



The
ANNUAL STATE
of the
COMMUNITIES
REPORT
with
FAMILIES

"You are not alone"

Funded by
MHSOAC
Mental Health Services
Oversight & Accountability Commission



Year
Two
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INTRODUCTION AND OVERVIEW

"Sadly, too often, the stigma around mental health prevents people who need help from seeking it...Whether an illness affects your heart, your arm or your brain, it's still an illness, and there shouldn't be any distinction. We would never tell someone with a broken leg that they should stop wallowing and get it together. We don't consider taking medication for an ear infection something to be ashamed of. We shouldn't treat mental health conditions any differently. Instead, we should make it clear that getting help isn't a sign of weakness — it's a sign of strength — and we should ensure that people can get the treatment they need."

– *Michelle Obama*

The family unit currently acts as one of the most important agents for providing psychosocial support for individuals with mental health conditions. Research would also suggest that patient outcomes improve when family members are provided with the information, clinical guidance, and support they request¹. Through NAMI California (NAMI CA) focus groups, families have reported that they continue to take part in as much of their loved one's treatment as they can. Families fill in the blanks for providers and they provide physical, financial, and emotional support for their loved ones with serious mental illness.

In Year 1 of the three-year project funded by MHSA, it was found that despite the increase in covered services by the Affordable Care Act, the number of available providers did not increase enough to make the new coverage very effective, rather, it caused longer wait times, overburdened systems, and lack of job growth in the field of psychiatry. In fact, a study by Coffman and associates found that by 2028, the current pool of mental health providers would decrease by 34%; CA will have 50% fewer psychiatrists and 28% less psychologists than will be needed².

In Year 2, NAMI CA conducted surveys, webinars, focus groups, and community gathering sessions to continue to gather feedback and recommendations from key community stakeholders to address the following questions:

- What does mental health look like within and throughout your community; and is that different from the way mental health looks in your own personal life?
- In your community, what is the primary barrier to accessing mental health care services and treatments, and what is that experience like? What could be done to improve this experience?
- When accessing services and treatments, how have providers made you feel understood and seen?
- How would you like to be involved in the local decision making and mental health planning? What is the best way for your community's experiences and voices to be heard?

Through the responses to these questions, NAMI CA was able to identify several of the obstacles to getting quality mental health care for the community at large and receive feedback from key stakeholder and recommendations for improvements to the public mental health system.

About the National Alliance on Mental Illness California

The organization that we know today as NAMI CA is the result of the efforts of a few courageous parent leaders, many families and thousands of individuals; friends and professionals that worked hard to give birth to an organization that would completely change the way we view mental illness. It all began at a meeting of 9 Northern CA parent groups in Oakland, CA on October 22 in 1977. The meeting was organized by three parents: Tony Hoffman, Fran Hoffman and Eve Oliphant. These three founded and led the organization from the late 70s into the 1980's. They were joined by many other parent-leaders,

families, consumers and supporters over the years. C. Allen Braswell, Helen and Hank Teisher, Olga Leifert and Peggy and Don Richardson are just a few of the many parents that provided critical leadership and support in the beginning. Together, they started an organization that turned into a national movement to inform and educate the country about mental illness and advocate for the rights and care of family members living with serious mental illness.



ACKNOWLEDGEMENTS

NAMI CA appreciates the tremendous commitment and compassion from family members leading groups, teaching classes and sharing experiences of family members and loved ones throughout the state. By utilizing and empowering the family members and loved ones that support individuals living with mental illness each step of the way we can create better mental health outcomes for all. Community leaders impact lives through shared dialogue, education, and advocacy with the shared focused of mental health as a public policy issue. Through surveys, meetings, trainings and shared experiences family members play a vital mechanism in supporting loved ones living with serious mental illnesses. NAMI CA extends infinite gratitude to families of individuals with lived experience throughout the state; this report is not possible without your collaboration, honesty, and involvement in this cause.

NAMI CA thanks the Families Advisory Committee for their contribution to the research through their communication and feedback throughout the duration of Year 2. We would also like to thank Proposition 63 Mental Health Services Act, the Mental Health Services Act Oversight & Accountability Commission (MHSOAC) for funds to continue reaching families and individuals whose lives have been affected by serious mental illness. Awarded funds will also ensure that families of consumers have a major role in the development and implementation of local and state level policies and programs, while also ensuring access to quality services and supports. This report is focused on the second edition of our Annual State of the Community Reports.



DEFINITIONS

- **Any Mental Illness (AMI):** a mental, behavioral, or emotional disorder. AMI can vary in impact, ranging from no impairment to mild, moderate, and even severe impairment.³
- **California Department of Health Care Services (DHCS):** is the backbone of California’s health care safety net, helping millions of low-income and disabled Californians each and every day. DHCS oversees the **Mental Health Services Division (MHSD)**, which administers a number of mental health programs for children, youth, adults, and older adults.
- **Consumer:** an individual of any age who is receiving or has received mental health services. Some consumers and agencies alike also use the terms ‘client’, ‘survivor patients’, or ‘ex-patients’.⁴
- **Department of Mental Health (DMH):** From 2004 until 2012, the California Department of Mental Health (DMH) was the primary state agency responsible for overseeing the implementation of the MHSA. In 2012, a change in state law dissolved DMH and transferred the majority of its MHSA duties to the Department of Health Care Services (DHCS).⁵
- **Family Member:** any individual who is now or ever was in the past the primary caregiver for a child or youth with a serious mental health condition who accessed services, particularly public services, for that condition. Families can include biological, adoptive, grand- or foster parents, siblings, or other kinship caregivers, friends, and others.⁶
- **Lived Experience:** a person who is employed in a role that requires them to identify as being or having been a mental health consumer or caregiver.⁷
- **Mental Health Services Act (MHSA):** also known as Proposition 63, is a law that was approved by California voters and took effect on January 1, 2005. MHSA establishes a 1% tax on personal income over \$1 million to expand mental health care in California.
- **Mental Health Services Oversight and Accountability Commission (MHOAC):** the role of the MHOAC is to oversee the implementation of the Mental Health Services Act (MHSA). The MHOAC is also responsible for developing strategies to overcome stigma. At any time, the MHOAC may advise the Governor or the Legislature on mental health policy.⁸
- **Peer Support:** A recovery-oriented treatment model in which individuals provide mental health services in a clinical setting who have received formal peer support provider training and/or certification; as well as having their own lived experience and recovery of a mental health condition.⁹
- **Public Mental Health System (PMHS):** Publicly-funded mental health programs/services and entities that are administered by the California Department of Health Care Services, or a California county. PMHS does not include programs and/or services administered by federal, state, county or private correctional entities or programs or services provided in correctional facilities (9 CCR § 3200.253).¹⁰
- **Recovery:** “A process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential.”¹¹
- **SAMHSA (Substance Abuse and Mental Health Services Administration):** the agency within the U.S. Department of Health and Human Services that leads public health efforts to advance the behavioral health of the nation. SAMHSA’s mission is to reduce the impact of substance abuse and mental illness on America’s communities.¹²
- **Serious Mental Illness (SMI):** a mental, behavioral, or emotional disorder resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities. The burden of mental illness is particularly concentrated among those who experience disability due to SMI.¹³
- **Stakeholder:** an individual or group which has an interest in or is affected by a nonprofit organization and its services. Examples of stakeholders include:
 - **Beneficiaries:** People who use the services provided by the nonprofit organization.
 - **Donors and Funding Sources:** Those who help fund the operations of the nonprofit organization.
 - **Community:** The surrounding community as a whole has a stake in how well a nonprofit organization completes its mission and objectives.
 - **Employees and Volunteers:** Provides vital services to keep the nonprofit running.
 - **Federal, State, and County Administrations:** Government entities require nonprofit organizations to provide various reports in exchange for funding, tax exemption, and tax deductions.¹⁴



METHODOLOGY

Similar to Year 1, NAMI CA conducted a variety of information gathering processes in Year 2, to gather information on the experiences and needs of consumers and family members navigating the public mental health system. NAMI CA used a variety of data collection processes such as communications with the Advisory Committee, qualitative interviews, stakeholder surveys, case studies, and focus groups.

