NAMI California
National Alliance on Mental Illness

The ANNUAL STATE of the COMMUNITY REPORT on DIVERSE COMMUNITIES

"Nothing about us without us"

Funded by MHSOAC Mental Health Services Oversight & Accountability Commission

Year One 17-18

CONTENTS

OVERVIEW OF PROJECT

It has been estimated that 1 in 25 Americans lives with a serious mental health condition. While mental health professionals have effective treatments for most of these conditions, in any given year only 60% of people with a mental illness get mental health care. Statistics for diverse communities are even more startling.

California is one of the most racially diverse states in the country. Today, multicultural communities make up 61% of California's population and will continue to increase.

While consequences are great for all persons suffering with mental illness and unable to receive timely services, the impact on multicultural communities is significant due to language barriers, stigma, and discrimination.

The primary goal of NAMI CA programs are to reduce stigma, end discrimination, and bring the message that one does not have to change their culture in order to seek mental health information or treatment. Rather, the information presented is within the bounds of their own culture. NAMI CA works with facilitators, teachers, mentors, and presenters who not only identify with the target audience but are themselves part of this audience. These individuals are intimately familiar with the subtleties of culture, language, socio-economics, and migration process.

NAMI California
National Alliance on Mental Illness

About the National Alliance on Mental Illness California (NAMI CA)

NAMI California's (NAMI CA) decades of experience serving diverse families and individuals affected by mental illness began when it was founded as a grassroots organization in 1978. With 62 local affiliates serving the state, NAMI CA has a unique ability to connect local services and supports to statewide strategies in training, education, outreach and advocacy.

NAMI CA continuously works within communities to engage in dialogues about the experiences of diverse populations and cultures, within the mental health lens. Since inception, our agency has been partnering with diverse communities through community presentations, social networking, written communication, focus groups, program trainings, advocacy events and town-hall meetings.

As California's demographics have shifted dramatically over the past 38 years, so have NAMI CA's approaches to engaging members of diverse racial and ethnic communities. One of the most obvious shifts has been the growing racial and cultural diversity among residents, and NAMI CA including its affiliates aim to reach the most underserved, marginalized communities of color through the development of responsive and culturally-specific outreach approaches. To this end, we also collaborate with ethnic and other community-based organizations to effectively serve diverse communities. Additional shifts in population have led to increased needs among transitional age youth (TAY), lesbian, gay, bisexual, transgender (LGBTQ+), and veteran populations.

ACKNOWLEDGMENTS

The National Alliance on Mental Illness (NAMI) California appreciates the tremendous energy and resiliency displayed by diverse populations. Community leaders of diverse racial and ethnic communities impact the hardest to reach populations through shared dialogue, education, and advocacy. Without cultural leaders we are not able to effectively reach diverse communities. Opportunities to empower individuals need to continue and can help with service delivery.

Through surveys, meetings, trainings and shared experiences, we've seen that diverse peers and family members play a vital mechanism in supporting and centering the voices of those affected by mental illness in marginalized communities. NAMI CA extends great appreciation to community leaders throughout the state who share their lived experiences and perspectives in this report and within their communities.

MHSOAC
Mental Health Services
Oversight & Accountability Commission

We would also like to thank the Mental Health Services Act Oversight & Accountability Commission (MHSOAC) for funds to continue reaching individuals from underrepresented communities whose lives have been affected by serious mental illness. Funds ensure diverse populations have a major role in the development and implementation of local and state level policies and programs. This report is focused on the first edition of our Annual State of the Community Report regarding diverse communities.

Mental Health 101 Presenter Training in Orange County.

NAMI CA METHODOLOGY

NAMI CA employed a mix of research and data collection procedures in the development of this Annual State of the Community Report. These procedures include the use of surveys, focus groups, and qualitative interviews. The methodology employed and the sample characteristics of these data collection procedures are detailed below.

Diverse Stakeholder Advisory Committee

The overarching working purpose of the Stakeholder Advisory Committee is to ensure the needs and perspectives of diverse communities locally and statewide are accurately represented in our research and data collection for annual reports. Advisory committee members reviewed items like piloting assessment tools, survey and focus group questions, social media campaigns, and drafts of reports. This is a community-based participatory approach to ensure community inclusivity and participation in NAMI CA's research and data collection. The advisory committee helps assure that data collected reflect local concerns from the standpoint of individuals, providers, county, and community-based agencies with perspectives serving diverse racial and ethnic communities. Feedback helped NAMI CA obtain this data in a culturally competent and truly representative manner.

Diverse communities considered for the purposes of this advisory committee are African American, Latino/a/x, Asian Pacific Islander, Native American, LGBTQ+, and non-English speaking or limited-English speaking immigrant communities.

Advisory Committee Participant Recruitment

Recruitment for the advisory committees included multiple emails to NAMI affiliates and diverse program networks throughout California over the span of two months. A screening rubric was created and used in the selection process, which rated applicants based on diverse communities with which they identified, region, identification as peer and/or family member, and involvement in mental health systems and advocacy in their communities. The primary criterion for selection was identity with diverse community, as we wanted to make sure a variety of diverse communities were represented. Other criteria taken into consideration in the selection proves included California region, and peer and/or family member identification.

Advisory Committee Member Composition and Background

The advisory committee consists of eight members, with two members of the Latino community, two members of the African American community, two members of the Asian community, one member of the Middle Eastern community, and one Caucasian member of the LGBTQ+ community. Next steps for this committee include recruiting at least one member from the Native American community.

Three members are from San Fernando Valley, three members are from Sacramento County, one member is from Tulare County, and one member is from the urban Los Angeles area.

Five members are family members of someone with mental illness, two members are peers, and one member is both a family member and peer.

State and Local Impact

Communications and feedback were exchanged via email and conference calls every other month. Members reviewed NAMI CA research tools and positive messaging campaigns, both of which aim to better represent and serve members of diverse communities who are affected by mental illness. Members were also encouraged to express additional concerns about their work at NAMI and disparities particular to their community. Many members expressed their concerns that their affiliates needed more support to reach those in non-English speaking communities. Members also expressed that cultural competence in the mental health system was lacking and adversely affecting members of diverse communities.

Questions for surveys, qualitative interviews, and focus

groups were reviewed by advisory committee members, and NAMI CA staff adjusted these materials based on this feedback. Members also reviewed a positive messaging initiative called Represent Recovery, and NAMI CA adjusted imagery and messaging according to feedback from the advisory committee. The initiative has been disseminated on a monthly basis across social media platforms, in newsletters, and on the NAMI CA website, reaching tens of thousands of followers across California.

Stakeholder Surveys

NAMI CA administered a statewide survey among public mental health providers, benefactors, and the NAMI CA network (members, affiliates, and partner organizations) seeking to understand the experiences of members of diverse communities navigating the public mental health system.

Respondents represent 27 of the 58 potential counties across the state. Survey respondents were asked to self-select how they identify based on a list of 27 different racial/ethnic groups and were allowed to choose multiple groups if they identified, resulting in percentage totals that are greater than 100%. Overall, NAMI CA collected responses from 175 individuals. The sample characteristics were as follows: Latino –Mexican (42%), Black/African American (16%), identifying as white/Caucasian/European (14%), American Indian/Native American/Alaskan Native (9%), identify as Filipino (5.8%), Indian (4%), Latino – Central American (3%), Chinese (3%), Korean (2.35%), 2.35% identify as "other Latino," 2.35% identify. The 14% of the sample that exceeds 100% represents individuals who identify as white in addition to another race. Responses were collected from February 2018 through August 2018. The survey was also offered in Spanish and simplified Chinese.

Focus Groups

NAMI CA conducted multiple focus groups oriented to understanding the unique barriers and recommendations from members of diverse communities during the 2018 calendar year. Focus groups were conducted at the NAMI CA Annual Conference and virtually. Some examples of the questions asked during focus groups include:

1. What are your experiences utilizing health services in their different forms (i.e. meeting with therapists, emergency psychiatric services, informal health services, etc.)?
2. How is mental health/illness understood in your community?
3. Do you feel your treatment has been culturally appropriate?
    a. Have you experienced discrimination when accessing mental healthcare?
4. What would you say is the primary barrier to accessing mental health services for you and/or your community in general?
    a. Follow-up questions depending on responses such as…
        i. Has stigma acted as a barrier? If so, how?
        ii. What could be done to mitigate/eliminate this barrier?
        iii. What level is this barrier (i.e. interpersonal, community, state, national etc.)?
        iv. How have you navigated this barrier in the past?

Individuals who attended NAMI CA focus groups came from a variety of racial and ethnic backgrounds including those representing the Latino, Chinese, African American, Biracial, and LGBTQ+ communities.

Qualitative Interviews

Recruitment

Qualitative interview questions were reviewed by the advisory committee before questionnaire was finalized. During recruitment, it was decided that a questionnaire would be the best way to reach community members, as scheduling phone interviews tended to skew participants to only those who work during certain office hours. Participants were prompted to select diverse communit(ies) with which they identify, their identities in regards to mental health (peer, family member, etc.), and the region in which they are located. The questionnaire was translated into Spanish and Simplified Chinese, and all three questionnaires were sent to diverse advisory committee members, affiliate leaders, and Mental Health 101 trainers for recruitment. Questionnaire participation was open to any peer and/or family member from a diverse community in California, not just NAMI members. Weekly recruitment emails were sent over the course of 6 weeks and participants were offered a $10 gift card as a stipend for their time.

Participant Composition

There were twenty-one qualitative interview participants. Eighteen responded in English, two responded in Chinese Simplified, and one responded in Spanish. Seven participants are Latino, six are Asian, five are African

American, and two are biracial—one of Native American descent, and one Asian and Latino.

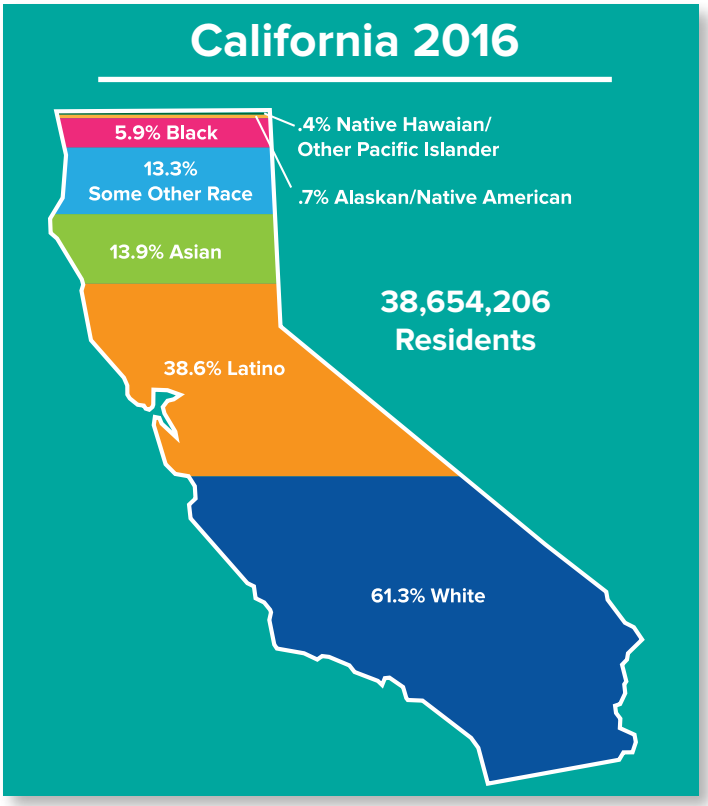
Seven participants are located in San Joaquin County, three are in Alameda County, and two in Santa Clara County. There is one participant each in Contra Costa, Riverside, San Diego, Napa, Los Angeles, and Sonoma counties. Three participants did not disclose their location.
Of the participants, seven are family members with lived experience, five are peers, and seven are both family members and peers. There are two unknown.

