



NAMI California
National Alliance on Mental Illness

The
ANNUAL STATE
of the
COMMUNITY REPORT
on
FAMILIES

“You are not alone”

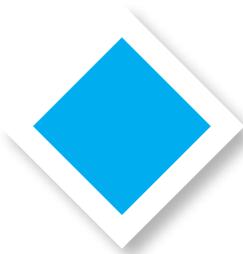
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INTRODUCTION AND OVERVIEW

The National Alliance on Mental Illness (NAMI CA) decades of experience serving families of those 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 listen and compile the voices of family members in California.



NAMI CA CEO, Jessica Cruz

NAMI CA is a grassroots organization of families and individuals whose lives have been affected by serious mental illness. We advocate for lives of quality and respect, without discrimination and stigma, for all our constituents. We provide leadership in advocacy, legislation, policy development, education and support throughout California. For 40 years, NAMI CA has provided leadership in mental health advocacy, legislation and policy development, and family education and support for California residents.

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 California parent groups in Oakland, California 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.

To this day, NAMI CA continues to reach out to families and individuals affected by mental illness, provides education and training around the specifics of various mental illnesses, how to access available resources, and promotes leadership in mental health advocacy, legislation, and policy development. These activities reflect our agency's primary strategies toward ensuring families and individuals can access quality programs, live with respect and dignity, and become empowered to advocate on their own behalf.



The Mental Health Services Oversight and Accountability Commission (MHSOAC) has generously funded NAMI CA to reach more family members across the state, to provide much needed programs, messaging about self-care and resilience, and advocacy and empowerment activities. As the organization founded by family members, NAMI CA understands the significant impact having a loved one with a mental illness can cause in a person's life. Through our work with the MHSOAC, we strive to provide support, services and advocacy for the family members in California.

Each year, we reach hundreds of thousands of people across the state in need of our services and supports. It is through these activities that we are connected with family

members of all backgrounds and experiences and are able to begin to understand their distinct perspectives. Listening closely to family members from across the state, we are in a unique position to note trends in mental health barriers and needs; their experiences with self-care and stigma; and the triumphs and struggles of loving someone who is on a journey through the mental health continuum. The following report shares the outcomes of listening sessions, focus groups, surveys, and interviews, and successfully demonstrates the state of the family member community.

The following report also seeks to review the existing literature regarding the unique needs of California’s families of consumers of mental health services. This report will define consumers as, “adult individuals who have received or are currently receiving mental health services, as well as those who have a mental health diagnosis in the past.” For the purposes of this report, the definition of “family” will be deliberately broad and inclusive and will refer to the parents, caregivers, relatives, and significant others of mental health service consumers.

Specifically, this report will seek to collate relevant information regarding specific factors of mental health need for Californian families, such as: the current access to mental health care; barriers to care; and families’ needs for treatment, and social supports. This report will rely

on a variety of sources to inform the before mentioned questions. These sources will include state and federally funded organizational reports, peer reviewed academic journal articles, and other public source documents and reports. Special emphasis will be given to reports and studies published in the past five years in order to insure the relevance of the research being referenced.

Research would suggest that individuals who live with serious mental illness (SMI) experience a slew of negative outcomes pertaining to their health¹, involvement with the criminal justice system², and economic attainment³. Within this context, it is important to note that, for Californians, it is estimated that over 75% of individuals who meet criteria for needing mental health services, do not receive “minimally adequate treatment.”⁴

Given the persistent and debilitating nature of SMI and the systemic lack of professional treatment that individuals living with SMI receive, it is not all too surprising that their family members and loved ones have been identified as a critical factor in promoting recovery for individuals living with these diagnoses.^{5 6} This paper will explore the variety of methods in which stakeholders, community based organizations, and the Public Mental Health System (PMHS) can help family members to support their loved ones who live with SMI.



Regional advocacy meeting in Kern County.

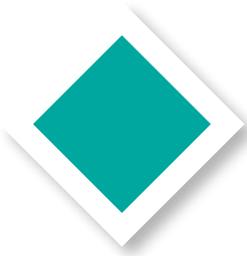


ACKNOWLEDGMENTS

The National Alliance on Mental Illness (NAMI) California appreciates the tremendous commitment and compassion from family members leading groups, teaching classes and sharing lived experience throughout the state. By utilizing and empowering individuals with lived experience we can create better mental health outcomes for all. Community leaders impact lives through shared dialogue, education, and advocacy with the shared focus 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 the vast families from around the state who share their lived

experiences and perspectives throughout this report and within their communities.