Advisory Committee

The NAMI California Advisory Committee consists of 9 members that are either consumers or family members/loved ones of those with mental health conditions. Of these members, six were family members and three were consumers and family members. 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 the unique issues of family members and caregivers with lived experience. Feedback helped NAMI CA obtain this data in a manner that truly allows family stakeholders to voice their concerns about the challenges of accessing mental health for their loved ones.

Focus Groups

NAMI CA conducted four focus groups with family members during 2018. Two of these focus groups took place with family members at the 2019 annual conference held in Newport Beach in June 2019 where we solicited responses from family members over a two-day period. NAMI CA also conducted focus groups virtually via webinar format and in-person in different California counties and heard from family members across the state.

Stakeholder Surveys

NAMI CA administered a statewide survey among public mental health providers and the NAMI CA network (members, affiliates, partner organizations) seeking to understand the experiences of family members navigating the public mental health system. NAMI CA collected responses from 259 individuals who identify as family members or loved ones of individuals living with mental illness from May 2019 through July 2019. Individuals from 40 of California's 58 counties took part in the survey. Questions utilized a variety of designs from Likert-style scale questions, rank order, and open-ended formats.



ROLE OF FAMILY MEMBER SUPPORT IN MENTAL HEALTH TREATMENT

With the passage of Proposition 63, known as the Mental Health Services Act (MHSA), the California Department of Mental Health began to shift from a medical model to recovery-oriented services for mental health treatment. The recovery-oriented services model holds consumer and family member participation as one of its core values. MHSA Code of Regulations defines a client or consumer as “an individual of any age who is receiving or has received mental health services” and a family member as “any individual who is now or was in the past the primary caregiver for an individual with a serious mental health condition who accessed services, particularly public services, for that condition...families can include biological, adoptive, grand- or foster parents, siblings, other kinship caregivers, friends, and others¹⁵. The largest component of MHSA focuses on Community Services & Supports (CSS), which includes client and family driven services and systems. This includes concepts of recovery and resilience integrated with service experiences for clients and families for improved outcomes.¹⁶ Services should engage clients, consumers, and families in all aspects of the mental health system, including planning, policy development, service delivery and evaluation. In the state of CA, consumers can authorize their family members and caregivers to request protected health information with a document called a HIPAA Waiver, so they can assist with treatment planning. NAMI CA’s focus group data suggests that although their loved one has submitted a HIPAA waiver to their provider, they are not always kept informed of the treatment plan by the provider. Often, the consumer will revoke the waiver during a psychiatric emergency, which is when two-way communication between the family and provider is most crucial.

Family Member Contribution to Mental Health Treatment

The role of family member support in the treatment of mental health conditions can significantly improve outcomes for both the consumer and family member. Qualitative research tells us that family members, friends and other individuals involved in the patient’s support network can be important sources of collateral information about the reason for evaluation, the patient’s current symptoms and behavior, and past history; including trauma exposure and psychiatric treatment. Communicating with family members or other caretakers can be particularly important when the patient requires assistance or supervision because of impaired function, unstable behavior, or neurocognitive impairment. The American Psychiatric Association (APA) ultimately recommends that an assessment, clinical procedure, or treatment plan must be made by the psychiatrist in light of the psychiatric evaluation, other clinical data, and the diagnostic and treatment options available. Such recommendations should be made in collaboration with the patient and family, whenever possible, and incorporate the patient’s personal and sociocultural preferences and values in order to enhance the therapeutic alliance, adherence to treatment, and treatment outcomes.¹⁷ Additional research indicates that family participation prevents relapse, decreases negative symptoms, and improves social and occupational functioning.¹⁸ Past research shows that between 30% and 77% of families have some sort of role in the treatment planning process.¹⁹ In fact, family member involvement has recently become a treatment standard in many European countries. In Ireland for example, mental health service policy stipulates that family members must be involved in care planning.²⁰ In England, the National Health System (NHS) defines collaborative care as “collaboration between adult mental health and social care services, with the aim to provide more ‘joined up’ provision of care for patients”.²¹ Social care in this context refers to the social supports a consumer may have in caretaking, such as a friend or family member.²²

While family involvement is strongly recommended in clinical guidelines, it suffers from poor implementation. One particular implementation challenge across all models has been a lack of a standard definition for ‘appropriate family involvement’ and how to implement it into



services.²³ Some studies suggest that reasons that make implementation difficult include: the ways in which medical staff conceptualize the patient-family-provider relationship; patients feeling coerced into involving family into the treatment process; the possible negative impacts the involvement may have on personal relationships between patient and family; tension on the family member from being “forced” to take on a caregiving role while they themselves have their own goals to achieve; and the risk of identity loss for each member of the treatment team.²⁴ This research also indicates that overall, families would like to have more involvement in the treatment of their loved ones. NAMI CA has collected data from stakeholder surveys and focus groups and this data reflects the current research. Access to treatment planning, information about medications prescribed, and hospitalization information seems to be a main theme when speaking with family members in the focus groups conducted over the past year.

NAMI CA Findings

Based on survey results, NAMI CA found that there is a high number of family members providing care for their loved one. In fact, 94% of respondents identified as a family member or loved one of someone with a mental health condition; 71% of respondents indicated that they provide their loved ones with their most basic needs, including housing, appointment scheduling, and social support. Despite the large number of respondents that are primary caregivers for their loved one, the majority of them feel that service providers do not seek input

from caregivers, do not include them in treatment planning, and do not feel the mental health professionals are approachable. Qualitative findings from NAMI CA programming for Families also expanded upon feelings of being unwanted in the process of trying to help their loved ones through their crises and recovery periods. This is especially frustrating to families when they act as their advocates and support in all scopes including financial, emotional, and physical.

“Family members should at least be allowed to know if their loved one is hospitalized or not. We can easily find out if they are incarcerated. Loved ones who are [experiencing psychosis] don’t make good choices”.

–Family Member; Monterey, CA

“My son attempted suicide and the doctors did not tell me; the only reason I knew was because he woke up and said, ‘Mom why am I still here?’ He joined a support group in our community with kids who have been through it [suicide attempts] too; and that brings me some peace of mind knowing that they speak about recovery there and that he can recover.”

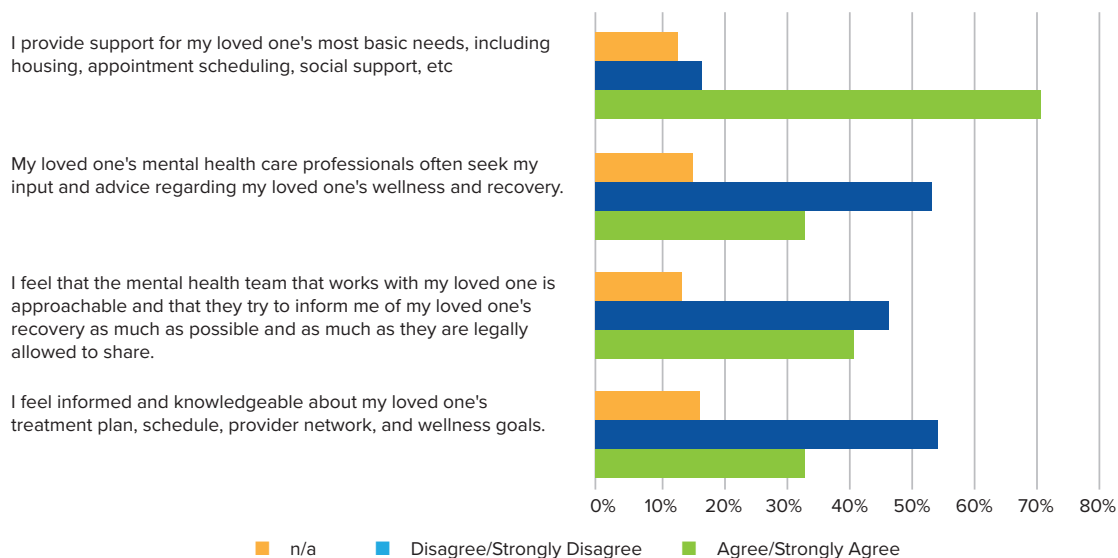
–Family Member; Hemet, CA

“When I had my son 5150ed, I gave them an entire history and showed the texts and evidence of him saying he was going to kill himself and even then they called [me] and said he was not eligible for holding or hospitalization.”