Advocacy Regional Meeting in Stockton, CA

DEMOGRAPHIC PROFILE OF THE STATE OF CALIFORNIA

In order to provide context for the variety of factors at play when discussing minority communities experiences with the mental health systems of California, it is important to first examine the demographic landscape of California. All data regarding population rates, unless otherwise stated, was retrieved from the US Census agency's "Factfinder" community profile page (which can be reached here https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_16_5YR_DP05&prodType=table) and analyzes American Community Survey (ACS) estimates.[1]

According to data from the US Census, California is the most populous state in the United States, reporting a total of 38,654,206 residents in 2016. Of the total population, approximately 61.3% of the population of California identifies as white. Latinos constitute 38.6% of California's population. However, Latino or Hispanic origin is classified under the U.S. Census designation as an ethnicity, opposed to a racial category. By race, the next largest racial group, after whites and Latinos, would be Asians, who represent 13.9% of the population. Following those who identify as Asian, "Some other Race" constitutes 13.3% of the population. After "Some other Race," those who identify as Black or African American represent the next largest racial group at 5.9% of the population. American



Indian and Alaskan Native represent 0.7% of California's population. Individuals who identify as Native Hawaiian and Other Pacific Islander represent 0.4% of the state of California, making this racial group the smallest minority in the state. Individuals in California who identify with two or more races represent 4.6% of the state population. Of those who identify as more than two races, the largest combination exists for those who identify as Asian and white (1.3% of total California population). These trends also vary considerably by county and city, and will be discussed in greater detail, when appropriate to understanding the variety of factors at play when examining racial and ethnic minorities' interactions with the mental health environment of California.

Latinos

According to ACS data from 2016, individuals who identify as Hispanic or Latino comprise 38% of respondents. This makes Latinos the largest ethnic group in California. Analyzed by ethnicity, approximately 32% of respondents identified as having Mexican origins, followed by Other Hispanic or Latino (16% of those who identified as Hispanic) which comprises those who have ethnic origins from Central and South America, the Dominican Republic, and Spain. Puerto Ricans and Cubans comprise the remainder of individuals who responded as Hispanic or Latino.

Ten counties in California have compositions where the majority of the population identify as Latino (Imperial, Tulare, San Benito, Colusa, Merced, Monterey, Madera, Kings, Fresno, San Bernardino, and Kern). Los Angeles County also has a close to majority percentage of Latino residents (48%). Even though certain metropolitan areas have large Latino communities, the top 8 counties (by percentage of population who identify as Hispanic) are actually quite rural and have very low populations, relative to the rest of California. For example, the counties with the highest percentage of the population identifying as Hispanic are Imperial, Tulare, San Benito, Monterey, Colusa, Merced, Madera, Kings, (82%, 63%, 58%, 57%, 57%, 57%, 56%, 53%) and combined, these counties represent only about 4.5% of the total population of California. In contrast, the counties with the greatest number of Latinos, overall, are Los Angeles (4,861,648), Riverside (1,102,968), San Bernardino (1,089,104), San Diego (1,076,319), and Orange (1,070,553).

Asian Americans & Pacific Islanders

Individuals who identified as Asian are the third largest racial group in California. Asians represent approximately 16% of California's population based on 2016 ACS data. The largest ethnicities for Asian Americans in California are: Chinese, Filipino, Vietnamese, Other Asian, Asian Indian, Korean, and Japanese. No single county in California has a majority Asian population. The top three counties, by percentage of county population identifying as Asian, in California are: Santa Clara (34%), San Francisco (34%), Alameda (28%) and San Mateo (27%). In terms of counties with the largest total numbers of individuals who identify as Asian, Los Angeles (1,431,361) tops the list followed by: Santa Clara (648,047), Orange (602,013) and Alameda (452,582).

Historically, the immigration of peoples to California from modern day Asian nations has largely been affected by a variety of domestic and foreign policies of the United States government. These include the development of sugar plantations in Hawaii, the development of infrastructure in the Western United States during the 19th century, racial animosity towards Asian immigrants during the late 19th and early 20th centuries, and the conclusion of the Vietnam War in the 1970s (Leong & Okazaki, 2009). These historical events have had a pronounced influence on the timeline with which different Asian peoples have developed communities within the US, their geographic distribution, and the different barriers that these communities face today when navigating California's mental health landscape.

African Americans

Individuals who identified as Black/African American comprise approximately 6% of California's population based on 2016 ACS data. Western historian Quintard Taylor (2012) notes that, in modern history, over 90% of the African American population in the West resides in metropolitan areas and cities. Using ACS data, counties with populations of African Americans that exceed the state average include: Solano (14%), Alameda (11.3%), Sacramento (10%), Lassen (8.9%), Contra Costa (8.8%), San Bernardino (8.6%), Los Angeles (8.3%), and San Joaquin (7%). Furthermore, about 73% of California's African American population reside in the counties of Los Angeles, Alameda, San Bernardino, San Diego, Sacramento and Riverside.

Native Americans/ Alaskan Natives

Based on 2016 ACS data, individuals identifying as Native American/Alaskan Native (NA/AN) represent 0.7% of California's population. The top 4 counties where NA/AN represent significant portions of the population are Alpine (19%), Inyo (11.44%), Del Norte (6.6%), Humboldt (5%), Trinity (4.3%), Mendocino (4%), and Lake (3.5%). It should be noted that of the top ten counties with the highest ratios of individuals who identify as NA/AN, collectively, represent approximately 0.1% of California's total population. In other words, counties that have significant percentages of the population that identify as NA/AN tend to have extremely low populations in general and to be more rural. It is possible that the rurality of this particular community also contributes to a potential undercount on certain census surveys and measures. An interesting statistical fact, when examining ACS data for NA/AN communities in California, those who identify as only one race, in this case NA/AN, comprise 0.7%, however, when we examine the data based on "race alone or in combination with another race," the percentage of California's population of NA/AN individuals rises to 1.9%.

Approximately 62% of NA/AN individuals in California reside within 9 counties: LA (62671), San Diego (21577), Riverside (20205), San Bernardino (17510), Orange county (12938), Sacramento (11133), Alameda (10176), Kern (10051) and Fresno (10034) where they constitute single digit percentages or less of these communities relative to whites and other minority groups.

CURRENT ACCESS TO CARE

The following section of this report will examine the factors that contribute to the levels of access to mental health care for California's diverse minority communities.

Penetration Rates, Service Utilization, and the Affordable Care Act

Penetration rates refer to figures compiled by County Behavioral Health Departments under the direction of the Department of Health Care Services (DHCS) that reflect the usage of mental health services by individuals enrolled in Medi-Cal. These figures are helpful for understanding service utilization and access to mental health services because 1) Medi-Cal beneficiaries comprise one third of the state of California[2], 2) the majority of Medi-Cal enrollees are non-White, and 3) Whites continue to utilize specialty mental health services more than other races.[3]

Statewide, the overall penetration rate has been on continuous decline, from 5.2% in fiscal year (FY) 13-14 to 4.2% for calendar year 16-17 . This decline reflects the increased number of eligible beneficiaries due to the expansion of the Affordable Care Act. For comparison, while the overall population of California has increased by less than 1% from 2012 – 2015, the Medi-Cal enrollee population has increased by about 6% in the same time frame with the percent increase between 2013 -2014 reaching almost 12 percent.[5]

In addition to penetration rates, the DHCS also collects data on service utilization, as measured by the unique count of adults receiving specialty mental health services (SMHS) in a fiscal year. These measures also demonstrate the racial disparities present in mental health care. For example, despite comprising only 20% of the Medi-cal population, 34.9% of adults receiving SMHS in fiscal year 16-17[4] were white. In comparison, Latino's comprised 25.1% of adults utilizing SMHS while constituting half of the Medi-cal population in general.

California Health Interview Survey and Minimally Adequate Treatment

Another useful source of data for estimating mental health need in California communities is the California Health Interview Survey and the studies produced from that data. This survey is conducted by the University of California, Los Angeles in collaboration with the California Department of Public Health and the Department of Health Care Services every year and routinely reaches roughly 20,000 participants. It is the nation's largest state health survey and is an important source of data regarding the disparities that exist in health care in California due to the survey's focus on collecting demographic information, including statistics regarding sexual minorities, an historically under-researched group, from the perspective of state funded research initiatives. Two separate studies that rely on CHIS data[6] [7] find a consistent rate of around 8% (2.2 million) adults having mental health "need" based on data collected from the CHIS between 2007 and 2013. Mental health need was calculated based on responses to the Kessler 6, a series of survey questions designed to estimate the prevalence of psychological impairment at the population level. This calculated rate of need was then cross-referenced with a variable of "minimally adequate treatment" (MAT) which was built on evidence-based guidelines for treating individuals with mental disorders. The two reports found near same levels of adults with mental health need receiving MAT; roughly 1 in 4 received MAT. Other consistent findings from the reports suggest that individuals with limited English ability, sexual minorities, certain ethnic/racial minority groups (American Indian/ Alaskan Native, Native Hawaiian or other Pacific Islander, and multiracial) had higher rates of mental health "need" and Asian Americans reported statistically significant lower rates of "need." In regards to MAT, both reports found that Latinos and Asians were statistically less likely to receive MAT and that, within these populations, those who were more recent immigrants were less likely to receive MAT then their second or third generation counterparts and that those with limited English proficiency were less likely to receive MAT.

Latinos

Within the context of overall declining penetration rates and increasing Medi-Cal enrollment, racial and ethnic disparities

in the data also emerge. For example, Latino/Hispanic beneficiaries, who comprise the largest racial/ethnic group in terms of the ACA expansion[8], have seen penetration rates that have remained lower than the state average of 5.90% in FY 13-14 and 5.16% in 2014, dropping in 2012-2014 from 3.81% to 3.59%.