We would also like to thank 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 first edition of our Annual State of the Community Reports.



NAMI CA METHODOLOGY

During the course of this State of the Community report, NAMI CA conducted a variety of information gathering processes to demonstrate the experiences and needs of family members navigating the public mental health system. Throughout this report, reference will be made to the range of surveys, focus groups, case studies, and the information gleaned from these activities. The following section will detail our methodology and sample characteristics of as it pertains to NAMI CA's own data collection procedures

Advisory Committee

The overarching working purpose of the Stakeholder Advisory Committee is to ensure the needs and perspectives of family members locally and statewide are accurately represented in our research and data collection for annual reports. Communications and feedback were exchanged via email and conference calls every other month. 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 family member 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 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.

Participant Recruitment

Recruitment for the Family Advisory Committee included multiple emails to NAMI affiliates and family program teacher and facilitator networks over the span of two months. A screening rubric was created and used in the selection process, which rated applicants based on region, family member relationship, and involvement in mental health systems and advocacy in their communities. Care

was taken to select family members based on location, in order to assure many California regions were represented. The next consideration was relationship to the loved one with mental illness—members were selected to represent a variety of perspectives including parent, spouse, child, etc., plus some family members who were also consumers. Finally, we took into consideration the importance of representing family members of diverse communities.



Advisory Committee Member Composition and Background

The Advisory Committee consists of nine members, with four family members with lived experience and five who are both a consumer and family member. Seven have adult children with mental illness. Two have had spouses with mental illness. One is the grandparent and caregiver for a child with mental illness. One member has a parent with mental illness. One member has a sibling with mental illness.

There are three members in Sacramento County. One member is in the Bay Area, one member is in San Joaquin County, one member is in Riverside County, one member is in Chino Valley, one member is in Shasta County, and one member is in South Central Los Angeles. Five Advisory Committee members are Caucasian, one is African American, and one is Asian. Two are multiracial, with one being African American and Latino descent and another member being of Native American, African American, and Latino descent.

Qualitative Interviews

Recruitment

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 their identities in regards to mental health (family member, consumer, etc.), diverse communit(ies) with which they identify, and the region in which they are located. The questionnaires were sent to NAMI family programs teachers and facilitators, as well as affiliate leaders for recruitment. Questionnaire participation was open to any family member with lived experience 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

NAMI CA had twenty-two family members with lived experience participate. Twenty participants are Caucasian. One is African American, and one identifies as Latina and Caucasian. Eighteen are family members with lived experience and four are both family members and consumers. Four participants are located in Los Angeles County, three are in Amador County, three are in Sacramento County and two are in Yolo County. There is one participant each in Santa Clara, Fresno, Solano, Lassen, Stanislaus, Tehama, Santa Cruz, and Alameda counties. Two participants did not disclose their locations.

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 153 individuals who identify as family members of individual with mental health conditions from June 2018 through August 2018. Individuals from 34 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.

Respondents were asked how they would describe themselves based on the following dimensions (*note that respondents were allowed to select more than one option, therefore percentages will total more than 100%*): A family member or loved one of an individual living with a serious mental illness (89%), A community leader/organizer/activist (20%), A Peer/consumer of mental health services with lived experience (19%), A professional employed in the mental health field (14%), Consumer Advocate (11%), State/County employee (9%), Employee of a research/public policy/think tank organization (0%), or Other.

Additional sample characteristics of our survey show that respondents were overwhelmingly older as individuals who were 55-64 years of age and those 65 years or more represent over 70% of our sample with individuals who were between the ages of 18 to 54 representing the remaining 30%. Our sample also skewed female, with 90% of respondents selecting that option. In an effort to capture a more detailed and accurate snapshot of family

member experience, NAMI CA included a variety of other gender options (i.e., Androgynous/Nonbinary, Trans Woman, Questioning, etc.) though no respondents selected these options. In regards to race and ethnicity, 78% of respondents identified as Caucasian/White, 10% identified as Latino/Mexican/South American/Central American, 7% identified as African American, followed by single digit percentages of Native American, Filipino, Chinese, Middle Eastern, and Pakistani.