–Family Member; Orange County

Family Member Contribution to Mental Health Support

n = 199





MENTAL HEALTH STIGMA

What is stigma?

Mental health stigma is the negative way in which people think about and view persons with mental illnesses. This stigma creates fear, rejection, avoidance, and discrimination toward persons with mental illness.²⁵ Public stigma causes society to question the safety and competency of those with mental illnesses. Research shows that stigmatizing beliefs “sets the context in which individuals in the community respond to the onset of mental health problems, clinicians respond to individuals who come in for treatment, and public policy is crafted”.²⁶

Why is Stigma Harmful?

Stigmatizing beliefs compromise an individual’s autonomy and self-efficacy. It prevents financial autonomy, restricts opportunities, and can lead them isolated and vulnerable to abuse. Public stigma causes society to question the safety and competency of those with mental illnesses. Research shows that stigmatizing beliefs “sets the context in which individuals in the community respond to the onset of mental health problems, clinicians respond to individuals who come in for treatment, and public policy is crafted”.²⁷

According to the CA Health Care Foundation, only slightly more than one-third of CA adults with AMI reported receiving treatment between 2011-2015. Adults might not be aware that they have a mental illness, fear stigma associated with being diagnosed, and/or experience barriers to treatment.²⁸ A 2014 CA Well-Being Survey was conducted, and results analyzed by RAND Corporation on stigma, discrimination and well-being among CA adults experiencing mental health challenges. Results of this study provide us with a better idea of how mental health stigma affects Californians on a broader scale:

- More than 2 in 3 respondents would definitely, or probably hide a mental health problem from coworkers or classmates, and more than 1 in 3 would hide it from family or friends;
- 1 in 5 respondents indicated that they might delay treatment out of fear of letting others know about a mental health problem; with nearly all of them indicating that they would eventually seek care.

Treatment in the US overall is a concern as the average delay for those seeking treatment for mood disorders is 6-8 years and 9-23 years for anxiety disorders;

- In 2013, 59% of respondents with serious psychological distress had obtained mental health treatment;
- 1 in 10 Californians reported that they would delay or not obtain treatment if needed due to stigma.
- 4 out of 5 survey respondents agree that a person with a mental illness will eventually recover.²⁹

NAMI CA Role and Findings

The fight against stigma is an important part of what we do at NAMI CA and we encourage our affiliates to do the same. All too often stigma prevents families from seeking out help. Questions like “what will people think, we will be outcasts if they know our story” haunt many families. Our signature programs attempt to break down some of that stigma by normalizing the process of getting support. NAMI CA believes that sitting with other family members who have a similar story or experience is a powerful way to reduce the internal stigma.

“What is most important to me as a F2F student and teacher is sharing with the students the simple fact that you are not alone; picture you're mentally ill loved one is drowning in the sea and you are in a row boat trying to save them. Despite all your efforts they are refusing to get into the boat with you. Do you jump in or do you save yourself?”

–*Family to Family/Familia a Familia Teacher NAMI San Luis Obispo*

Internal cultural stigma is another barrier keeping families from seeking out support. As one family member put it:

“Since I grew up in a Hispanic household I can speak from my heart about the cultural boogie-man, the privacy issues and the non-involvement path that most (not all) Hispanic families take when faced with a (mental health) family crisis. My family would never talk about anything so sensitive outside of the house.”

–*Familia a Familia Student and Teacher NAMI San Luis Obispo.*

Having the 12-week Family to Family Class in Spanish helps break down some of the cultural obstacles. The language barrier that often keeps Families from being able to join a class or a support group vanishes, and the hope is that the stigma washes away as well.

Based on stakeholder survey findings, an overwhelming 65% of respondents indicated that they or their loved one has delayed or refused to seek services and/or treatment due to stigma from others regarding mental health conditions. Stigma was the number two reason why people did not want to seek services, second only to access to care. Responses from throughout community forums also noted that stigma toward their loved one for having mental illness has remained persistent. Additionally, the following are interviews with two individuals who identify as a family member of an individual living with a mental illness.

Maria Rosa Alvarado

Maria Rosa Alvarado is deeply connected with her community and can see the strength and comfort it brings. The lack of knowledge and understanding of mental illness is a common thread she sees in her community and felt in her personal/family life. When her daughter was diagnosed with PTSD, the family recognized that they needed help to live with and understand what her daughter faced. Likewise, through her work with NAMI, Alvarado sees communities facing an issue but often lacking the resources to address it.



Knowledge can also build trust. Alvarado knows that families often do not trust the mental health system because it is difficult to understand and to access. Knowledge brings understanding and the capacity to request and make changes. Knowledge brings an end to the silence so that families and professionals can work to the same goal—appropriate treatment for their loved ones. Alvarado takes her knowledge and support to her Family to Family classes and demonstrates how creating a “safe environment” in her home makes a difference in her family.

Paul Lu

Paul describes the journey with his daughter and their search for answers about mental health. Lu and his family went from the recognition of a problem to the questioning of how to address it. His family did not have answers nor even a clear understanding of the issue; they were completely at the mercy of the medical professionals. While Lu and his family do not like the mental health system, they came to understand it. They concluded that they wanted to be better than they were at that moment. Lu feels a deep spiritual obligation to provide service for others and to act as part of a solution.



Lu sees the various aspects of an individual’s and a family’s health; there are comprehension and physical components as well as emotional and spiritual wellness. His personal connection to faith showed Lu that many people turn to faith leaders in times of distress or confusion. However, when it comes to mental health issues, many faith leaders are not prepared nor equipped to deal effectively with families. Lu discovered that few, if any, of his seminary classmates had training in mental health issues. Lu found NAMI and Faithnet as a partial solution to this problem.



ACCESS TO MENTAL HEALTHCARE

One of the main themes of the research conducted by NAMI CA was access to mental healthcare and provider availability. New reports show that there is a substantial shortage and of mental health services in CA, which have been on the decline in recent years. “California’s Current and Future Behavioral Workforce”; a study done with the University of California, San Francisco; indicates that due to the decline in qualified providers and services, many people with diagnosed mental health conditions will have trouble getting the medication and services they need.³⁰ The number of providers is projected to decline significantly over the next 10 years due to providers retiring and the number of new providers coming into the workforce becoming stagnant.

Studies have reported that 86% of psychiatrists suffer from high exhaustion, an alarmingly high number compared to previous years. In addition to such a high burnout rate, in all of the United States (US), 45% of psychiatrists are older than 60; thus, the workforce continues to decline as many older psychiatrists started to retire within the last decade.³¹ The report goes on to indicate that if nothing is done to attempt to remedy the shortage by 2028 (approximately 10 years), the hardest hit communities will be minorities in the Central Valley and Inland Empire, where the lack of qualified providers is the worst.³² Availability of services also creates a barrier to treatment access.³³ There is a large, growing gap between mental health needs of the population and the number of qualified providers available. This gap is even more noticeable in suburban and rural areas throughout the US. The number of mental health providers that are retiring and the lack of new providers specializing in psychiatry is quickly widening the gap.³⁴

Acute psychiatric beds per 100,000 population decreased by 42% from 1995-2014. During the same time period, 44 facilities either eliminated inpatient psychiatric services or closed completely. CA needs at least 1158 more beds to reach the national average of 20 beds per 100,000. In 2015, when it came to acute care, there were only 8,102 adult psychiatric beds available in the entire state and a total of 25 CA counties had no adult acute psychiatric beds and 46 counties did not have any beds for children.³⁵ The number of available behavioral health professionals vary by geographic location causing large service gaps in many CA counties. Currently, only 24 out of 58 CA counties have any

comprehensive mental health services.³⁶ The Greater Bay Area has a 38% to 67% greater number of behavioral health professionals, whereas the Inland Empire and San Joaquin Valley regions have 39% to 88% lower than average. The Northern and Sierra regions are approximately 40% lower than average.³⁷ While the Bay Area has approximately 70 psychologists per 100,000 people, the San Joaquin Valley only has 16 per 100,000.³⁸