> *"One, STIGMA: my siblings sometimes don't wish to seek services/resources for fear of being labeled 'crazy.' Two, the location of services provided: we live in Whitewater, CA. Three, the timeliness of the services available: appointments take a while to have. And when the individual is willing to seek services at that particular moment, an "in two-weeks" or "month-out" appointment is A LOT of time for the individual to back out of the willingness to seek services.*
>
> *Accessing treatment in Spanish is difficult because my mother speaks very little English and the doctors are almost never bilingual, making it difficult for her to understand what is being said to my brother. The doctors are almost never Hispanic, thus have a hard time relating to the patient (my brother & sister) and/or the person accompanying the patient (my parents). However, there are some resources where Spanish-only advocacy groups (NAMI) are provided; thus have been the avenues my parents have taken to assist in their education."*
>
> – Latina family member in Riverside County

As part of the Reducing Disparities Project established in 2008, the Latino Strategic Planning Workgroup[9], found that Latinos are less likely to have access to mental health services, to have poorer quality services, and are less likely to receive needed care compared to whites. Research on the responses to the 2007 California Health Interview Survey found that there exists statistically significant differences in the rate at which Latinos receive MAT compared to other racial groups in California.[10] Based on the data, 23.4% of Californians, who require treatment for a diagnosable mental health condition, receive MAT while 30.5% and 18% of whites and Latinos, respectively, receive MAT. Within the Latino population in California there also exists significant differences based on nativity status of participants. US – Born Latinos receive MAT at 24% of their respective population while only about 10% of foreign born Latinos receive the mental health services they require.

Asian Americans and Pacific Islanders

Penetration rates for Californians who identify as Asian or Pacific-Islander are some of the lowest in the state. The DHCS statewide aggregate data report that, for FY 2013-17, penetration rates for Asian or Pacific Islanders decreased from 2.8% in FY 13-14 to 2% in FY 16-17. For perspective, the penetration rate for Whites in FY 16-17 was 5.6% despite the fact that Whites make up only 20% of California's Medi-cal enrollment population and Asian or Pacific-Islanders make up 13% of the Medi-cal population.[11]

> *"Chinese-Taiwanese family and community are highly resistant to mental wellness, as it's considered a sign of weakness and shamefulness. I'd estimate their level of knowledge between 0 to 3 out of 10 depending on the part of the country and world they live in. [The most challenging aspects of accessing mental health are] COST, quality, availability and consistent care for Medi-Cal or Medicare beneficiaries. It's hard to access Chinese Christian therapists in Fremont since they do not accept insurance. We pay out of pocket at $150 per session. First therapist MFT through Medi-Cal not culturally appropriate at all. Wealthy white woman did not understand the social and family dynamics of Chinese-Americans."*
>
> - Chinese American peer in Fremont CA

One of the themes that consistently appears in research into the mental health practices of Asian Americans is the underutilization of services relative to other racial and ethnic groups in the United States.[12] For example,

one national study[13] found that despite having a lifetime prevalence rate of 9.2% of the population experiencing a psychiatric disorder lasting 12 months, only 3.1% of Asian Americans utilized specialty mental health services. A study by Abe-Kim and colleagues[14] Found that only 8.6% of their Asian American sample sought any mental health services compared with approximately 18% of the total sample population of the study. Based on findings from the 2007 California Health Interview Survey[15] California's Asian population received MAT for a mental health need for only 13.4% of individuals who needed care, compared to 23.4% of California in general, and 30.5% of white Californians. This would suggest that over 86% of Asian Californians who need mental health care are going without professional treatment.

There are also important immigration and generational factors to consider when examining the level of access to services for the Asian community and what form of care is utilized. For example, one study[16] found that, at the national level, third-generation Asian Americans utilized medical and mental health services at significantly higher levels (19.3 % of population) compared to first (7.4%) and second generation (8.1%). However, in California, US born Asians and Asian immigrants had roughly the same, low rate of MAT (12.1% and 13.9%, respectively) based on the 2007 data from the CHIS. Spencer and colleagues[17] found that, in a national sample, Limited English Proficiency (LEP) and perceived discrimination were ***not*** associated with a decreased use of mental health services, but were associated with an increased use of informal services (i.e., a religious or spiritual advisor; any other healer, such as an herbalist or doctor of oriental medicine; hotline, internet support groups).

African Americans

Penetration rates for African Americans in California (7.2% in FY 16-17) are among the highest in the state. This may be, in part, due to the large concentration of African American communities in urban environments and the ability of those large and very-large mental health plans to absorb and provide services to the community.

Research from the 2007 California Health Interview Survey would suggest that African Americans do not receive adequate amounts of treatment relative to the community need. For example, of African Americans in need of mental health services to treat a diagnosable condition, only 17.6% received MAT, compared with 30.5% of white Californians and 23.4% of Californians in general.
Research by Snowden and colleagues[18] examined Medi-Cal claims for mental health services for children younger than 18 years from 1998 to 2001 and they found that African-American children were significantly more likely to access

emergency psychiatric services for crisis stabilizations. This is informative in that the researchers' findings suggest that preventive, early intervention, and specialty mental health care are being underutilized by African American children and that emergency services, which are reactive as opposed to proactive, are the primary vehicle with which African American children are accessing mental health services. Research would also suggest that, once enrolled in treatment, African American children dropout from treatment at higher rates than other minorities.[19] Research by Horvitz-Lennon and colleagues[20] analyzed Medicaid claims data from California, Florida, New York, and North Carolina from 2002-2008 and found disparities in treatment outcomes for African Americans diagnosed with schizophrenia across each state, suggesting that African Americans were benefiting less from their treatment than other racial groups, regardless of county and state.

Native American / Alaskan Native

A study from the National Center for Health Statistics[21] concluded that, nationally, in 2014 the suicide rate per 100,000 persons for Non-Hispanic NA/AN males was 27.4 and for females was 8.7 compared with 20.7 and 5.8 for the aggregate of suicides by all races and ethnicities. These differences in the averages was statistically significant. However, differences exist at the national vs. California level. For example, a study conducted by the RAND Corporation (Ramchand & Becker, 2014) found that NA/AN have the lowest suicide rate across all of California's racial groups and a significantly lower rate compared to the national average (4 per 100,00 vs 11 per 100,000). Similar to other minority groups in California, Snowden and colleagues (2008) found that NA/AN Californians use disproportionate amounts of emergency psychiatric services and use less recurring treatment services, suggestive of a potential lack of access to preventative mental health care. According to the 2007 California Health Interview Survey (Grant, et al., 2012), while lower than white Californians (30.5%), NA/AN actually received the most MAT of any other minority group (24.7%) and were slightly higher than the state average (23.4%). A similar study analyzing CHIS survey date (Tran et al., 2017) found that individuals identifying as NA/AN reported higher than state average for mental health need (13% compared to 8%).

It is important to be aware, however, of the high proportion of the Native American community of California live in very rural portions of the state and this could potentially lead to issues such as underreporting of service need or lack of adequate sample sizes for the various state surveys that are the basis for much of the current research cited in this report.

NAMI Contribution to the Literature

Respondents to our stakeholder survey were asked to rate their level of agreement ("strongly agree", "Agree", "Neither Agree or Disagree", "Disagree", "Strongly Disagree") for a variety of questions designed to help understand community perceptions of the current access to care.

Four questions were designed to inform NAMI CA of stakeholder perceptions:

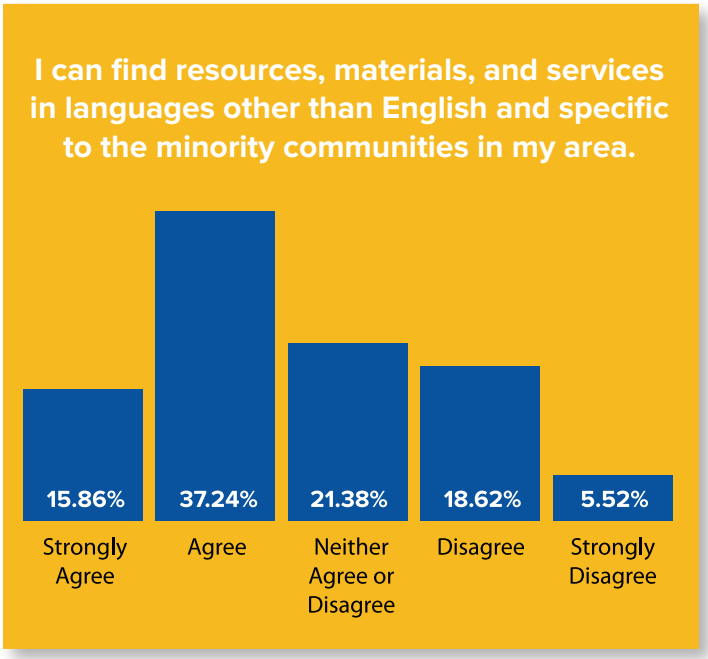
- "There are programs and services available in my community to address the specific needs and barriers of racial/ethnic minority members."
- "My county offers mental health services that are culturally appropriate (i.e., translation services, cultural competency training, partnerships with minority service focused community based organizations, etc.)"
- "My county's mental health professionals and staff reflect the diversity of the communities they serve."
- "Minority members of my community receive the mental health treatment and services they need."

Figure 1.1 shows the weighted average of responses to these four questions. Statements were weighted as follows

- Strongly Agree = 2
- Agree = 1
- Neither Agree or Disagree = 0
- Disagree = -1
- Strongly Disagree = -2

This results in a weighted average wherein positive scores are indicative of greater agreement and negative scores demonstrate disagreement regarding a statement. For example, a question with a weighted average of 2 would indicate that all respondents selected "strongly agree" as their answer to the question.

As we see in Figure 1.1, respondents, in general, are in a slight positive agreement with most of the statements indicating that most respondents agree or strongly agree that their exist specific programs that are available to them, that the mental health services available to them are culturally appropriate, and that mental health staff reflect the diversity of their service populations. The single statement where respondents generally disagree, is in regards to the final question, "Minority members of



my community receive the mental health treatment and services they need." This may suggest that, despite the average positive perception of services that, while broadly defined, issues of program access and competency meet respondent expectation, most respondents still feel that minority members of their community go without the mental health services they need.

Interestingly, the effects seen in Figure 1.1 also seem buoyed by the perspectives of individuals who identify as "a professional employed in the mental health field" who comprised approximately 45% of our sample. When we remove individuals who work in the mental health field from our analysis, and only examine the perspectives of family members and peers from diverse communities, 3 out of 4 questions have a negative weighted average as we see in Figure 1.2, as opposed to the aggregate responses in Figure 1.1 where only 1 out of 4 responses averaged a negative weighted average. Furthermore, the average perception of whether or not minority members of the community go without mental health treatment doubles in Figure 1.2.

Given the prevalence of language based difficulties related to addressing mental health care, NAMI CA asked, in our Community Survey, "I can find resources, materials, and services in languages other than English and specific to the minority communities in my area." The question responses were weighted in a similar matter to previous questions which results in higher averages representing stronger agreement to a statement and negative averages representing disagreement. For the question NAMI CA asked, the weighted average was 0.4, indicating general, overall agreement with the statement. The following graph represents the distribution of responses in Figure 1.3.

The results of this survey question would suggest that, overall, survey respondents can find materials and educational programs for mental health issues that are in languages other than English.

NAMI CA also asked respondents to rate their level of agreement regarding a variety of questions related to community resources including:

- My local county Behavioral Health Department has a robust relationship with Community Based Organizations, non-profits, or faith-based organizations who work with diverse racial/ethnic communities.
- The Mental/Behavioral Health Board in my county is comprised of individuals from diverse racial/ethnic backgrounds.
- My local behavioral/mental health board actively engages diverse communities in an effort to represent stakeholder communities who have historically been underrepresented.
- My county behavioral/mental health department strives to fulfill the duties and recommendations set forth in their Cultural Competency Plan.