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 2018 annual conference held in Monterey in June 2018 where we solicited responses from family members over a two-day period. NAMI CA also conducted two focus groups virtually via webinar format and heard from family members across the state.

The following questions were developed, with feedback from our Advisory Committee members, for use in NAMI CA focus groups:

1. In the past year, what are your experiences utilizing or helping a loved one utilize mental health services in their different forms (i.e. meeting with therapists, emergency psychiatric services, informal mental health services, etc.)?
 - What were your best and worst experiences?
2. What are the top three ways you support your loved one?
 - What resources do you need to support your loved one?
3. What is the biggest barrier you face in helping your loved one access services?
 - How has stigma impacted you and your loved one?
4. How has your loved one's disease affected you?
 - Do you have a self-care plan?
5. *Additional question to assess UCLA's Minimally Adequate Treatment Standards*
 - a. Definition
 - i. Has your loved one had four or more visits with a health professional in the past 12 months and at least two months of prescribed medication, or eight visits of psychotherapy lasting at least 30 minutes in past 12 months



ROLE OF FAMILY MEMBER SUPPORT IN MH TREATMENT

History of Family Member Involvement in Mental Health Treatment

Today, in the 21st century, there exists substantial evidence that family member involvement for the treatment of serious and persistent mental illness (SPMI) is associated with a variety of positive outcomes including, but not limited to: improved ability to manage symptoms, decreased hospitalizations, increased quality of life indicators, and mitigation of a variety of factors considered to be detrimental consequences of living with SPMI.

Historically speaking, however, this has not always been the case. As noted by Dr. Neil, Associate professor of Psychiatry and Psychology at the University of Kentucky College of Medicine, “American psychiatry in the mid-twentieth century was dominated by a strong environmentalist or ‘nurture’ bias in the search for the roots of psychopathology.”⁷ In other words, psychiatric theory of the 40s through 60s primarily viewed pathological psychiatric diagnoses, most notably schizophrenia, as being caused primarily by “nurture” as opposed to “nature.” Tellingly then, the individuals most responsible for the environments that led to the formation of schizophrenia were the parents of individuals with the condition. In fact, medical and psychiatric professionals of the mid twentieth century were so convinced that parents, specifically mothers, were responsible for the onset of schizophrenia they even coined and proliferated a term ubiquitous with the thinking of the era: the *schizophrenogenic mother*, or, in other words, the mother who causes schizophrenia. With this underlying theory at the roots of the condition, treatment of the time also viewed family intervention as harmful or unconstructive to treatment, treatment that often took place in institutionalized settings.

It would not be until the deinstitutionalization of psychiatric care of the mid twentieth century that the role of family care for the treatment of psychiatric disorders would become a topic of concern amongst psychiatric and medical professionals. Deinstitutionalization of psychiatric care in the US was the result of a variety of factors such as: advances in psychopharmacology, the advances of the Civil Rights movement, the high cost of care for state psychiatric hospitals,

and political decision making.⁸ According to Dr. Scheff, Professor Emeritus of Sociology at the University of California at Santa Barbara, California’s history with deinstitutionalization began with the passing of the Lanterman-Petris-Short (LPS) Law in 1972.⁹ According to Scheff, the original author of the LPS Bill, Jerome Waldie, was aware that the shuttering of state mental hospitals would result in the release of former patients into the streets of California’s cities and had anticipated this by crafting the law to take money saved by closing these institutions and using those funds to create county mental health clinics.

Family Contribution to Mental Health Care

Policy makers originally envisioned that the transition from hospital based and institutional care to the community would involve some form of community care that would be in place as individuals transitioned out of state hospitals. This was not the case. Instead, this shift has placed a greater emphasis on families to provide ongoing care and social support.¹⁰ Additionally, the World Health Organization estimates that deinstitutionalization has resulted in nearly 50% to 90% of individuals who utilize mental health services now reside with their family.¹¹ These findings are further supported by our focus group findings, wherein participants describe being active in assisting their loved one in finding services, navigating administrative and bureaucratic hurdles to find services and care.