In 2016, CA had about 75,000 licensed behavioral health professionals; 31,349 are MFTs, 18,974 are LCSWs, 16,683 are clinical psychologists, 5,806 are psychiatrists, 1,207 were LPCCs, and 306 were psychiatric RNs.³⁹ In addition to declining availability of services, CA has a complex public mental health system. Most services are available through county systems and safety-net services, while others are available through Medi-Cal managed care plans and on a fee-for-service basis.⁴⁰ More and more providers are refusing to accept insurance. Only around 55% of psychiatrists accept private insurance and even fewer are accepting Medi-Cal,⁴¹ leaving several patients with inadequate health care professionals diagnosing their chronic mental health conditions, or with no treatment whatsoever. Therefore, poorer communities, like that of the Central Valley in CA, are left with even more inferior mental health treatment due to their inability to afford psychiatric help outside of publicly-funded health care. Poorer patients are typically those that are sicker both physically and mentally.⁴²

In order to address the provider shortage, one study suggests training other health care professionals, such as primary care physicians, in basic psychotherapy techniques and prescribing pharmaceutical treatments for common psychiatric disorders will become an essential future strategy for expanding access to mental health care in the US.⁴³ Through efficient training of primary care providers and social workers, Dr. Hersevoort, Associate Director at the UC Davis Train New Trainers Primary Care Psychiatry Fellowship, believes that “one psychiatrist and one social worker can take on much of the care for 10,000 or more patients, comparing this to the maybe 500 or so that could be managed in a classic psychiatric setting.” Significant training reforms like this will end up going a long way to positively impact a community in dire need and make use of the resources CA already has.⁴⁴

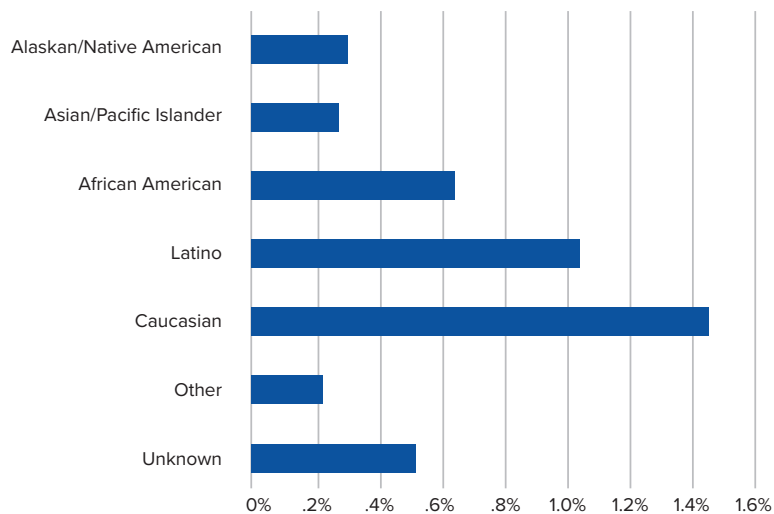
Peer Support

“A Peer Support Provider (PSP) is a person with lived experience of mental illness and/or addiction who is trained to provide emotional and social support to others with mental illness/addiction. Peer support providers carefully leverage their own lived experience to connect, support, and inspire hope in others”.⁴⁵

Medi-Cal Penetration Rates – Adults

According to the California Department of Health and Human Services, in 2018, approximately 8,220,974 adults were eligible for specialty mental health services (SMHS), however, only 341,362 (4.15%) adults utilized these services. The highest utilization rate was with the Latino population at 2.35% and the lowest was the Alaskan/Native American Americans at 0.02%.

Unique Count of Adults Receiving SMHS by Fiscal Year 2018



Youth Mental Health

Youth mental health conditions have steadily increased in the last several years, particularly in the areas of depression and suicide. Some of the most alarming statistics in the state of CA include the following:

- 32% of high school students (grades 9-12) report they felt sad or hopeless almost every day for 2 or more weeks in a row so that they stopped doing some usual activities.
- 13% of youth (ages 12-17) reported they had at least one major depressive episode in the previous 12 months.
- 17% of high school students report they have seriously considered attempting suicide within the last 12 months. 9% of students report they actually attempted suicide 1 or more times and 3% reported their suicide attempt resulted in an injury, poisoning, or overdose that needed to be treated by a doctor.

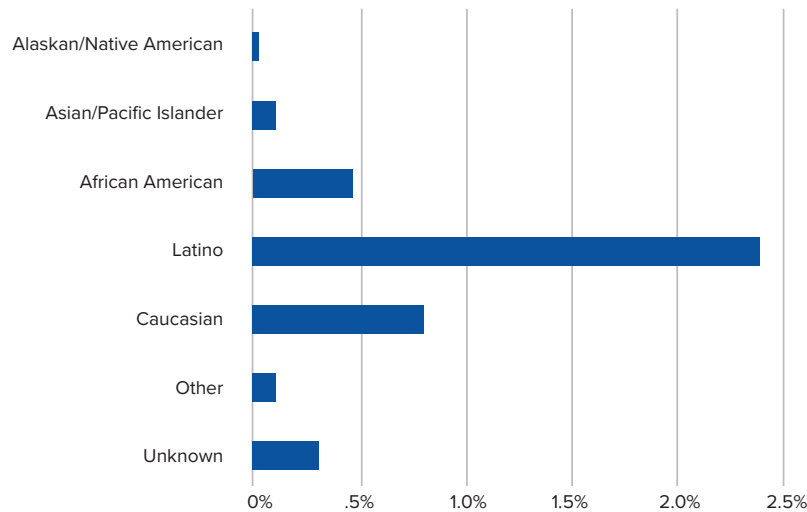
- Approximately 89,000 adolescents aged 12–17 with MDE (30.5% of all adolescents with MDE) per year from 2010 to 2014 received treatment for their depression within the year prior to being surveyed.⁴⁶

Based on feedback from family member caregivers, parents, and guardians, the youth in their communities have the most pressure on their mental health. Peer pressure and bullying all contribute to sadness, hopelessness, depression, and in some cases, suicide. Parents also indicated that they are not equipped to handle their children’s mental health concerns and there should be more information and education readily available to them. Many parents reported that mental health early intervention should be incorporated into the school system and teachers should be required to become more educated on crisis intervention. With early intervention services, many serious mental health conditions can have minimal impact on the child or may be prevented all together.

Medi-Cal Penetration Rates - Youth

According to the CA Department of Health and Human Services, in 2018, approximately 6,313,485 youth were eligible for specialty mental health services (SMHS), however, only 259,870 (4.1%) youth utilized these services. The highest utilization rate was with the Latino population at 2.35% and the lowest was the Alaskan/Native American Americans at 0.02%.

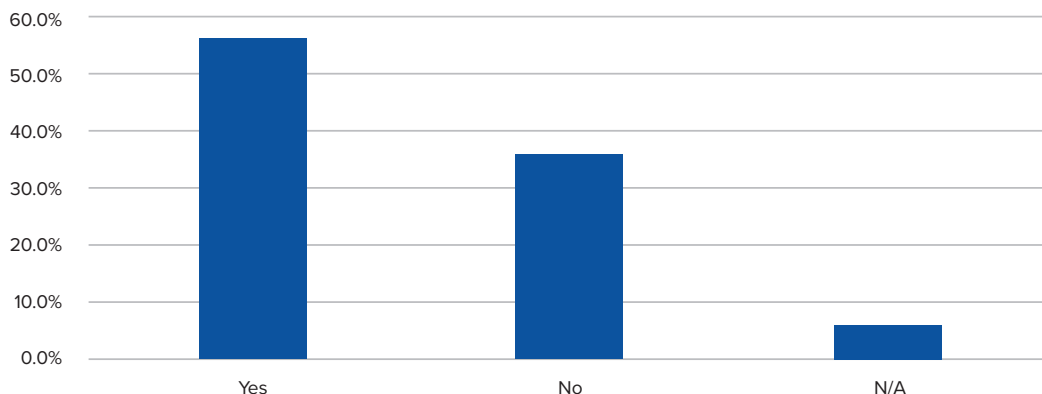
Unique Count of Children & Youth Receiving SMHS by Fiscal Year 2018