Overall, respondents tended to agree with the four statements, though only due to a slim margin. The complexity and nature of the questions and variables involved, (i.e., race, socioeconomic status, gender, region, diagnoses, family support, etc) suggest that these results could yield interesting and telling variations across California and across the PMHS regarding access to mental health services. Figure 1.4 shows the distribution of responses of these questions.

It is important to note that this comparison does not demonstrate statistically significant differences – it only offers one potential perspective of how the diverse communities of California understand and interact with the PMHS.

Please rate your level of agreement with the following statements:

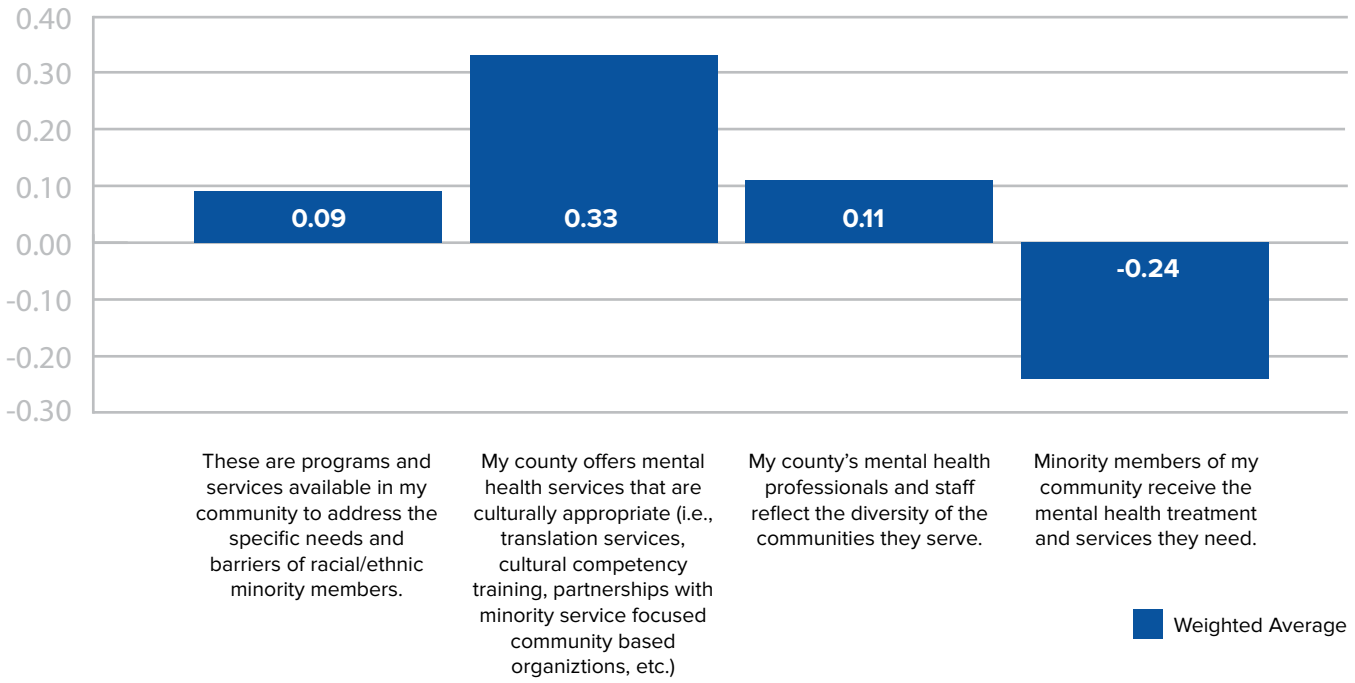


Figure 1.1

Please rate your level of agreement with the following statements (family members and peers alone):

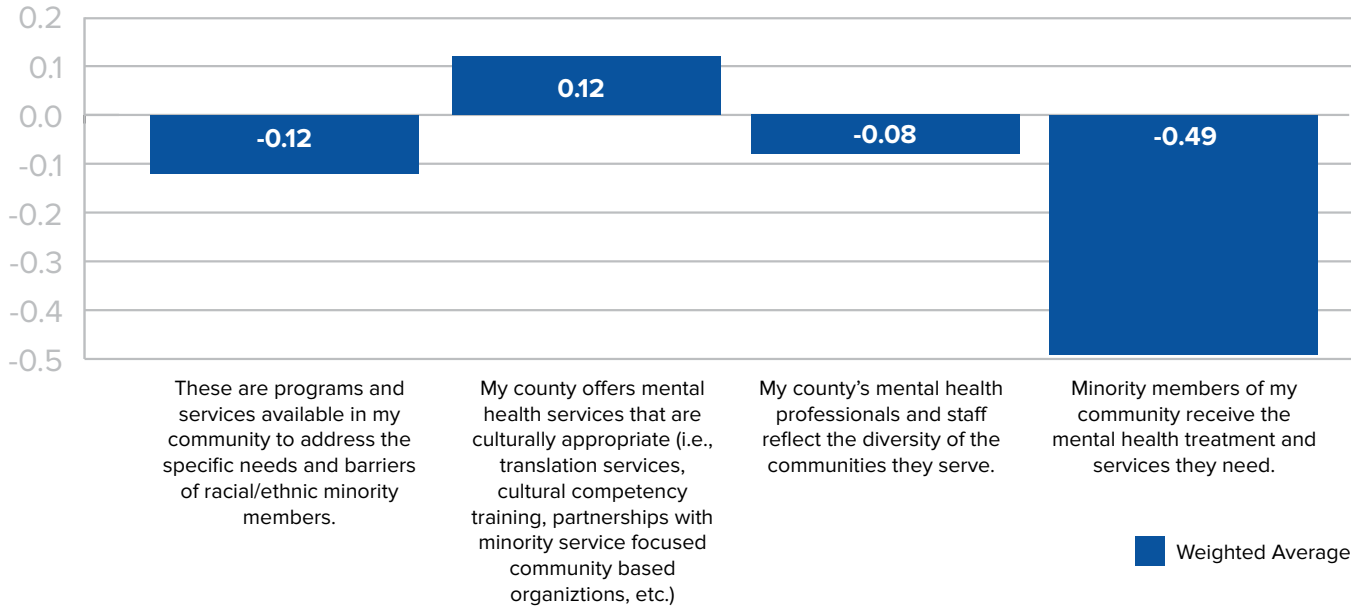
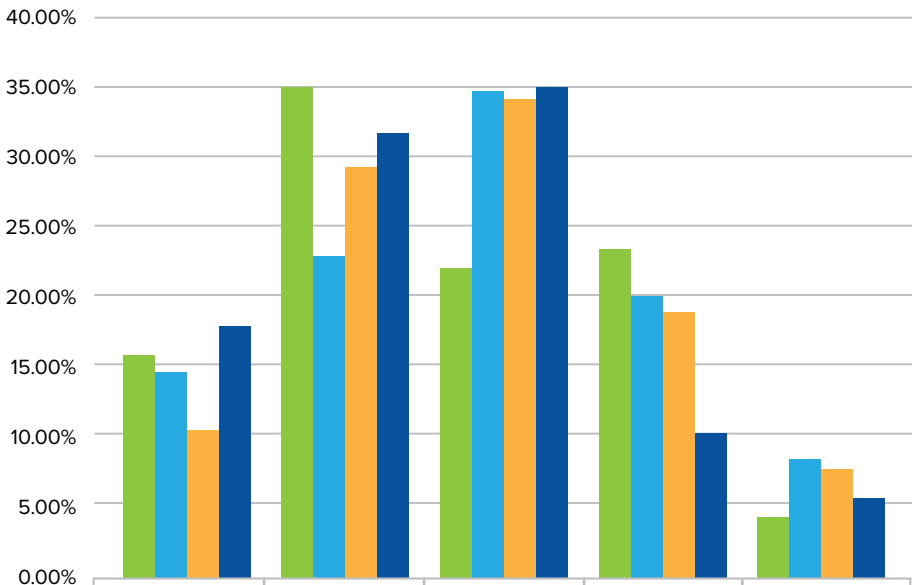


Figure 1.2

Please rate your level of agreement with the following statements:



	Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
My local county Behavioral Health Department has a robust relationship with Community Based Oraganizations, non-profits, or faith-based organizations, who work with diverse racial/ethnic communites.	**15.75%**	**34.93%**	**21.92%**	**23.29%**	**4.11%**
The Mental/Behavioral Health Board in my county is comprised of individuals from diverse racial/ethnic backgrounds.	**14.48%**	**22.76%**	**34.48%**	**20.00%**	**8.28%**
My local behavioral/mental health board actively engages diverse communities in an effort to represent stakeholder communities who have historically been underrepresented.	**10.42%**	**29.17%**	**34.03%**	**18.75%**	**7.64%**
My local behavioral/mental health board actively engages diverse communities in an effort to represent stakeholder communities who have historically been underrepresented.	**17.81%**	**31.51%**	**34.93%**	**10.27%**	**5.48%**

Figure 1.3

BARRIERS TO CARE

Latinos

One primary barrier Latino communities face when accessing mental health services, shared amongst other minority groups in California, revolves around linguistically appropriate services. For example, a study by Aratani & Cooper[22] examined data from the California Department of Mental Health's Consumer and Services Information System for mental health care users under the age of 25 and how long this sample population continued service in 11 counties: Alameda, Butte, Humboldt, Imperial, Placer, Los Angeles, San Diego, San Francisco, Santa Clara, and Santa Cruz. Their study suggests that a lack of English fluency negatively influenced the likelihood of continuing participation, and successfully completing, treatment.

Another key barrier includes a large amount of uninsured Mexican Americans in California. Mexican Americans are statistically the most uninsured population in California.[23] In addition to impacting the availability of regular health services, a lack of insurance has been observed to increase cost barriers for mental health services as well.[24] If we combine these findings with other research into the barriers affecting California's Latinos, it also becomes apparent that rural, immigrant Latinos are facing cumulative barriers ranging from a lack of insurance, a lack of culturally or linguistically appropriate services, and other structural barriers, in addition to individual or community level barriers such as stigma or violence.

Urban Latino communities also encounter their own brand of specific barriers. For example, Guerrero and Kao[25] examined the geographic availability of facilities offering integrated mental health services in substance abuse treatment facilities in Los Angeles County. Their research suggests that portions of the county with higher concentrations of Latino residents were associated with less access to these integrated facilities. Research by Sharma, Casas, Crawford, & Mills[26] support these findings as well, however their research analyzed data from multiple counties and other municipal collections, accounting for approximately 91% of California's population.