“ I fill in information that is missing for them. My son cannot tell them his whole history accurately and doesn’t even have insight, so I have to make sure the professionals really know what is going on. I try in my limited way to help my son see the positive in each situation he is in and how he might be able to gain more independence. It has not worked well, but I try. ”

– Family Member from
NAMI CA Focus Group

A plethora of research would suggest that the family unit now acts as one of the most important agents for providing psychosocial support for individuals with mental health conditions.¹² Psychosocial support can be conceptualized as the support, primarily emotional and interpersonal, that families provide to individuals with mental health conditions which aid them in their recovery journey and better prepare individuals to manage their symptoms. In addition to the psychosocial support that family members provide, ample research¹³ has long identified that family members also provide case management support, financial assistance, advocacy, and housing. Research would also suggest that patient outcomes improve when family members are provided with the information, clinical guidance, and support they request.¹⁴ Our own focus group findings would suggest that housing is a particular stressor that may be more unique given California's housing crisis. For example, participants often mentioned the stress of loved one's becoming homeless, due to crisis or a break in care, and the lack of processes to find/connect with loved ones if they become homeless.

Furthermore, there is global evidence that chronic mental health conditions, such as schizophrenia or bi-polar disorder, may cause debilitating hardships for the families that care for

their sick loved ones.¹⁵ For example, many family caregivers will devote much of their time to the aforementioned caregiving tasks, which causes many them to neglect their own social support networks which can lead to feelings of isolation and even clinical depression.¹⁶

“ My son's illness has affected every part of my life, physically, emotionally and financially. I have anxiety that I never had before. I have been able to take care of myself better in the year and a half since he has been in a locked facility. I can sleep at night knowing he is safe. But that is not going to last forever. He will probably be discharged within the next 6 months and there is a good chance he will relapse, and we will be back at square one again. This cycle continues with so many family members that it is a cliché. ”

– Family Member from NAMI CA Focus Group



CURRENT ACCESS TO CARE

Rates of Mental Illness in General Population

According to a study by Coffman and colleagues¹⁷ approximately one in six adults in California were diagnosed with a mental health condition in 2014 and 1 in 25 Californians were diagnosed with a serious mental illness.

Another important source for information about California residents' current access to care can be found in the University of California, Los Angeles's California Health Interview Survey (CHIS) and the research based off



that data. The CHIS is the largest state health survey in the nation¹⁸ which typically reaches upwards of 20,000 California households per year. Additionally, the survey specifically oversamples certain minority groups in California and is conducted in a variety of languages in order to generate representative samples of these populations.

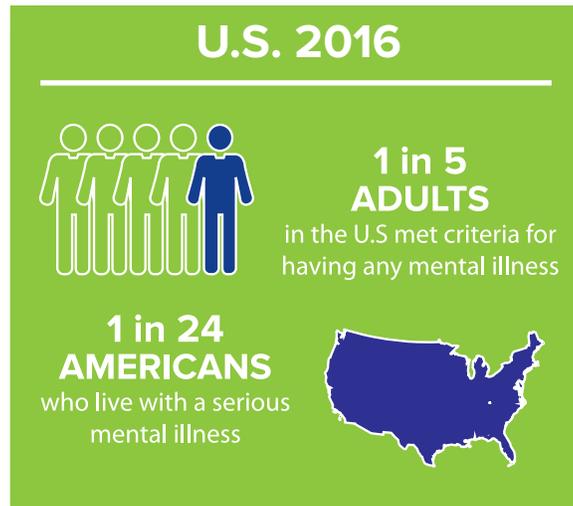
Two studies analyzed CHIS data from 2007¹⁹ and aggregated data from 2011-2014²⁰ and found surprisingly similar results. For example, both studies report

that approximately 2.2 million Californians (8% of the state population) would qualify for having “mental health need,” a criteria based off responses to the Kessler 6, a survey designed to estimate rates of non-specific psychological distress within a given population and utilized by the CHIS. An additional measurement variable employed by both studies includes the concept of “minimally adequate treatment (MAT).” The MAT variable was developed based on evidence-based guidelines for the treatment of mental disorders which recommends 1) four or more visits with a physician and at least two months of appropriate medication or 2) eight or more visits of psychotherapy. Based on these criteria, CHIS respondents are considered to have MAT if they have had four or more visits with a health professional in the past 12 months and used prescription medication for mental health problems in the past 12 months. Results from both studies are nearly identical; approximately one quarter of Californians who qualify as having mental health need actually receive MAT with the remaining three-quarters) not receiving the suggested treatment minimum (approximately 1,689,000 people do not receive MAT vs. 511,000 who do receive MAT).