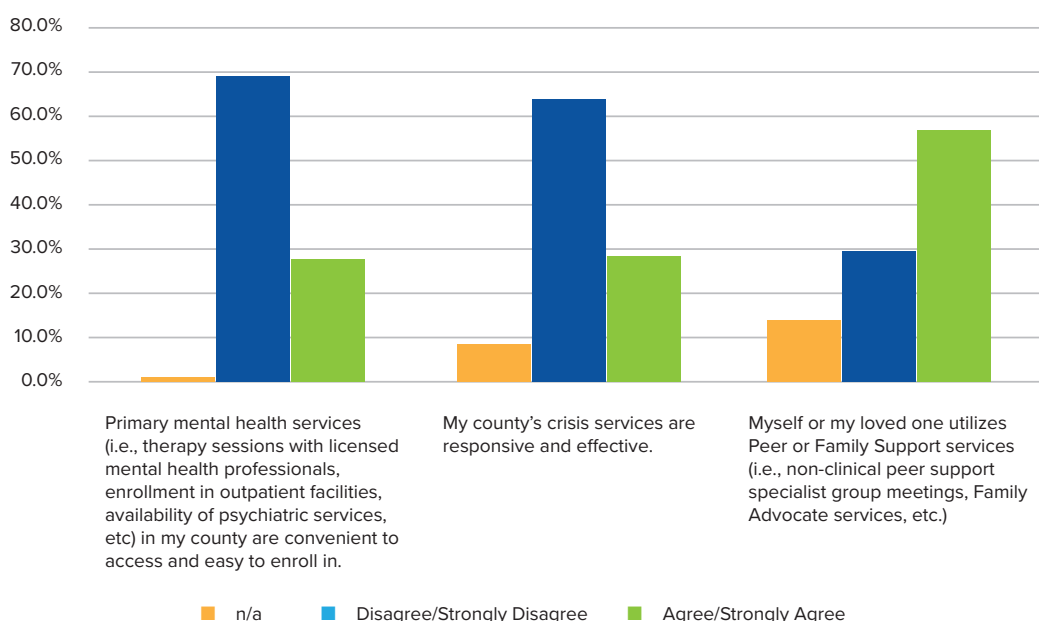
NAMI CA Findings

Data collected from stakeholders indicates that just over half of the respondents would be able to schedule an appointment with a mental health professional within 30 days. In addition to scheduling appointments, other barriers to accessing care included transportation issues, stigma and/or discrimination from care providers and family members, access to childcare to go to the appointments, lack of time, cost, and lack of insurance.

If you needed to, could you schedule an appointment with a medical health professional (e.g. therapist, counselor, LMFT, LCSW, etc.), for yourself or a loved one, within the month?



Access to Services



Participants shared various experiences in accessing services and treatments for their family members. They shared the sentiment that the whole family experiences something like hospitalization not just the consumer and it can be a very intimidating place. They also shared issues outside of the public mental health care system that also added obstacles to accessing the correct services for recovery of their loved one:

Difficulty Working with School System

"We had to change schools 3 times in 2 years. The ADMINISTRATION at the schools viewed our daughter as a problem to eliminate. My daughter was very depressed, as part of her bipolar symptoms, during school days and had multiple bouts of crying. This was her only visible symptom and still the school administrations were not open to working with us. The teachers and counselors were ALL open and understanding - it was always the school administration that hindered progress."

–Family Member, Focus Group

Lack of Education for Families

"I think there should be early education in the schools [for us parents] because a 14-year old girl committed suicide and there are also bad YouTube videos with cartoons that make small children hurt themselves. So, I think there should be more [education] and not just in the middle schools and high schools but the elementary schools too."

–Family Member, Rural Area

Lack of Prevention and Early Intervention (PEI)

"Early intervention is critical because parents can still intervene. When he [son] turned 18 he had to go to behavioral health and do intake as adult – he has to come by himself and access treatment and services. [My] older daughter has depression because of her brother's situation. As a therapist I help so many people, but I can't help my own family."

–Family Member, Orange County Focus Group



NEW INTERVENTIONS & TREATMENT MODALITIES

In addition to traditional intervention and treatment methods, there are some new and exciting treatment modalities on the horizon.

Collaborative Care

While collaborative care may seem like common sense to most, the reality is that there isn't always collaboration between providers when it comes to mental healthcare. The mental health team should consist of mental health coordinators (MHCs), family physicians, and psychiatrists. In addition, all primary care team members can be involved, including nurses, nurse practitioners, dietitians, and auxiliary staff. In most cases, primary care physicians are not in contact with their patient's mental health team or any other providers they may be working with.⁴⁷ NAMI CA's data indicates that there is very little collaboration, despite the overwhelming evidence of its efficacy.

In 2013 the World Health Organization published the "Mental Health Action Plan 2013-2020", which outlines four major objectives:

1. More effective leadership and governance for mental health;
2. The provision of comprehensive, integrated mental health and social care services in community-based settings;
3. Implementation of strategies for promotion and prevention; and
4. Strengthened information systems, evidence, and research.⁴⁸

With MHSA funding, Los Angeles County's public mental health system was able to transform service delivery in response to policy mandates. Funds being restricted to new services for recovery-based interventions that are focused on patient-centered treatment goals. This new structure created opportunities to build stronger provider-client relationships.⁴⁹

In a 2012 study in Canada, it was determined that co-located services, both psychiatric and non-psychiatric, significantly improved wait times for services. In this study, psychiatrists and physicians worked together in the same offices, made notes in the same patient files,

and exchanged information about referrals and health conditions regarding mutual patients.⁵⁰ The main takeaway of the research was that the shared care site offered services more than 40 days sooner and helped to reduce the wait time at non-shared care sites. When compared to the previous 3 years of non-collaborative care, the shared care services offered the lowest overall wait times, about 13 days shorter.⁵¹

Additional literature similarly indicates that the multidisciplinary team, including mental health coordinators, ensures the physician is aware of all referrals and services recommended to the patient. It prevents duplication of services and continuity of care is maintained. Patients are treated holistically as their medical concerns and mental health concerns are not separated from their psychosocial ones.⁵²

The downside however is that access and coordination of crisis management is still difficult. After hours care for mental health emergencies is an ongoing topic of discussion and requires attention to address and improve collaboration from this angle.⁵³ Despite its downfalls however, the main concerns regarding access to care is the long wait times to see a mental health professional and ease of access. Continuity of care also seems to be an issue, especially with those on MediCal and consumers that are not on an HMO insurance plan. Many focus group participants discussed the disconnect between providers and the lack of empathy for the frustrations they have when they need to have referrals duplicated because the originals are lost in the shuffle.

Peer Support

With dwindling access to mental health services, the field is relying more on the work of Peer Support Specialists, to help lessen the gap, to triage, and get more people immediate services. As previously discussed in the definitions section, peer support is a recovery-oriented treatment model in which individuals provide mental health services in a clinical setting who have received formal peer support provider training and/or certification; as well as having their own lived experience and recovery of a mental health condition.⁵⁴ Recent studies show that peer providers with lived experience positively contribute

to treatment and recovery of those experiencing mental health conditions. Peer support can come in all different forms including peer-run support groups, peer-led advocacy organizations, and peer involvement in mental health treatment, to name a few.⁵⁵ Research shows that peer support work not only improves outcomes for the consumer, but for the peer support worker as well. According to a 2013 study, peer support workers reported that their positive experiences included health benefits, social networks, career advancement, increased self-esteem, increased confidence, and a way to reintegrate into their communities.⁵⁶

Peer support has shown to bring the following outcomes to service delivery:

- Dedication and commitment to work;
- Ability to create an immediate connection with the people they serve;
- Ability to use their stories and lived experiences to inspire hope;
- Ability to build bridges that engage other providers on the treatment team;
- Ability to guide people in accessing community resources and services;
- Support people in the development of intentional relationships and meaningful roles in their community;
- Demonstrate to the team, family members, and others that people do recover;
- Ability to bring a different perspective to other treatment team members;
- Support the use of recovery language by reminding others to minimize the use of labels that are demeaning to those seeking help;
- Provide living proof that people recover to other members of the treatment team.⁵⁷