> *"Los especialistas en salud Mental son insuficientes para atender la población con esta necesidad: a) Se cuentan con poquisimos Psiquiatras que hablan español en el area. Inclusive en otras areas aledañas al condado de Riverside. b) El Plan de Obama Care, aunque positivo , ha aumentado el número de personas aseguradas que pueden accesar servicios de salud Mental , pero no asi la disponibilidad de Médicos especialistas en ese rubro."*
> *["Mental health specialists are insufficient to meet the population with this need: a) there are very few psychiatrists who speak Spanish in the area. Even in other areas bordering Riverside County. b) The Obama Care Plan {Affordable Care Act}, although positive, has increased the number of insured persons who can access Mental Health services, but not the availability of Medical specialists in that area."*
>
> — Latina Peer and Family Member from Riverside County

The researchers conducted a geographic analysis of mental health professionals in relation to area code and sociodemographic variables and concluded that mental health professionals, such as psychologists and Licensed Clinical Social Workers, invariably cluster in regions that skew whiter, wealthier, and older. This effect was persistent in that even if Latinos lived in a county with a high proportion of mental health professionals, they are less likely to live in cities or census-designated places (CDP; CDPs are specially designated areas used by the

Census Bureau to track smaller, rural, and unincorporated municipalities) with access to mental health professionals.

Asian Americans & Pacific Islander

When discussing the particular barriers to service for California's Asian American communities, it is important to delineate that the different ethnic Asian groups in California have had a varied historical timeline in their immigration stories. These historical differences have implications for differences in the communities related to: English proficiency, educational attainment, income level, perceived discrimination, intergenerational trauma, and community integration.[27]

Yu and colleagues[28] determined that disparate and heterogeneous health care access was endemic among California's different Asian ethnicities. For example, Korean children were 4 times less likely to have health insurance, a barrier to mental health access discussed earlier in this report. Filipino children were twice as likely to not have had recent contact with a doctor, compared to white, non-Hispanic children. The same analysis conducted by Yu and colleagues also found, in their sample, that Korean and South Asian children had the highest rates for noncitizens and foreign-born children which, based on Abe-Kim and colleagues[29] research, would suggest much lower utilization of mental health services for these populations over their lifespan. Finally, much has been written about the Asian American communities' stigma with mental health.[30] Typically, stigma within many Asian American communities revolves around the belief that it is inappropriate to share personal or family troubles with individuals outside of the family or wherein it is perceived as shameful to admit that one has a mental health related concern.

African Americans

The barriers effecting access to mental health care for California's African American population are systematic and structural. Social fragmentation, overt racism, and inequality within the African American community parallel California's own history. Systematic labour and housing discrimination from labour unions, realtors, and industry groups have suppressed the accumulation of social capital in African American communities and led to racial segregation in California since the 1860s.[31] Today, African American communities are less likely to live in geographically accessible regions to mental healthcare professionals. Research[32] would suggest that lifetime exposure to adversity and trauma has a negative cumulative effect, increasing the likelihood of negative physical and mental health consequences. The African American Health Institute of San Bernardino County sums up this point with an excerpt from their Strategic Planning Workgroup, convened in 2012, which states, "The social context in which mental illness occurs was very significant and includes trauma exposure, daily struggles to survive, high levels of stress, and setbacks to social mobility…individuals are inseparable from the communities they are connected to…"[33]

Native Americans/ Alaskan Native

The UC Davis Center for Reducing Health Disparities conducted a series of community stakeholder meetings designed to hear underserved communities thoughts and concerns about mental health programs in their community. During these stakeholder discussions, the researchers identified a variety of barriers effecting the California NA/AN in community: a lack of culturally appropriate mental health care by providers; racism and discrimination by mental health service providers; perceptions of misdiagnoses; deficient available mental health services or funding to secure these services.

One notable barrier that emerged during this literature review was the lack of research into the different barriers experienced between urban and rural NA/AN community members. As mentioned earlier, close to half of California's NA/AN population resides in the top 5 most populous counties yet counties where NA/AN individuals make up a significant proportion of the county population are decidedly rural. A report by the American Indian Research Program at the University of California for Health Policy Research[34] suggests that the percentage of the NA/AN population 55 and older will double between 2000 and 2050 and, while about 60% of NA/AN elders live in urban areas, the population as a whole as the highest percentage of elders living in rural areas of any race or ethnicity. Based on these findings, transportation and logistical barriers may be significant among these rural, elder NA/AN.

NAMI CA Contributions to the Literature

NAMI CA asked respondents to our statewide survey to rank a list of common barriers that previous research would suggest is prevalent in minority communities.
The following graph, Figure 2.1, represents the ranked responses to the question of *"Please rank the following topics based on 1 being the most substantial barrier to accessing treatment and 7 being the least substantial barrier to treatment."*

Please rank the following topics based on 1 being the most substantial barrier to accessing treatment and 7 being the least substantial barrier to treatment.

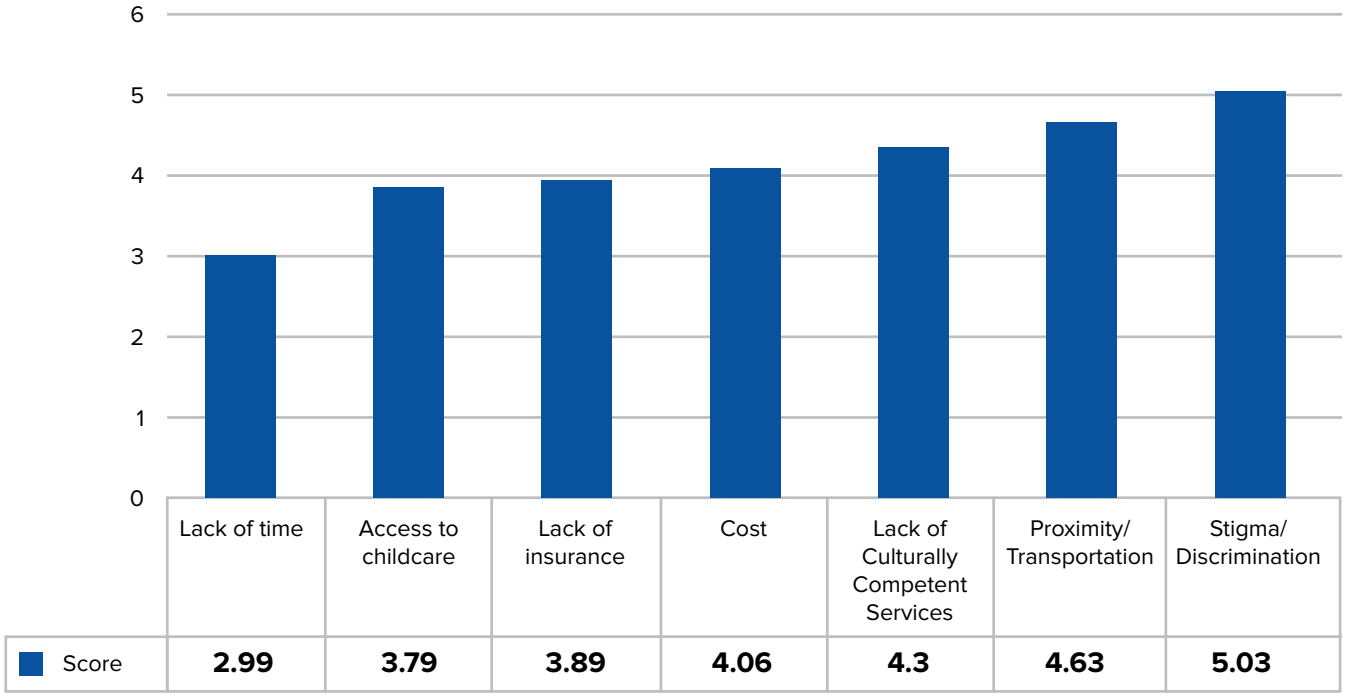


Figure 2.1

Higher scores indicate that the item chosen was closest to 1, or, in other words, the *most substantial barrier to accessing treatment.* Based on the data from our survey, respondents state that Stigma/Discrimination is the most substantial barrier to treatment, followed by proximity/ transportation, and a lack of culturally competent services. Further research will further examine these responses by breaking up the top items in more specific subsections. For example, by asking about the different impacts of self-stigma, community-based stigma, provider stigma on seeking services.

The following information was collected using a qualitative research questionnaire. We shared this community engagement opportunity with people directly in the community via trainings, meetings, public gatherings and shared via email, newsletter or other online communications with community members across the state.

Perhaps the most prominent barrier to care identified by our participants is the shortage and lack of availability of providers. Stigma, both within participants' ethnic communities and the general stigma experienced by society and health systems, was also cited by many participants. Several participants spoke of the difficulties accessing culturally diverse practitioners, and culturally appropriate care and programs, particularly in regard to language barriers for those who speak little to no English. Several participants across cultures said that inter-familial and inter-community stigma and resistance to treatment were some of the biggest challenges to their respective diverse communities. These participants called for a need for educating these communities to foster acceptance. Fear of deportation for seeking mental health treatment is a common fear among undocumented individuals and families. On the other hand, one participant said that accessing mental health care has been so difficult here that his family member went back to Mexico for treatment. Several participants also recommended educating providers on cultural competence.

Participants involved with NAMI credited their involvement with much of their current knowledge on mental illness. Many expressed that even with all of their involvement, they still want to do more to help other individuals and family members affected by mental illness.

Testimonials provided below, representing diverse communities voice regarding barriers with access to mental health care.

The following are actual accounts on barriers faced in accessing care are from those who participated in our qualitative interviews:

> *Accepting that you need to seek help, letting someone know your need to seek help, access when you actually go to seek help.*
>
> — African American peer from San Joaquin County

> *Getting meds on time, access to providers, dealing with med side effects.*
>
> — Chinese American peer in Santa Clara County

> *Sometimes it's transportation and parking. The stigma and language being used.*
>
> — Biracial Native American peer in San Joaquin County

> *Availability of services and providers, poor attitudes of mental health providers and accessing the appropriate therapy for my son.*
>
> — Latina / Asian American peer and family member from Napa County

> *I remember in college having a woman give me a referral phone number without any follow up. She looked frightened of me. I am doing this work because of her.*
>
> — African American family member and mental health counselor from the Bay Area

> *Shortage of mental health providers, counselors etc.; lack of referral from Primary care provider, etc., needed medical help is listed but [does] not really exist or [isn't] accessible due to insurance coverage.*
>
> — Chinese American family member from Bay Area

> *Knowing what's wrong, finding someone that specializes in trauma, cost for services.*
>
> — African American peer and family member in San Joaquin County

> *A lack of networking, knowledge, and services.*
>
> — Latina peer, family member, and provider in San Joaquin County

> *Our culture has our own way of dealing with treatment, and we are not exposed to anything else.*
>
> — Mexican American peer and veteran from San Joaquin County

> *The most challenging aspects of access are location, population, and curriculum.*
>
> — Latino peer and family member in San Joaquin County

> *Being African American, it would be removing stigma associated with mental health, the absence of culturally sensitive MHSA programs, and lastly a lack of culturally diverse practitioners and professionals. Spanish speaking people also have some barriers to accessibility.*
>
> — African American advocate and health services administrator in San Joaquin County

COMMUNITY RECOMMENDATIONS FOR TREATMENT

NAMI CA Contributions to the Literature

The following information was collected from diverse individuals within California. Testimonials are pulled from completed questionnaires, survey responses, and focus groups. Information below is in reference to the community needs and recommendations of support, as reported on by participating community members.