In order to provide context for these population estimates, it is helpful to contrast these results with data from the National Institute of Mental Health (NIMH). The NIMH relied on data from the 2016 National Survey on Drug Use and Health (NSDUH) as administered by the Center for Behavioral Health Statistics and Quality. Their data found that, in 2016, it was estimated that there were 44.7 million US adults who met criteria for having any mental illness (AMI) or about 18% of the total adult population or almost 1 in 5 US adults. The NSDUH data would also suggest that there are approximately 10.4 US million adults who live with serious mental illness (SMI) or 4.2% of the total adult US population or about 1 in 24 US adults.

Penetration Rates

Another useful metric for determining access to mental health services can be derived by examining reports related to evaluations of County Behavioral Health Departments. The California Department of Health Care Services (DHCS) contracts with 56 county Mental Health



Plans (MHPs) to provide Medi-Cal covered specialty mental health services (SMHS) to Medi-Cal beneficiaries under the provisions of Title XIX of the federal Social Security Act.²¹ Under larger, federal provisions from the United States Department of Health and Human Services Centers for Medicare and Medicaid Services, each MHP is required to be evaluated by an External Quality Review Organization (EQRO). These EQRO reports provide us with aggregate measures

of penetration rates. Penetration rates are calculated by dividing the total number of beneficiaries (individuals receiving Medi-Cal eligible mental health services) by the monthly average number of Medi-Cal eligible individuals. This results in a measure of the availability of mental health services for the Medi-Cal population and is a widely used measure within multiple health care areas.

Statewide, the overall penetration rate has been on continuous decline, from 5.9% in calendar year 2012 to 5.16% for calendar year 2014.²² This decline most likely 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 with the percent increase between 2013 -2014 reaching almost 12 percent. As we will continue to see throughout this report, the rapidly expanding population of individuals eligible for mental health services has not seen a similar increase in mental health services, bed, or mental health professionals to keep pace with this expanding need for treatment.

Availability of Psychiatric Beds

The availability of psychiatric beds serves as a convenient proxy for discussing the potential access and availability of mental health services for a given service area. While the number of psychiatric beds can be a very helpful indicator of available services, this report stresses that the individuals who are in need of psychiatric care are much more than ‘just a bed’ and acknowledges that conversations around bed access are by no means the definitive viewpoint regarding mental health care access.

California operates five, large, state owned hospitals across the state with bed totals that number 6,078 (*retrieved from <http://www.dsh.ca.gov/Hospitals/default.aspx>*). However, these facilities are generally not open to the public; instead, these facilities provide services primarily to individuals necessitated treatment via a court order (i.e., incompetent to stand trial, Lanterman-Petris-Short conservatorships, Mentally Disordered Offenders, etc.). Psychiatric resources to the public include a variety of health care settings. According to a report²³ by the California Hospital Association that is based on 2015 data from the Office of Statewide Health Planning and Development, California operates 29 hospitals licensed as freestanding Acute Psychiatric Hospitals (APH) and 28 county-based Psychiatric Health Facilities (PHF). An additional 80 facilities are located within General Acute Care Hospitals (GACH). All the programs, together, represent about 6,610 beds available across the state that are available for the public in need of short-term, psychiatric inpatient services. Viewed collectively, the total psychiatric beds in California would number about 32 beds per 100,000 people, based on 2017 California population estimates (*retrieved from: <https://www.census.gov/quickfacts/CA>*) however when just viewed in the context of “publicly available” beds, the number shrinks to about 17 beds per 100,000 people.

A widely cited report from the Treatment Advocacy Center²⁴ solicited opinions from 15 experts with experience in psychiatric practice regarding appropriate rates of available psychiatric facilities to meet population needs. The experts achieved consensus of around 50 beds per 100,000 people as being an adequate number for meeting population requirements for forensic, child, and adult psychiatric services. Furthermore, among the member states of the Organization of Economic Cooperation and Development (OECD), the median number of psychiatric beds per 100,000 people in 2013 was 68 (*Retrieved from: <https://www.oecd.org/els/health-systems/Health-at-a-Glance-2013.pdf>*), demonstrating that comparative developed countries to our own are performing within the upper bounds of professional census. Notably, even with generous inclusion criteria for the state of California’s psychiatric beds, California still falls well short of expert and international opinion regarding bed availability.