There are roughly 6,000 peer support workers all over CA, according to the Steinberg Institute, a nonprofit focused on mental health policy that's sponsoring the bill. They say CA is one of only two states that don't have a certification process in place.⁵⁸ However, recently, CA recently introduced SB 10, which would establish a state certification process for peer providers -- people with lived experiences as family members, clients, or caretakers of individuals recovering from addiction or mental illness -- who guide and help their clients.⁵⁹

Based on further research, peer-run agencies are suggested for intervention and treatment services. One such study indicated that consumer-run mental health agencies were seen as a place where they feel more accepted and understood. The emergent narratives captured in the study suggest that consumer-run mental health agencies function as low-demand, accepting, safe, and sheltering environments while offering opportunities for human connection, shared agency ownership, and community. In fact, a qualitative study conducted in 2004 found there were five major themes that emerged as most significant in consumer-run agencies. The themes were termed (1) sanctuary, (2) recovery and survival, (3) respect and humanity, (4) shared 'ownership', and (5) networks of caring. While there are many components that go into a successful consumer-run agency, these five were the most mentioned.⁶⁰



Participants in the 2018 Family to Family Teacher Training in El Dorado County

Many of the participants had difficulty finding success in the community and most find the world to be uncaring and overwhelming. Many seek sanctuary in a place that is safe and comfortable. They look for relief from the demands of the outside world and want the safety and comfort of a low-demand environment where they are free to be themselves.⁶¹ From this sanctuary, they are able to focus on goal-setting in a recovery-oriented fashion. Some participants indicated that the peer-run agency is seen as an integral stepping stone to recovery and creation of a meaningful life; that it was the only place for that the nature and extent of their struggle for survival and recovery was truly recognized by others. Respect and humanity were felt when, rather than being patronized and “treated as mental health cases”, they were treated with basic decency and genuine respect. Shared life experiences led to a non-judgmental environment and genuine acceptance. Shared decision-making within the agency made consumers feel that they had a sense of ownership which led to more commitment to the agency by consumers.⁶² Our findings suggest that families respond well and feel more respected and integrated with the help of peer support style programs and trainings (both clinical and non-clinical settings) for them in their roles as family members. The following section highlights some of those qualitative findings.

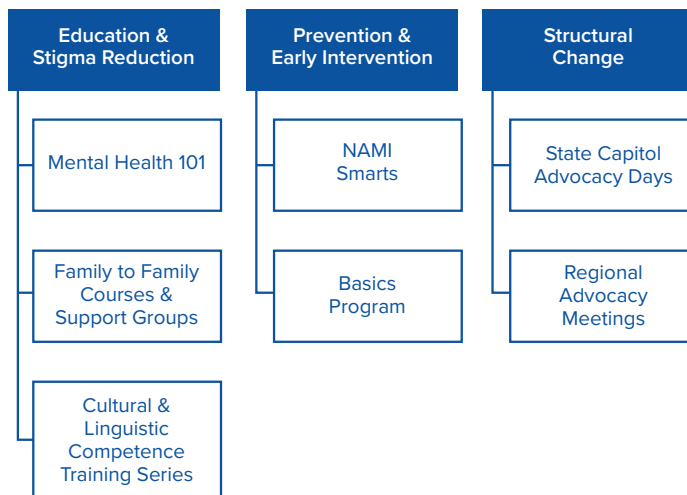


ROLE OF NAMI CA PROGRAMMING

Americans throughout the country both in rural areas and cities have experienced caring for a person with a mental illness. NAMI National states “1 in 25 Americans lives with a serious mental health condition, yet in any given year, only 60% of people with a mental illness get mental health care.” This means that families are often struggling to support their loved one who is either undiagnosed or who is unable or unwilling to seek treatment. With these high rates of mental illness, it is easy to infer that many families care for a loved one who has been living with a mental health condition. Mental illness doesn’t exist in a vacuum. Friends, extended family and coworkers can also be affected by caring about someone who struggles with a mental illness.

NAMI considers Family to include friends, teachers, neighbors, coworkers and others in the community. Even if the “family member” isn’t completely involved in the care of the person struggling they can still benefit from outside support. The interest in NAMI Family Programs primarily arises from families who reach out to their local NAMI affiliate for support. It often happens when the family doesn’t know where else to turn for help. The local Affiliate connects individuals to the NAMI Family classes and Support Groups that are being offered in their area.

The NAMI CA State Office supports families in numerous ways. One example is our State-Wide Trainings which instruct individuals to be Teachers and Facilitators. Affiliates send interested individuals to the trainings, therefore replenishing their pool of teachers and facilitators. This allows more families to be reached and supported locally. Based on supported evidence, programs help build mental health awareness and reduce stigma. The following are the programs and trainings that NAMI CA offers and supports through partnerships with NAMI Affiliates. For more detailed information on some of these programs, please refer to the 2018 Annual State of the Community Report for Families. Counties reached in the 2018-2019 year: Sacramento, Yolo, Contra Costa, El Dorado County, Shasta County, San Diego, Amador, Merced, San Mateo, Urban LA, Monterey, Solano, San Luis Obispo, Kern, Marin, San Gabriel Valley, Antelope Valley, Fresno, Western Riverside, Coachella Valley, and Bakersfield.



NAMI CA Mental Health 101 (MH 101)

Innovative presentations that give 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. Our May 2019 Mental Health 101 Presenter training was held in Victorville, Ca. 10 members from our San Joaquin, East Bay, Inland Valley, and San Bernardino affiliate were certified.



Attendees engaged in discussion at our May 2019 Mental Health 101 Presenter Training in San Bernardino County

Basics Program

Free education program for families with children and adolescents living with mental illness. Curriculum is covered in 6 classes and introduces stages of emotional reactions from crisis to acceptance; it also offers insight to understand the lived experience. 10 people from 5 different counties were trained and certified in Basics during the Basics state training that was held in San Diego County.

Families Support Group

Free, weekly 90-minute support group for individuals who support a loved one through their mental illness, mainly family members. Participants share their experiences, challenges, and successes and offer mutual encouragement and understanding. The Family Support Group (FSG) Training was held in Shasta County in November 2018. 10 people from 6 different counties have been trained and certified in FSG.



Family Support Group Facilitator Training participants upon certification in Shasta County

De Familia a Familia/ Family to Family Program

12-week support-focused educational programs in Spanish and English consisting of 12 two-hour sessions designed for family members of individuals with lived experience. The program helps individuals to understand a relapse prevention plan, learn how to interact with health care providers, learn practical resources on how to support a loved one on their journey towards recovery, and how-to self-care in the midst of these complex processes.

- 6 Family State Trainings and 2 Family to Family state trainings conducted.
- 35 people from 10 CA counties have been Family to Family trained and certified.
- Our De Familia a Familia State Training was held in San Luis Obispo in December 2018. 11 people from 6 different counties were trained and certified.

"NAMI Family Support Group has been very helpful to me. My facilitators got me through some very tough times with empathy, knowledge and understanding."

–Family Support Group Facilitator NAMI Yolo

The OAC Family Affiliate Funding is another way that Affiliates can reach more families. Thanks to grants from the OAC we are able to offer our local affiliates training and program funding which enable them to do their own trainings without having to wait for the State Office to conduct them.

One local affiliate let us know that their Family Support Group is very valuable to the community.

"There are typically 7-16 people. We talk about finding services but also talk about the more emotional things"

–Family Support Group Facilitator NAMI El Dorado County



Attendees practicing their presentation and facilitation skills at a training in Solano County



STATE AND LOCAL ADVOCACY EFFORTS

Through regional meetings and local advocacy trainings NAMI heard many common themes from family, friends and loved ones of individuals living with serious mental illness. NAMI has heard many stories of parents whose children went through the criminal justice system and had multiple interactions with law enforcement, some of which do not end well and some of which dramatically change the trajectory of an individual's life.

Many instances have been shared throughout various community engagement activities and advocacy meetings in which family members share losing loved ones to an overburdened criminal justice system. Crisis Intervention Trainings are vital towards building stronger and more positive relationships with law enforcement. When families do call law enforcement for help with a loved one during crisis or psychotic situations everyone should be able to trust and believe that individuals will be treated with respect and referred to care, whenever possible.