NAMI CA believes the best way to share community recommendations to improve the mental health care system for diverse communities is to share community voices with you as shared with us:

> *Si me converti en un defensor después del suicidio de uno de mis seres queridos, si mi familiar hubiera recibido servicios de salud mental se hubiera evitado esta terrible perdida de mi ser querido. Si yo hubiera tenido el conocimiento que tengo ahora sobre las enfermedades mentales hubiera sido diferente.*
>
> *[I became an advocate after the suicide of my loved one. If my loved one had received mental health services, this terrible loss would have been avoided. If I had the knowledge I have now have about mental illness, it would been different.]*
>
> – Latina family member in Los Angeles County

I don't want to say that all my family and Latin community aren't knowledgeable about mental health. We wish not to talk about it, or try to avoid speaking about mental health in general. Generally, Latin communities differ from place to place, however, where I am located. We have a couple Latin organizations that help our community with Spanish resources, like NAMI, and assist them. My family personally, we have an understanding of taking care of yourself, and spreading love because there are so many of us. However, understanding topics like co-occurring disorder, PTSD, and Depression we didn't know at all until it hit our family. Until it happens that is when you have to start exploring and learning what is going on.

Stigma – it's hard to say it's obvious, but it's challenging to accept you have a mental health condition. Culturally, keeping it within the family and telling yourself it's normal to live this way is what tends to happen. Additionally, accepting that you're "sick" comes with stigma and wanting to access services. I had to do something outrages just to get attention I needed; I would've rather (at the time) harm objects than talk about my feeling.

Language Barrier – Most agencies will have someone who is monolingual, however, a challenge with what my family has gone through is that there is only one big place to receive the help we want instead of having access very quickly. In my small town, there is only one fully Spanish-speaking clinic in town, and multiple English speaking clinics, hospitals, and help readily available.
Support – We only had our family for support, not a community. Sometimes it still feels like that, sadly.
English was very easy and accessible. For Spanish, we had to get out of the county and get some services. I had a family member go back to Mexico, because the mental health system hasn't helped.

My family members that spoke both English and Spanish have been culturally appropriate due to the fact that we knew what we were getting into, and the people there made us feel comfortable and respected. However, my only Spanish-Speaking family member didn't have a similar experience and felt disrespected of services and help.

My family and I are really close. We are a family of eight in total and we make sure we give each other love and respect. We feel stigma because we don't want others to judge us, and fear of having help and maybe getting deported. That is a big reason why we don't get help. We don't want some services or providers to judge, however, we have been stigmatized about it in the past. Which has been uncomfortable, but we know we will get better if we all go through it together. Medication is a hard topic, just because, culturally we don't believe in it. We have felt some stigma from friends and family coming over and noticing prescriptions bottles of antidepressants. The word gets out really quickly in a small town. At some points the small community in town is very stigmatized of where you can get access to services depending on your location and income. That is always the question for some services. It is hard, but we make it work.

– Latino family member in Sonoma County

“From family, I am definitely more educated/ informed than they are. And a large part has to do with the field that I work in. I am a Housing Navigator (case manager) for a non-profit that provides housing services to homeless and chronically homeless individuals and family. We work directly with the household. The population we work with have high barriers, which could be a combination of: drug addiction, physical disabilities, mental health conditions, physical health conditions, criminal histories, etc.

Education helps with acceptance of the family member’s condition and is highly advantageous to the individual’s long-term success and quality of life. It makes it a lot easier as a family to cope and understand when the individual has an “episode” or having a hard time dealing with the condition. I have many clients where one of the contributing factors to their homelessness is the lack of a healthy support network and lack of acceptance of their condition, or perhaps may have never had it, and end up in the situation they are in.

[Stigma] comes from relatives, friends, strangers, the general population, church, acquaintances, etc. On a few instances, it has even been from co-workers, despite doing the same job as I do. I have noticed a pattern: individuals who they themselves, or have relatives with a mental health condition of any kind, almost always tend to accept and understand more, and stigmatize less. When it’s an individual who has only dealt with it in their work life because of the population they work with, many STILL stigmatize or

feel uncomfortable when I share my lived experiences (I can feel their discomfort).”

- Latina family member in Riverside County

“I feel that families do not understand their loved ones who have the illness and those in the community also do not understand and therefore there is still the stigma that goes along with having a mental health diagnosis. My loved ones family has never understood that he has a mental health illness and he feels that he needs to take medication and sometimes he cannot work. That is why I work hard so that he could rest.”

– Mexican American family member and peer in San Diego County

“I think [providers] understanding the African American culture would have been helpful.”

– African American peer and family member in the Bay Area

> *I lost my children during the first years of being diagnosed. I was thought of as 'crazy' and had to fight through the court for supervised visits.*
>
> – Biracial Native American peer in San Joaquin County

> *For my family, in comparison to me and the community, I think there's a lack of knowledge and information that is in the community or even relayed to them.*
>
> – African American peer from San Joaquin County

> *I myself know a fair amount and am learning new things. I am more informed than my family and community. I try to help them learn and bridge the gap.*
>
> – Biracial Native American peer in San Joaquin County

> *My family and community have limited knowledge. There's still a stigma.*
>
> – African American peer and family member in San Joaquin County

> *Our organization deals with mental illness in veterans on a daily basis. I advocate as a disabled veteran with 2 tours in Iraq and 1 in Afghanistan as a US Infantryman.*
>
> – Mexican American peer and veteran from San Joaquin County

> *Usually stigma is found within the black community and also family.*
>
> – African American advocate and health services administrator in San Joaquin County

NAMI CA TRAINING AND EDUCATION FOR DIVERSE COMMUNITIES

A mainstay of NAMI CA activities is our evidence-based and consumer-supported, education and training programs. Program effectiveness has been supported by both evaluative and anecdotal evidence including recognition as an effective program by the Substance Abuse and Mental Health Services Administration (SAMHSA) National Registry of Evidence Based Practices and Programs (NREBPP). Diverse consumers and family members have repeatedly expressed to staff that our courses have been life-changing.

> *"Once the realization entered our lives that my daughter had been diagnosed with paranoid schizophrenia my quest to learn more was a part of my life. I presently have been trained as WRAP, mentor on discharge, LEAP trainer, NAMI Family and Friends Family Support facilitator, NAMI Family to Family teacher, NAMI Family and Friends facilitator. [She] was finally able to get the treatment she needed for her recovery because I was relentless."*
>
> – African American family member and peer in the Bay Area

NAMI CA in partnership with local affiliates and community-based organizations has continued their commitment to serve diverse communities across the state. With an increase in unexpected events in 2018 such as wild fires, school shootings, budget deficits, immigration policies separating families, among others, support and access to information are more important than ever. That is why we continue to work with affiliates and organizations to continue the offering of various programs such as Familia a Familia, Persona a Persona, Conexion, Mental Health 101 and more which help with access to care.

These programs cannot exist without program trainings which provide teachers and facilitators to be used at the local level. In the past year alone (September 2017-August 2018), with generous support from the MHSOAC, NAMI CA in partnership with local affiliate organizations has conducted five program trainings for peers and family members, which in turn has trained over 36 teachers/facilitators in different counties across the state that include: Los Angeles, Riverside and San Bernardino County.

NAMI De Familia a Familia

National Alliance on Mental Illness

De Familia a Familia (Family to Family) Program

NAMI De Familia a Familia is a free, education program in Spanish for families with adults living with mental illness. The curriculum includes current information on a variety of mental illnesses such as schizophrenia, bipolar disorder, major depression and other mental health conditions. It provides possibilities for treatment and recovery for some conditions, as well as skills-training to address crisis and relapse; to cope with stress and emotional overload; and to advocate for the families' needs. The curriculum is covered in 12 classes, taught by trained teachers who are also family members with lived experience with a loved one living with mental illness. In Class 11, family members learn about ways to advocate for their loved ones and how to change the system. They are able to meet and learn from community members who have navigated the mental health system.

> *"I am educated in the mental health field due to working in the community and having my own diagnosis as well as my family members and friends. However, I learn something new every day when it comes to mental health. I am an advocate for others. When my loved one was diagnosed I was not sure how I could work, etc... I went to NAMI family to family class and it changed my life in that way that I now work for NAMI working with Peers and Families."*
>
> – Mexican American peer and family member in San Diego County

NAMI CA is constantly responding to the needs of diverse populations. Therefore, peers and families participating in the program are asked to provide feedback through surveys and program evaluations. The feedback gathered below are from participants who took part in family classes and answered the following question:

What personal changes have you made, or do you expect to make, because of participating in the course?

A *"Hice un cambio muy grande en mi vida personal...la informacion cambio mi familia y la ayuda que le brindo ahora."* —Familia a Familia participant

- (Translation) I made a big change in my personal life...the information changed my family and the help that I offer them.

A *"El ver a la situaciones como manejable y ver a la persona que padece la enfermedad como una persona individual y no como la enfermedad...y ser mas paciente."* —Familia a Familia participant

- (Translation) To see the situations as manageable and to see the person that has a mental health conditions as an individual person and not as a mental illness...to be more patient [with them].

A *"Entender a los familiares y amigos y poder comunicar a otros que debemos apoyar y ser empatia con ellos."* —Familia a Familia participant

- (Translation) Understand my family members and friends and to be able to communicate to others that we need to support them and have empathy towards them.

A *"Me ayudo a comprender y evaluar cada situacion dificil que se me presente en mi vida y sobre todo como ayudar a mi hija."* —Familia a Familia participant

- (Translation) It helped me to understand and evaluate each difficult situation that presented in my life and overall to help my daughter.

A *"Se que hacer cuando mi esposo le ataca su PTSD o depresion."* —Familia a Familia participant

- (Translation) I know what to do when my husband gets PTSD or depression.

NAMI Conextión
National Alliance on Mental Illness GRUPO DE APOYO Y RECUPERACIÓN

Conexion Grupo De Apoyo Y Recuperación (Connection Recovery Support Group) Program

NAMI Conexion is a support group program that meets once a week, designed for Latino adults living with mental illness. The structured group provides a place that offers respect, understanding, encouragement, and hope. NAMI Conexion groups are led by trained facilitators from the Latino community who are currently living in recovery. The program helps individuals living with a mental illness to see oneself first, not the illness, aim for better coping skills, find strength in sharing experiences, and reject stigma and not tolerate discrimination.

NAMI De Persona a Persona
National Alliance on Mental Illness

Persona a Persona (Peer to Peer) Program

This program is a 10-week recovery-focused educational program consisting of 10 two-hour sessions designed for adults (18 and over) living with mental health issues. Each class contains a combination of lecture and interactive exercise materials and closes with techniques that develop and expand awareness. The program helps individuals to create a personalized relapse prevention plan, learn how to interact with health care providers, and access practical resources on how to maintain one's journey towards recovery.

NAMI CA is constantly responding to the needs of those we serve. Therefore, families participating in the programs listed above are asked to provide feedback through surveys and program evaluations. The feedback gathered below are from participants who took part in family classes and answered the following question:

What personal changes have you made, or do you expect to make, because of participating in the course?