California’s Behavioral Health Workforce

According to an independent, external quality review of Medi-Cal specialty mental health services, California has more psychiatric health professional shortage areas than

any other state in the nation.²⁵ A report by researchers with UC San Francisco²⁶ notes that the current supply of licensed mental health professionals (i.e., psychiatrists, counseling psychologists, LMFTs, clinical counselors, psychiatric mental health nurse practitioners, etc.) are subject to a host of supply issues across the state. Their report would suggest that by 2028, the current pool of psychiatrists in California will decrease by 34%, largely due to an aging psychiatric workforce and a lack of training infrastructure in place in key regions of California. The report also found that, based on forecasts modeled using current service utilization plus unmet need, that by 2028, California will have 50% fewer psychiatrists and 28% fewer psychologists, LMFTs, LPCCs, and LCSWs than will be needed.

“ *The Psychiatric bed shortage in CA has a direct impact on how patients get hospitalized, but Mental Health Departments get the blame for not getting people treatment. It is difficult to fix this problem without having treatment options.* ”

– Family Member from Stakeholder Survey

A report produced by Resource Development Associates in partnership with the Office of Statewide Health Planning and Development (OSHPD) found the mental health workforce in California has grown 52% from 2010 through 2015, from 103,169 providers in 2010 to 156,541 in 2015.²⁷ Within this context, the report classified providers along three categories: 1.) non-licensed providers, 2.) Licensed, Non-prescribing providers, 3.) Licensed, prescribing providers. Of these three categories, non-licensed providers constitute the largest segment as well as the fastest growing provider type in California’s PMHS.

NAMI CA Contributions to the Literature

“How would you rate the ‘ease’ at which members of your community can access mental health services in your county? This would include: scheduling appointments, referral services, follow-up from your County Behavioral Health Department, treatment from other mental health providers in the community, etc.” 82% of respondents rated the “ease of access” as either difficult or very

difficult, demonstrative of the continued burden that family members face when attempting to assist their loved one in accessing mental health services.

“ *Difficulty navigating the system (government/judicial/financial/health) and finding compassion, understanding and help for my family member. Taking time off work to care for my family member, take to appointments, get signed up for SSI. The frustration of seeing my family member get taken advantage of while they are in a manic/depressive state.* ”

– Family member response to survey in Yolo County

“ *There are many resources, however, access, actually getting enrolled and the actual ‘start’ of services can take longer.* ”

– Family Member response to survey from Sacramento County

When participants were asked to rate their agreement with the statement, “My county’s behavioral health department utilizes ‘Family member voice’ in service delivery or outreach initiatives,” 49.6% of participants stated they either disagreed or strongly disagreed to this statement compared to 26% of respondents who agreed with this statement and only 3.8% of respondents who strongly agreed with the statement. This data would suggest that family members are much more likely to feel as though they’re input, as a loved one, was not being utilized to its full potential by behavioral health staff.

Participants were asked to rate the effectiveness of their county’s crisis response services for mental health

emergencies and over 82% of respondents rated their county’s crisis services as either “somewhat effective” or “ineffective” compared to 13% of respondents stating that crisis services were “effective” and less than one percent of respondents claiming their county’s crisis services were “very effective.”



Gigi Renee Crowder, LE

Gigi Renee Crowder, LE is the family member of several loved ones with mental illness, including a foster son with bipolar disorder. In her storytelling video, she discusses the disparities facing communities of color, particularly for black men, and how the faith community has

been a source of healing for her family. Gigi works in the behavioral health field and had vowed to never call 9-1-1 for a 5150-psychiatric hold, but when a mental illness crisis occurred in her own family she had to break that vow. Gigi is a fierce advocate in her roles as Executive Director and FaithNet Coordinator for NAMI Contra Costa County and her role on the African American Strategic Council at Each Mind Matters. But her advocacy begins at home, for her son, in the mental health systems. Her work focuses on reducing disparities, particularly for young African American males like her son, within mental health and criminal justice systems and promoting faith as a source of healing and community for families and peers with mental illness.

Examined collectively, the data would suggest that family members still perceive significant difficulties to access and utilize services, do not feel that their input as a family member is properly utilized in their loved one’s treatment, and that crisis services for mental health emergencies are still far from the levels of effectiveness that family members expect.