Policy Priorities

Every year NAMI CA survey's families and individuals impacted by serious mental illness. Through the survey results policy priorities are developed and help guide what policy positions the State Affiliate will take. It is through membership feedback, Public Policy Platform and dialogue in which NAMI takes positions on certain legislative proposals.

NAMI SMARTS

In Year 2, NAMI CA was able to train more individuals on the NAMI Smarts for Advocacy program. NAMI Smarts is a grassroots advocacy program taught in a series of educational modules. All modules build on the foundation of teaching individuals a straightforward process for sharing lived experience with policy makers. Currently there are over 60 trained NAMI Smarts Teachers and for the most recent training NAMI CA had one participant from Denver, Colorado and one participant from San Antonio, Texas. It is very interesting to see the need for Mental Health advocacy tools and supports not just in CA, but across the Country.

In addition to NAMI Smarts Teacher training, modules have been presented at the NAMI CA Annual Conference and throughout various other engagements including Regional Advocacy meetings.



Group photo including attendees and NAMI Smarts trainers, Santa Clara County

NAMI CA currently has trained over 50 NAMI Smarts Teachers representing many diverse communities across CA. We hope that more individuals will have the opportunity to utilize materials to develop their stories as a method of public policy.

Annual Advocacy Days in Sacramento

Every year NAMI CA organizes and coordinates an Annual Capitol Advocacy Day in addition to the Bebe Moore Capitol Day. Advocacy Days are designed to help increase awareness on mental health issues and advocate for increasing mental health services in CA. In Year 2 of the OAC Families contract, NAMI CA collaborated with The CA Association of Mental Health Boards and Commissions to conduct a joint Advocacy Day. NAMI CA sees coalition building as a powerful apparatus to strengthen the collective voice.

Areas of focus included; access to treatment, crisis services, expanding and growing a diverse behavioral health workforce. Individuals were encouraged to participate in a preparation webinar a week before the event and the materials covered legislative priorities and the basic format of a meeting with a policy maker.



2019 State Capitol Advocacy Day

Legislative Focus

The priority sponsor bill for NAMI CA in 2019 is Assembly Bill 680 introduced by Assemblymember Chu. This bill would require the commission, on or before January 1, 2021, to develop mental health training courses for local public safety dispatchers, incorporated in the dispatchers' basic training course and as a continuing training course, that cover specified topics, including recognizing indicators of mental illness, intellectual disabilities, or substance use disorders, and conflict resolution and de-escalation techniques. AB 680 ultimately aims to reduce the number of people with mental health conditions involved with the criminal justice system and into mental health service care.

The focus of Advocacy Days is to create opportunities for individuals to share lived experience as a method of positively influence and informing mental health policy. Before individuals met with legislative staff there was the opportunity to hear from Assemblymember Kansen Chu and the energy seemed to invigorate advocates. Every effort should be made to have families and individuals impacted by serious mental illness speak directly to policy makers.

Advocates shared great appreciation for the coordination and materials shared to support advocacy back in their communities. It is important for individuals to have the opportunity to see what mental health advocacy and a legislative meeting with a policy maker can look like. NAMI CA will continue outreach in the community and to organizations who might support individuals and families impacted by mental illness. We want every individual and family to have the tools available to them at the local and state level to advocate for a better coordinated public mental health system.

Building Relationships with Policy Makers

A lot of family members are involved at some level with advocacy either at the local and/or state level. Some currently engage with County leaders throughout program planning and service updates. This makes sense given the trajectory of interactions with NAMI and the prospect of engaging with advocacy after going through education, training or support groups with local NAMI Affiliates. Advocacy is important and the more individuals and families involved the more informed decision a policy maker will vote.

Stakeholders can work with County Behavioral Health staff, local and state policy makers to identify improvements in coordinating county resources for people who need

mental health treatment. Being persistent in mental health advocacy is what ultimately drives change and will help strengthen the mental health movement.

More and more policy makers and high-level decision makers are becoming aware of the effects of untreated mental illness. Research shows without mental health care, we all pay the price. One way is with school failure. Students with serious mental health conditions have the highest dropout rate of any disability group. Approximately 1 in 5 youth aged 13–18 (21.4%) experiences a severe mental disorder at some point during their life. We also pay a high price in unemployment. Very few adults with mental health conditions get the supports they need to get a job and stay employed.



2019 Advocacy Day attendees from throughout the state with NAMI CA Advocacy Manager, Marcel Harris, and Assemblymember staffer

The Stepping Up Initiative is a great example of a strategic partnership and collaboration process to reduce individuals who live with serious mental illness from being involved and detained within the Criminal Justice system. A National Initiative to reduce the number of people with mental illnesses in jails, in which a network of collaborators and many counties share ideas for coordinating across sectors. A major concern right now is how the Criminal Justice system has become the biggest Mental Health provider in the absence of more humane treatment settings and infrastructure that promotes recovery.

As of June 2019, 36 out of 58 counties in CA have passed the Stepping Up resolution. Too often, untreated mental illness is the reason individuals become involved with law enforcement in the first place. All Californian's living with SMI deserve access to appropriate treatment and not criminalization. Counties have the ability to connect with other counties who have successfully implemented services and programs to reduce the number of individuals involved with the criminal justice system.

Engaging Individuals & Families with Awareness & Advocacy

Regional Advocacy Meetings are designed to engage family members, program leaders, and the general public in local planning and problem solving with county board members, city officials, and Affiliates. The meetings provide advanced opportunities for individuals to participate in processes impacting programs and service delivery.

Open to all community members impacted by mental illness individuals learn how to advocate effectively, discuss local advocacy plans for their respective County and engage in a dialogue with local representatives. Every effort is made to create safe spaces in which groups of individuals can learn about current mental health legislation, ways to engage, and information about accessing services.

For the Monterey County regional meeting NAMI CA decided to focus on the importance of reducing individuals with mental illness within the criminal justice system. This grew out of what was expressed by the community and local affiliate. One of the most important aspects is designing a panel discussion with local leaders to talk about community access to mental health services.



Monterey County Regional Advocacy Meeting

The panel consisted of four representatives:

- Melanie Rhodes, LMFT, LPCC is the Forensic Services Program Manager for Monterey County Behavioral Health Adult Services. She is also the Behavioral Health liaison with the county jail, parole, public safety and law enforcement personnel. She also coordinates the Crisis Negotiation Team, Critical Incident Stress Management team and the Crisis Intervention Team. Rhodes is a trainer for behavioral health and first responder personnel in the areas of mental health, crisis intervention, safety, self-care, verbal intervention and de-escalation.
- Linda Prowse Fowler is the Chair of the Behavioral Health Commission of Monterey County.
- Chief Jim Bass spoke on behalf of our original panelist, Undersheriff John Mineau. Bass represented the Monterey County Sheriff Department.
- Sergeant Brian Johnson represented the Salinas Police Department and was able to speak on the training of police officers in interacting with individuals with mental illness.

Overall, it was a fruitful discussion which allowed meeting participants to ask questions in a neutral setting. Often, family members and peers will interact with the criminal justice system in a context with high tension and aggression. However, the panel discussion was positive, and the representatives provided meeting participants with contact information to continue these discussions of ways to improve the intake process and to collaborate with family members and peers.

The development of the panel and questions are in collaboration with NAMI CA and the local NAMI affiliate. We strive to coordinate these meetings in tandem and make sure that the needs of the community are being address through trainings, materials and dialogue. All efforts at the local level should be led by individuals and leaders in the community who can also continue the support and link individuals to action items such as Board of Supervisor meetings, local mental health board meetings and other important interactions where local mental health programming and support decisions are ultimately grown.



FAMILY-INFORMED RECOMMENDATIONS

Based on current research and membership feedback, there are 6 key areas that should be addressed in Year 3 of this project. The following section outlines the recommendations for further research.

Access to Treatment

NAMI CA believes that individuals with mental illness should have timely access to clinically appropriate medications and evidence-based treatments that are provided in a whole person-centered approach. Access to treatment continues to be an area of research and advocacy for Year 3.

