALmatters, Homeless in California—What the Data Reveals, June 27, 2018.](#)

arrangements provided by either charitable organizations or government programs. Rather, they have been found living on the streets, parks, or other places not meant for human habitation.

According to a 2015 literature review by SAMHSA, between 20 to 50% of the homeless population in the United States lives with some form of SMI.⁷

California's point-in-time homeless population count conducted in January 2018 revealed almost 130,000 individuals experience homelessness in this state on any given night,⁸ representing a quarter of the entire nation's homeless population. If SAMHSA's estimates are correct, between 26,000 – 65,000 of these individuals have SMI.

Prevalence of Homelessness in PMHS clients

A 2005 study of individuals served in California's PMHS found that 15% were homeless at least once during a one-year period.⁹ If this finding still holds true, then 90,731 individuals, 15% of all people served in the PMHS (604,874), were homeless at some point in FY16-17.

IV. FEDERAL PROGRAMS IMPACTED BY CENSUS DATA THAT SERVE INDIVIDUALS WITH AMI/SMI

Given the data and statistics above, individuals living with mental health conditions – and particularly those with SMI – are high utilizers of programs that rely on federal funding, including but not limited to:

- Medicaid (Medi-Cal)
- Section 8 Housing Vouchers/Assistance
- Low Income Home Energy Assistance
- Supplemental Nutrition Assistance Program
- State Children's Health Insurance Program
- Child Care & Development Fund
- Supplemental Insurance for Women, Infants, and Children
- Head Start
- Special Education
- National School Lunch Program

Counting everyone living with chronic mental health conditions, especially those eligible for services in the PMHS and who are difficult to find, is critical to secure the necessary federal funding to effectively serve California's growing populations experiencing homelessness and SMI.

V. BARRIERS IN COMMON WITH OTHER DISABILITY COMMUNITIES

Individuals experiencing SMI can be hard to locate for a variety of reasons. They may not be living independently and/or may reside in non-traditional settings:

- Homeless (sheltered and unsheltered)
- Transient/unstable living arrangements

⁷ [SAMHSA, Treatment Improvement Protocol 55: Behavioral Health Services for People Who Are Homeless, A Review of the Literature, November, 2015, p. 1-4.](#)

⁸ [Public Policy Institute of California, A Snapshot of Homelessness in California, February 19, 2019.](#)

⁹ [Folsom et al., Prevalence and risk factors for homelessness and utilization of mental health services among 10,340 patients with serious mental illness in a large public mental health system, American Journal of Psychiatry, February, 2005.](#)

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- Inpatient hospitalization (short term and long term)
 - Board and care
 - Supported housing
 - Crisis residential
 - Conservatorships
 - State prisons and county jails

VI. BARRIERS UNIQUE TO THE MENTAL HEALTH COMMUNITY

While persons with mental health disorders encounter many of the same barriers to being counted as individuals with physical, developmental, and intellectual disabilities, some challenges are unique to the mental health community.

Involuntary Detentions

State Prisons

A Stanford University study from 2016 concluded that over the past decade, the percentage of state prisoners with mental illness has increased by 77 percent. This same study found that over 30 percent of California prisoners currently receive treatment for a “serious mental disorder,” an increase of 150 percent since 2000. In total numbers, 37,907 state prison inmates in 2016 received treatment for SMI (this figure does not include the number of inmates treated for AMI). The California Department of Corrections and Rehabilitation (CDCR) estimates that the population of prisoners with mental illness will continue to climb.¹⁰

County Jails

While the total county jail inmate population is unknown for this year, the California DHCS reports that in FY 2016-2017, 2,352 adults were admitted to inpatient psychiatric treatment in county jails (2,157 involuntary admissions + 195 voluntary admissions). During this same year, 73,697 adults participated in voluntary outpatient mental health treatment in California county jails.¹¹

The combined number of state prison inmates and county jail inmates receiving any form of mental health services while incarcerated in 2016-2017 totals 113,956 individuals.