A *"Entender mas a mi hijo y ser paciente."* —Persona a Persona participant
- Understand my son and to be more patient.

A *"Me gusto el curso y quiero aprender mas."* —Persona a Persona participant
- I like the course and I want to learn more.

Peer to Peer Presenter Training in San Bernardino County

Mental Health 101 Program

Mental Health 101 (MH101) is an innovative presentation program that highlights the strengths of diverse communities to raise awareness and reduce stigma surrounding mental health conditions and treatment. MH101 is a 60 to 90-minute presentation designed for diverse audiences, with targeted attention to cultural responsiveness. The program gives individuals an opportunity to learn about mental illness through an informative presentation, short videos, and personal testimonies representing a variety of cultures, beliefs, and values.

Community members participating in the programs listed above are asked to provide feedback through surveys and program evaluations. The feedback gathered below are from participants who took part in the MH101 presentations and answered the following question:

In your opinion, what was the strongest part of the presentation?

A *"I believe the strongest part was hearing about the personal experiences from the speakers; it allowed the audience to connect better/understand mental illness and how important it is."* —MH101 Participant

A *"The speaker was very inspiring and gave motivation to seek out help."* —MH101 Participant

Mental Health 101 Presenter Training, Riverside County

"I would give myself a 7 or 8 out of 10 scale about knowledge /education about mental illness. The only reason being is that by supporting NAMI with the support group, family-to-family class, and presentations I have learned much more than I did in college. However, I am not an expert on medication, information around that topic or politics surrounding mental illness. This is why I wouldn't give myself a 9 or 10 out of 10.

Since getting help, I still didn't know about NAMI until I graduated. I graduated in a field of Mental Health because I was interested how families are affected by mental health and how they deal with it. After graduating I learned about NAMI's local affiliate from a senior project I overheard and looked into them. I saw a position of program coordinator and have been happy since. I am a presenter of ETS (Ending the Silence) and MH101 (Mental Health 101). I have been involved with being a facilitator in Family-to-Family and Family Support. Hopefully, soon I will be able to start a De Familia-a-Family and a Groupo De Apollo in our county. Lastly, I also am part of NAMI Sonoma County Warmline, to receive calls and give out local resources, both in English and Spanish. I still wish I could do more."

– Latino family member in Sonoma County

> “I am educated in the mental health field due to working in the community and having my own diagnosis as well as my family members and friends. However, I learn something new every day when it comes to mental health. I am an advocate for others. When my loved one was diagnosed I was not sure how I could work, etc... I went to NAMI family to family class and it changed my life in that way that I now work for NAMI working with Peers and Families.”
>
> – Mexican American peer and family member in San Diego County.

STATE AND LOCAL ADVOCACY EFFORTS

Statewide Priorities

In late 2017, NAMI CA issued a survey to its membership to ascertain policy priorities for the upcoming 2018 legislative session. We received 662 surveys from membership, who listed the following five priority areas as most important: (1) access to services; (2) crisis services; (3) housing; (4) family involvement; (5) full spectrum of services for all ages. Many of the priority areas were reflected in both NAMI CA focus groups and regional meetings, as well as in state legislative efforts.

Advocacy Activities

One of the ways that NAMI CA engages with local communities is through regular regional advocacy meetings.

In these meetings, NAMI CA coordinates local affiliates and behavioral/mental health departments to provide an overview to participants on how to get involved in local advocacy.

This year, NAMI CA held regional advocacy meetings in San Joaquin County and Riverside County. Both meetings were designed to focus on bringing diverse communities to the table to ensure that we have as many different voices at the decision-making table as possible.

Outcomes noted by participants include empowering individuals to share lived experience; equipping attendees with tools to engage with advocacy at both the local and state level; and teaching ways to participate in local MHSA Community planning processes.

NAMI CA also supports advocates through hosting capitol advocacy days. In June, we hosted our annual Bebe Moore Capitol Advocacy Day. Bebe Moore Campbell was an accomplished author, advocate, and co-founder of NAMI Urban Los Angeles who passed away in 2006. Campbell advocated for mental health education and support among individuals with mental illness and their families. Bebe Moore Campbell National Minority Mental Health Awareness Month (NMMHAM) was created in her honor to carry out the

Advocacy Regional Meeting in Stockton, CA

goal of creating mental health awareness and eliminating stigma among diverse communities.

This year, we conducted 24 legislative meetings, where participants advocated for the following priorities: access to treatment, crisis services, and criminal justice. The day after the event, Senator Holly Mitchell introduced a resolution to recognize the month of July 2018 as Bebe Moore Campbell National Minority Mental Health Awareness Month in California. This resolution, sponsored by NAMI CA, continues a long tradition of the state support for July as Bebe Moore Campbell National Minority Mental Health Awareness Month.

In July, several NAMI affiliates put on local Bebe Moore activities to further raise awareness of the month. NAMI Sacramento held its 4th annual Multicultural Town Hall on Mental Wellness. This year the focus was on trauma-induced mental health struggles. This town hall meeting was designed to bring people together, inform them, and empower them to go back to their communities to do the same for other members. The forum had diverse demographics and 70 – 80 attendees -- overflowing the event space. It provided the opportunity to connect with others within the community and with others from other cultural communities.

MENTAL HEALTH AND ILLNESS IN DIVERSE COMMUNITIES

> *"I want to get better and help others get better."*
>
> – Chinese American peer in Santa Clara County

Individuals from diverse communities face specific, additional challenges when it comes to accessing mental health services. NAMI CA conducted a series of focus groups to better understand the lived experience of individuals from diverse communities who are engaged in the mental health system. From these focus groups, the following themes emerged:

High levels of Stigma in Diverse Communities

Multiple mentions were made of the disproportionate level of stigma that is often found in diverse communities. Participants noted that this stigma can be rooted in a lack of information or different cultural norms that affect the way that mental illness is viewed.

Need for Materials for All Cultures and Languages

One of the most common refrains from focus group participants was that there is a significant lack of materials that are appropriate for all cultures or accessible in multiple languages. This includes materials that are not visually representative of different communities as well as language accessible for all education levels. It was also noted that it is particularly important to ensure that advocacy materials are translated and that there is a way for individuals with language barriers to still have their voices heard and understood by decision makers.

In addition, participants identified that a lack of diverse providers was a significant issue. Participants indicated that seeing a provider that was outside of one's race or culture,

or not well-versed in LGBTQ-specific issues, was a source of discomfort and a barrier to continued participation.

Importance of Identifying and Engaging Community Leaders

Participants noted that one of the best way to engage communities that have historically been underserved and disconnected from the mental health system and advocacy is to take cues from community leaders and community-based organizations (CBOs). Too often, entities engage with communities without first identifying community stakeholders and leaders. Participants in a small group discussion during a NAMI Regional Meeting in San Joaquin noted that using CBOs and community leaders to facilitate meetings increases attendance and the trust of participants.

Sharon Woolfork (NAMI Kern County) and Paul Lu (NAMI Orange County) sharing information and experiences.

Challenges in Diverse Communities

Through our focus groups, participants brought up the specific challenges that face different diverse populations. One participant noted that Latino families are significantly more likely to serve as a caregiver for a loved one living with mental illness compared to white families. Another individual described the challenge of reaching diverse communities in large counties, particularly when those communities have been disconnected from the mental health system due to stigma, lack of information, or fear. Underlying all the feedback we received was this: it is critical to address the unique historical context of each community in order to more fully understand community experience and need.

Diverse Communities in Merced County

In the area of family support and early intervention, NAMI Merced facilitates connections to effectively serve the community. When an at-risk LGBTQ student needed assistance, NAMI Merced became involved with all the engaged personnel—CPS, CIT, school resource officer, etc.

NAMI Merced recognized the need for intervention and support from the spiritual leader of the Hmong community. NAMI Merced personnel was able to determine the appropriate clan and connected with those leaders. NAMI Merced is pursuing funding for language translations and cultural adaptations in their services and programs.

In July, the “Listening Event” attracted over 40 attendees including families and organizations. The community spoke about their concerns with policy makers. NAMI Merced was able to frame priorities based on this community input. Again, the presence of support in schools and trainings for teachers became an apparent need.

In August, in response to fears expressed around current immigration policy, NAMI Merced held a community forum to help address children’s fears and the effects on their mental health. Respecting families’ fears of government officials, NAMI Merced insisted that the County send only clinicians to be on the panel.

Collaboration and cooperation among all community groups is a driving force for NAMI Merced.

ISSUES

Expanding Access to Care

Expanding access to mental health care is one of the most important aspects of mental health advocacy. This is because less than one-third of adults and one-half of children with a diagnosable mental disorder actually receive mental health services in a given year. This gap in service is even larger in racial and ethnic minorities, who are less likely to have access to mental health services and often receive a poorer quality of care when they do receive treatment.

Across the nation, peer support programs have emerged as a practice with proven benefits to both peers and the consumers. Peers can include people who have lived experience as clients, family members, or caretakers of individuals living with mental illness. However, California lags behind the nation in implementing a peer support specialist certification program, while approximately 40 states already have a certification process in place for mental health peer support specialists. Increasing the number of Peer Support Specialists is critical for expanding access to mental health care to underserved populations.

Bringing in more culturally competent peer support specialists into the mental health care field allows California to not only reach more people, but also provide a higher quality of care to underserved groups.
In response, state representatives introduced SB 906, a bill requiring the creation of a Peer Support Certification program that would also bring in money from the federal government to fund the program. NAMI CA has supported this bill as one of its top priorities this legislative session. NAMI CA has collected a large number of support letters on this bill, with members highlighting this bill as one of the most important issues to them. Approximately 10% of support letters received were regarding SB 906. Additionally, SB 906 was one of the bills featured on NAMI's Bebe Moore Minority Mental Health Awareness Month Advocacy Day. Furthermore, in 2017, NAMI CA trained 160 peer support specialists through its Family & Peer Support Specialist training program.

Student mental health

Addressing mental health needs in schools is a critically important challenge not just in California, but across the

United States. An estimated 1 in 5 children ages 13-18 have or will have serious mental illness, with 50% of all lifetime cases beginning by age 14. Additionally, not only is the average delay between onset of symptoms and treatment 10 years, but suicide is the 3rd leading cause of death in children and young adults between the ages of 10 and 24. Student mental health became a big focus this year, with an emphasis on suicide prevention among youth and college students; and increasing access to mental health services at all levels of the educational system. These efforts were rooted both in local grassroots work and at the state level as several bills met with varying levels of success at the California legislature.

In August 2018, NAMI CA held a regional meeting at Delta College in San Joaquin. The school and the county both expressed and overwhelming need for mental health resources for their students. In other communities, advocates took charge of local dynamics to shift school policies on suicide prevention and access to care.

Suicide Prevention in Merced County

That growth in the school population creates some unexpected issues for the families in that community. County mental health services are not provided to peers and family members.

In Merced County, families turned to the local NAMI affiliate for support after the tragic suicide of a young elementary student. What NAMI Merced realized is that the school district did not respond to the suicide as the district had responded in other crisis situations involving the death of a child. Thus, began the journey to enlist the district and to educate school personnel about mental illness.