- Advocate for additional funding to promote multiple points of access to mental health treatment in communities and schools including family and peer support programs and certification.
- Ensure that all Californians are insured with a health care policy that supports robust mental health care from providers of their choosing when possible.
- Increase awareness and acceptance of mental health issues in local communities by funding stigma and discrimination reduction programs.
- Advocate for policies that increase access to mental health services for all populations regardless of social determinants.

Housing

NAMI CA believes that individuals with serious mental illness must have access to permanent, decent, and affordable housing. NAMI CA affirms that consumers have the right to privacy, security, stability, and dignity in housing.

- Support a wide array of options for permanent, decent, and affordable housing, based on an individual's needs and choices.
- Advocate for housing options that include appropriate supportive services, such as case management, tenancy support, clinical services, employment, transportation, and crisis intervention.
- Promote the availability of housing options across the continuum of care, including requiring the inclusion of safe and secure housing in discharge plans, and the protection of an individual's housing during times of inpatient treatment.

Crisis Services

NAMI CA believes that persons experiencing a mental health crisis deserve access to timely, competent and compassionate medical care during a psychiatric emergency.

- Support the development and use of community-based crisis intervention, crisis stabilization, and residential crisis services.
- Support the staffing of emergency departments and first responders with mental health professionals and providing mental health training to staff as a mean to reduce ER crowding and delays in receiving crisis care.
- Encourage partnerships between hospitals, health systems, counties, law enforcement, families and individuals in order to maximize capacity, provide the best possible care, and develop more comprehensive services.

Criminal Justice and Forensic Issues

NAMI CA believes that the law should be used, whenever possible, to promote the mental and physical wellbeing of the people it affects. The criminal justice system should not be relied on to provide mental healthcare to those in need. Instead, the mental health system has the ultimate responsibility for treating all people with severe mental illness.

- Support a variety of approaches to divert persons with serious mental illness from unnecessary incarceration and into programs designed to address their treatment and service needs.
- Educate all persons involved at all levels of the judicial and legal systems – including judges, lawyers, police officers, correctional officers, and emergency medical personnel among others – about serious mental illnesses.
- Improve collaboration between mental health authorities and correctional and law enforcement agencies to develop strategies and programs for compassionate intervention.

Family Involvement in Treatment

NAMI CA believes that family members are a central resource in the treatment of children and adults living with serious mental illnesses and that families should be an integral part to facilitate mutually agreed upon treatment team goals. Families should take an active part in treatment decisions and use their unique knowledge of and relationship with the consumer to create better outcomes.

- Promote a client- and family-centered approach that gives the consumer encouragement to participate fully in planning, monitoring, and evaluating treatment; and gives the family the information, skills, and support to make informed decisions as equal partners in treatment (provided the consumer wants his or her family to be engaged in the process).
- Ensure that families of children living with serious mental illness can easily access mental health and related services for their child without being required to navigate multiple, complex, and overly bureaucratic systems.

"Early intervention is critical because parents can still intervene. When he turned 18, he had to go to behavioral health and do intake as adult – he has to come by himself and access treatment and services. As a therapist I help so many people, but I can't help my own family."

-Family Member, Orange County

Complete and Comprehensive Services for All Ages

Children, youth, and young adults living with mental illness should have access to a comprehensive array of treatment, services, and supports that promote resiliency and recovery and include evidence and research-based interventions.

- Promote policies that help identify mental health issues in children, intervene with clinically approved services, and prevent mental illness from going undiagnosed.
- Ensure that schools provide and sustain key mental health services, supports, and appropriate accommodations. Encourage schools to maintain close connections with community mental health and primary health care systems.



FURTHER RESEARCH

Mental Health Crisis at the Border

Since early 2018, CA has seen an increase of mental health concerns at the US/Mexico border. Between April and August 2018, over 2300 immigrant children were separated from their parents and relocated to separate child detention shelters all across the country. Reunification after the parent's case is resolved remains the goal but is not always guaranteed. By late June 2018, President Trump signed an executive order ending the separation policy, however and lack of planning made the transition problematic. As of August 2018, there were still an estimated 700 children, including 40 children under the age of 4 years old, remained separated from their parents.⁶³

Immigration studies show that separations such as these found that longer separations from parents during the immigration process led to higher rates of depression and anxiety. Children may also be at increased risk of post-traumatic stress disorder. Research also shows that the trauma caused by separation affects the mental health as much as the atrocities families experience in the countries that they're fleeing.⁶⁴

Additional research tells us that young children that are institutionalized at a young age can create irreversible changes in the brain; so much so that a study of 110 adolescents who had been institutionalized during their first year of life had significantly lower volumes of prefrontal cortex in the brain compared to the control group. While some children are resilient, others suffer from complex trauma, attachment disorders, generalized and social anxiety, and self-harming behaviors such as cutting.⁶⁵

The Trauma Continuum

Childhood trauma occurs when a child is in a situation that induces a sense of intense fear and helplessness. There are three levels of trauma:⁶⁶

- **Type I** trauma occurs after a single, isolated trauma incident, such as a car accident. It is limited exposure to an extreme event and can be recovered without significant injury in an environment with supportive adults.
- **Type II** trauma occurs when a child is exposed to repeated and prolonged exposure to significant trauma, such as physical abuse at home.
- **Type III** trauma occurs when a child experiences multiple, prolonged, pervasive, and violent actions beginning at an early age, creating an extremely hostile environment for development. This type is the most severe and most difficult to recover from. This level of trauma initiates the fight, flight, or freeze hormones epinephrine and cortisol.⁶⁷

Families that are separated during border detention has a more significant impact on children and leads to difficult and even traumatic reunifications. Children adapt to a constant level of function that seeks to preserve life, which then manifest into maladaptive behaviors such as hyper-vigilance, agitation, flashbacks, emotional reactivity; and hypo-vigilant behaviors such as dissociative responses, emotional numbing, self-harm, passive compliance, and poor access to cognitive functioning. The separation of children from their parents threatens the attachment bond, forming an additional root of fear and lack of safety. When



children believe they have been abandoned by their parents, they begin to believe they have done something wrong to cause their parent(s) to leave. This feeling of abandonment creates shame and complex emotions that can damage lifelong relationships with themselves and others.⁶⁸

Socioeconomic Stressors and Co-Occurring Conditions

Mental health conditions, in many cases, are not stand-alone issues. Many times, stressors either bring on or exacerbate serious mental health conditions, even causing suicide. Issues such as substance abuse, poverty, incarceration, adverse child experiences, and even lack of social support should be addressed in upcoming research.

- Poverty is linked to a higher burden of mental illness, with variables such as education, food insecurity, housing, social class, socioeconomic status, and financial stress having a strong correlation.
- More than 4300 Californians died by suicide in 2017, which is a 52% increase from 2001. The CA population increased by 14% during the same time period.
- Comorbidity is very common, which complicates diagnosis & treatment. People with comorbid disorders are 6 times more likely to commit suicide than those without.
- Over 30% of CA's inmates receive treatment for mental health disorders, which is an increase of 150% in the last 20 years.
- The number of people admitted to state hospitals as "incompetent to stand trial" has increased by 60% in the last 5 years.
- An estimated 43,000 of approximately 130,000 homeless individuals have a diagnosable mental illness.
- Between 10 and 20 million depressed individuals attempt suicide every year and approximately 1 million complete suicide.⁶⁹



CONCLUSION

As NAMI CA moves into Year 3 of the project, we will continue to solicit feedback from the families of those with mental illness and key stakeholders to further educate and inform our research. NAMI CA strives to bring mental health concerns to the forefront of the conversation about providing the best mental health care for California families and their loved ones.

Throughout this report, NAMI CA references a variety of articles, internally conducted surveys, and other sources. Much of the literature and research that NAMI CA references is listed in the following reference section. However, we are aware that some of the sources, specifically academic journal articles, are often inaccessible to the public due to cost and a lack of open access to research journals. NAMI CA encourages any consumers of this report to contact our state office in Sacramento where staff will be more than happy to share articles and reports we cite as well as what internal data NAMI CA has generated within the bounds of maintaining the confidentiality of our participants.



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