Other Involuntary Detentions

Involuntary Treatment-Related Detentions of CA Residents with SMI: 191,346 Adults in FY 2016-2017

- 72-hour holds (adults only): 136,116
- 14-Day Intensive Treatment: 51,603 + 689
- 30-Day Intensive Treatment: 2,908
- 180-Day Post Cert Intensive Treatment: 30¹²

Conservatorships of CA Residents with SMI: 7,017 Adults in FY 2016-2017

- 1961 Temporary + 5056 Permanent¹³

¹⁰ [Stanford Justice Advocacy Project, CONFRONTING CALIFORNIA’S CONTINUING PRISON CRISIS: The Prevalence And Severity Of Mental Illness Among California Prisoners On The Rise, 2017.](#)

¹¹ [DHCS, California Involuntary Detentions Data Report, Fiscal Year \(FY\) 2016/2017, p. 7.](#)

¹² [DHCS, California Involuntary Detentions Data Report, Fiscal Year \(FY\) 2016/2017, p. 4.](#)

¹³ [DHCS, California Involuntary Detentions Data Report, Fiscal Year \(FY\) 2016/2017, p. 7.](#)

Additional Barriers: Outside In

Despite numerous advocacy campaigns over the past decade funded by the California Mental Health Services Act, stigma against individuals living with SMI remains unacceptably high. People fear interacting with individuals who have SMI, and still wrongfully assume most with mental illness are:

- Violent
- Criminals
- Substance users
- Homeless

Furthermore, rampant NIMBYism in California areas with high rates of homelessness and people experiencing SMI hinder community-based solutions that help integrate individuals back into social settings. As a result, those with SMI are often pushed to the margins of society, further limiting their opportunities for public participation and community inclusion.

Additional Barriers: Inside Out

A strong consumer culture founded in the Civil Rights Movement of the 1960's still exists within California's mental health community. This culture emerged as a response to the harsh and inhumane treatments consumers were subjected to by psychiatric professionals, such as institutionalization, lobotomization, forced sterilization, shock therapy, hydrotherapy, forced sedation and medication, isolation, seclusion and restraints, etc. Psychiatrists who were mostly white, male, and of European origin regularly pathologized normal reactions to social indignities and injustices, leading to the misdiagnosis, overdiagnosis, and forced treatment of women and minorities as a form of social control.

While treatment methods have greatly improved since the early days of psychiatry, consumers still see their civil rights, dignity, and autonomy under fire from politicians and bureaucrats. Examples include involuntary treatment laws, medication compliance conditions (where PMHS providers can refuse services to clients who reject medication), and criminalization of behaviors and circumstances related to their illness (such as anti-camping and anti-loitering ordinances and punishment of homelessness). In most California communities, individuals experiencing a mental health crisis cannot go directly to an inpatient psychiatric facility for treatment. Rather, they must go to a hospital emergency room and wait (sometimes for **days**) for a referral to an open bed, or must be taken directly to an inpatient facility by law enforcement, which in and of itself can be extremely traumatizing and dehumanizing. As a result, mistrust of authority remains high within the consumer culture.

VII. POTENTIAL SOLUTIONS

Locate

To ensure all Californians living with SMI are counted, census staff must first find these individuals. They can start by working directly with the following entities to help locate them:

- CDCR and California Prisons
- County Jails
- County/Public Conservators
- County Mental/Behavioral Health Departments (there are 59 public mental health systems in CA)
- County Providers (especially inpatient, crisis residential, supported housing, board and care, and wellness/recovery centers)
- Hospitals and Locked Facilities
- Local Law Enforcement

Outreach

In addition to developing far-reaching marketing campaigns and local outreach strategies, census staff should identify and utilize liaisons from the mental health and diverse cultural communities to establish trust and credibility in their outreach efforts. These liaisons are critical in explaining the importance of completing the census and persuading reluctant individuals to get on board. Potential liaisons include:

- NorCal MHA’s ACCESS Ambassadors
- Statewide mental health advocacy programs funded by the MHSOAC: NorCal MHA, NAMI California, California Youth Connection, California Association of Veterans Service Agencies, United Parents, Health Access Foundation
- County-designated client and family advocates (see county mental health departments)
- County Patients’ Rights Advocates (see county mental health departments)
- Community mental health workers (see county mental health departments)
- Local mental health advocacy organizations (MHA and NAMI affiliates)
- Peer support workers

Engage

Finally, to encourage as many individuals with SMI as possible to complete the census, census staff and community liaisons must: (1) meet them where they’re at, and (2) offer comfortable environments and appropriate supports to assist them in completing the questionnaire. Options include:

Where They’re At

- Prisons/jails
- Hospitals and inpatient facilities
- Board and care facilities
- Supported housing
- Crisis residential
- Clinics and services providers
- Shelters
- Homeless encampments
- Food banks

Comfortable Environments

- Wellness and recovery centers
- Peer support programs
- Day centers/programs
- Community centers
- Community-based organizations
- Faith-based organizations

Supports

- Transportation
- Technology (computers, tablets, smart phones) to gather responses in the field
- Assistive/adaptive technologies (for dual disabilities)
- People to read and explain the questions
- Interpreters and translated materials for all threshold languages
- Lots of encouragement

VII. CONTACT US

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