NAMI Merced worked with the district to increase training for teachers and staff—at one afternoon session, nearly 150 teachers attended the training presented by NAMI Merced. One critical component is teachers knowing and understanding the district policy. Previously a teacher with a story from a student displaying warning signs did not know what action to take.

When middle school students wanted to bring an *Ending the Silence* presentation to school, they found resistance from the district who required many limitations. Enlisting the help of NAMI Merced, the students persevered. Fearing the effect on community members, the school principal asked to leave out personal stories, but NAMI Merced insisted that mental illness was a disease and that, like cancer or heart disease, should be appropriately discussed. In the end, principal's bias was changed. NAMI Merced found a strong and powerful advocate who, upon promotion within the district, was instrumental in getting programs in schools and more teacher training. As result of county support, five schools had teacher training and *Ending the Silence* presentations.

In May 2018, NAMI Merced had more requests for programs than the available facilitators could fulfill.

This fall, NAMI Merced is working with the local group, Phoenix Project. Working with middle school students, the group fosters and encourages creative story telling around mental illness.

To assist college students, NAMI Merced is working with UC Merced to grow *NAMI on Campus*. The University only services students within the clinical setting. NAMI Merced understands that there needs to be complimentary services for students with mental illness. Additionally, there needs to be support for students with peers and family members effected by mental illness.

At the Capitol: Mental Health Resources in Schools / Suicide Prevention

In 2018, the California legislature acknowledged this pressing issue by focusing on bringing mental health care and resources to middle schools, high schools, and college campuses. SB 968 requires California State Universities and Universities of California to have one full-time mental health counselors for every 1,500 students enrolled on their campuses. AB 2022 initially required that all schools employ one school counselor for every 600 students, with a minimum of one counselor in each school.

While later versions of the bill were amended to require school districts to notify students and parents twice annually of how to initiate access to available student mental health services on campus or in the community, the bill's original intent and the widespread support it received from the Steinberg Institute, NAMI CA, and other partners show the public will to increase access to mental health care in schools.

To combat suicide among young people, the legislature wrote SB 972 requiring schools with students in grades 7 through 12 to be issued student identification cards with telephone numbers for the National Suicide Prevention Lifeline and the Crisis Text Line. Additionally, another bill introduced this session, AB 2639, requires local education agencies to review and update their pupil suicide prevention policy every 5 years.

NAMI CA has supported all four of these bills and collected support letters from both individual NAMI members as well as county affiliates to try and get these bills signed into law. Additionally, SB 968 was one of the bills featured during both NAMI CA's 2018 Children's Mental Health Advocacy Day and Bebe Moore Minority Mental Health Awareness Month Advocacy Day.

As NAMI CA looks towards year two, we are passionate about our mission of continuing to broaden access to advocacy for diverse communities. Too often, diverse communities are not connected with the decision-making process because of lack of information, different cultural norms, too few materials appropriate and accessible to different cultures or languages, or mistrust of a system that has historically been exclusionary towards persons from diverse communities.

Our efforts will include expanding our Bebe Moore Campbell Capitol Advocacy Day to more deeply engage diverse communities and our partner organizations that are connected to additional networks and communities. In addition, this year, we developed a tool to engage diverse communities in the advocacy process. We will roll out our curriculum in year two, and create tangible advocacy opportunities for individuals who participate in this training.

Legislatively, we will continue to support mental health bills that aim to improve the lives of communities of color, the LGBTQ+ population, students and youth, as well as individuals living with both visible and invisible disabilities. We will continue to support the robust NAMI affiliate-led efforts to bring the family perspective into crisis intervention training for our law enforcement. Finally, we will continue to build policies and priorities with a clear focus on the structural inequities that create barriers to accessing mental health services across the state.

MULTICULTURAL SYMPOSIUM

This year, NAMI CA continued the conversation around mental health in diverse communities in its 5th Annual Multicultural Symposium with the theme, "Diversity in the Face of Adversity." We aspire to bridge the gaps created by mental health stigma, to bring together statewide community leaders and health care providers from diverse communities. The event fostered an open dialogue about

the successes and challenges various communities and organizations throughout California have experienced with innovative and strength-based approaches to achieving wellness and equity for unserved and underserved populations. We were proud to host our inspiring lineup of speakers, who have all made significant changes in their communities and throughout the state of California. Their expertise, experience and passion for creating positive change provided outstanding examples of what we can all achieve together as a global community.

The Immigration and Trauma breakout session discussed the current challenges facing immigrant communities and the impact of immigration trauma on mental health. Facillator Gustavo Loera, EdD, Vice President of the NAMI CA Board of Directors, posed several questions to participants regarding their personal experience, experience as providers, and thoughts and recommendations to mitigate trauma and promote mental health in immigrant communities.

The Access to Resources breakout session discussed the impact of the current political climate on the availability and accessibility of mental health resources and services, especially for marginalized populations. Participants purposed several practical measures to implement in their community to help increase access to resources for diverse communities.

> *"Wonderful example of community collaboration and amazing/powerful energy from presenters."*
>
> —Symposium Attendee

> *"Breakout sessions allow for engaging conversations between multicultural communities."*
>
> —Symposium Attendee

Attendees suggested networking with other local Community-Based Organizations (CBOs) already serving specific cultural communities to provide NAMI resources to these communities. Improved data collection was also suggested along with the need to share information to create positive change.
Participants were treated to cultural performances, including a dance from HuaDu Chinese Lion Dance Team and an original poem and traditional song from Native American community advocate Bonnie Lockhart, MSW.

Moderated by Kimberly Knifong, MBA, the Community-Based Innovations Panel discussed the California Reducing Disparities Project (CRDP). This project seeks to reduce mental health disparities in five focus populations: African Americans, Asian and Pacific Islanders (API), Latinos, LGBTQ+, and Native Americans. The panelists, each representing one of the five focus populations, provide technical assistance and capacity building to help grantees implement innovative projects aimed at reducing mental health care disparities for marginalized communities.

Bebe Moore Campbell National Minority Mental Health Awareness Month: Represent Recovery Video Series

A common theme mentioned in the Advisory Committee and by research participants, was that of representation in storytelling to show members of diverse communities affected by mental illness that they are not alone. This year, based on feedback from this research, NAMI CA launched the Represent Recovery campaign, an initiative calling for a paradigm shift in the way we view mental health in diverse cultural communities. The crux of the campaign is our storytelling video series, five personal stories launched during Bebe Moore Campbell National Minority Mental Health Month. Below are highlights from two video stories, one from a peer and one from a family member.

Roopa Grewal

Roopa Grewal discusses life with Borderline Personality Disorder and Post Traumatic Stress Disorder, the stigma around mental health challenges within her family and the Indian community, and what it means to be part of a compassionate community of peers.

Tracing the origins of her mental illness to being torn from her native country of India and the grandparents who initially raised her, Roopa says that she knew she was depressed as young as five years old. Despite her father being a psychiatrist, her family brushed off her symptoms and she was not diagnosed with Borderline Personality Disorder until she was an adult. However, Roopa has been determined to prove to herself and the community at large that she can still accomplish the life she has dreamt for herself. After her experiences with dialectal behavioral group therapy and her work in NAMI peer support, she now runs her own company providing support services for other peers.

Elaine Peng

Elaine Peng tells the story of the challenges she and her daughter with bipolar disorder faced. Elaine says a lack of education contributed to many of their hurdles, but after she and her daughter found NAMI programs and support groups, the knowledge they each learned combined with the right treatment team allowed them to learn the skills needed to cope.

Elaine tells her story in Chinese Mandarin, with English and Simplified Chinese subtitles, in hopes of reaching as many Chinese community members as possible. Now the president of the Mental Health Association for Chinese Communities, Elaine demonstrates that being open about mental illness within one's ethnic community has the potential to have enormously beneficial and therapeutic results by providing a support system and helping members overcome stigma and language barriers in mental health.

FUTURE OF NAMI CA PROGRAMMING

After listening to the communities' powerful and valuable feedback, NAMI CA is entering Year 2 with a broader perspective on the outreach, engagement and delivery of Signature Programs to diverse communities. In Year 2, one of our primary goals in Programming is to continue to provide trainings in Cultural Competency to counties across the state to educate communities to foster acceptance and to educate providers about cultural appropriate care and services. Furthermore, our second goal is to reach rural, unserved, underserved, and/or inappropriately populations in the state of California and support them in the implementation of programs such as Conexion Grupos de Apoyo, Familia a Familia classes, Persona a Persona classes, Mental Health 101, and more. To reach that goal, NAMI CA will be outreaching and partnering with NAMI Affiliates, community-based organizations serving diverse communities and stakeholders across the state and supporting them through trainings and program support to make sure they are able to provide the services and resources to their communities.

Through this process, we plan to dive deeper into the questions regarding linguistically appropriate services, inter-familial and inter-community stigma, resistance to treatments, fear of seeking mental health treatment due to fear of deportation, among others by engaging with diverse communities as they enter and leave classes and trainings. We hope to be able to expand their voices throughout the year and support them in their journey moving forward by offering continuous support at the state office and locally by affiliates and organizations.

Moreover, we plan to vocalize and provide the platform for diverse communities to share their stories and the impact that classes and trainings have had in their counties. Those unique needs are important for all organizations, Behavioral Health Departments, stakeholders and overall people that serve diverse communities, to have access to and review to really create sustainable change in the long term. We need to step away from "cookie cutter" approaches to delivering programs and services and deliver new, innovative programs which are reflective and delivered in a respectful manner to all community members across the state. To achieve that, NAMI CA will be working closely with local affiliates who serve communities that speak a variety of languages. By doing so, will we be able to expand the reach and understand the nuances on how programs are delivered for diverse communities and barriers to access in those respective communities. Furthermore, community members will be able to provide their own recommendations on what they hope to see and what we can all do in the long term.

Direction of Future Research

In Year 2, through program trainings, engagements and supports NAMI CA would like to capture the experiences after community members attend a class or presentation. We seek to understand what successes or challenges those individuals face in their counties and how they vary as well depending on the background and different factors of an individual. Furthermore, we hope to understand what the impact of local trainings has on the person being trained, the participants who take the class of that person being trained and the overall gap that the class/presentation addresses in the community being served. For example, NAMI San Bernardino was supported by NAMI CA to provide a local training to train new Peer to Peer Mentors in the area which has been the first time ever. Due to this training, there were free programs to support both English and Spanish speaking community members. We hope to be able to understand further how other counties like San Bernardino County who require support during times where resources are limited and how to go about planning to be there for them and other organizations who serve diverse communities in the long term.

NAMI CA also plans to expand opportunities to participate in research endeavors such as through the use of qualitative interviews, surveys, and focus groups during the Year 2 cycle. We invite all interested stakeholders to reach out to the state office for opportunities to become involved. Moving forward, NAMI CA will continue to bring stakeholders form diverse communities and backgrounds to the table to better enable the communities served by the PMHS to advocate for a more equitable and effective system of care for Californian communities who have lived with disparate care for too long.

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