BARRIERS TO CARE

According to data from the World Health Organization, between 30% and 50% of individuals in high income countries such as the United States receive no treatment whatsoever for their psychiatric difficulties. There exist a variety of factors that contribute to this lack of service utilization that range from: cost, stigma, lack of services, and other issues that will be explored in greater depth.



found that in half of the studies they examined, participants reported “cost” as a significant barrier. This cost could be construed in terms of fee for service and indirect cost (i.e., loss of wages and travel costs). The researchers also found the demands on services, such as long and egregious wait times,

were a common and recurring system barrier that parents reported and, as we will see later in this report, a common theme among Californian family members.

Previous Research

Researchers analyzing CHIS data²⁹ analyzed over 80,000 responses representing 4 years’ worth of data and found that, when asked why they had not seen a mental health professional in the past year, 64% of respondents cited cost as the primary reason for not seeking help, followed by 47% who stated that they “did not feel comfortable talking with a health professional” or were concerned if “someone found out they had a problem.” Essentially, these two statements, taken together, that stigma was the primary reason 47% of respondents cited for not seeking treatment. Finally, 20% of respondents said they had difficulty getting an appointment.

Previous research that used CHIS data³⁰ found that insurance status was associated with “minimally adequate treatment” insofar as individuals without insurance and those with private insurance were less likely to have received MAT than those on public insurance. However, the researchers looked at data from 2007, before the ACA expansion had taken place which, with the rapid growth of Medi-Cal eligible adults in California, has significantly changed the availability of services.

A systematic review by Reardon and colleagues³¹ analyzed research regarding parents and family members of individuals with mental health conditions to understand their perceptions of the barriers to accessing psychological treatment for mental health problems. These researchers

The other primary cause for under-utilization of mental health services is stigma. Stigma is largely conceptualized in the academic world as public and self-stigma; public stigma being where individuals fear being identified by their community as someone who has a mental health condition; self-stigma refers to negative thoughts and views one has about themselves. Tellingly, the World Health Organization notes that “the single most important barrier to overcome in the community is the stigma and associated discrimination towards person suffering from mental and behavioral disorders.³² Furthermore, stigma is even prevalent amongst healthcare providers. For example, research would suggest that persons with SMI die, on average, 25 years younger than those without, in large part because of stigma from the self, the public, and even healthcare providers such as nurses and even psychiatrists.³³ In NAMI CA’s own research, testimonials of stigma and discrimination from medical and mental health professionals support these research findings.

NAMI CA Contributions to the Literature

NAMI CA’s own research into the barriers that contribute to mental health access mirror much of these findings with some key differences. For example, in our stakeholder surveys, 119 respondents ranked a set of potential barriers that impact their loved ones ability to access treatment. The primary barrier, according to our respondents, were a “lack

of available services”, followed by a virtual tie for 2nd place between “Stigma/Discrimination” and “Cost” of services.

This is supported by respondent testimonials as they cite long appointment times, sometimes of 6 months to find an appointment with a psychiatrist, amongst other systemic barriers. Despite the ACA expansion, and its mandatory mental health/substance use disorder provisions, many of the respondents in our sample report difficulties in finding therapists who accept Medi-Cal. This view is further supported by data from other reports. For example, a study by researchers at UC San Francisco³⁴ found that, in 2015, only 46% of psychiatrists accepted Medi-Cal patients and were also less likely to accept new Medi-Cal patients than other specialties. In comparison, the same study found that 77% of psychiatrists were likely to accept private health insurance.

“The inability of crossing services with other services sometimes can be limiting. For example, my daughter had one psychiatrist in one family center but there was another county service that provided many more classes, so I inquired whether my daughter could attend those classes. Was told that unless she dropped her counselor and enrolled into their program with their psychiatrist she could not. I think that all county programs should allow their mental health management classes to be open regardless of where the person gets his psychiatric care. My daughter is on Medi-cal.”

– Family Member from Riverside County

In our stakeholder survey, we posed the question “If you needed to, could you help schedule an appointment with a mental health professional (e.g., therapist, counselor, LMFT, LCSW, etc.) for your loved one within the month?” While the majority of respondents either answered “yes” (61%) or “N/A” (13%), 27% of respondents answered “No.” When asked to describe why they would be unable to help schedule an appointment within the month, some respondents indicated that there were not enough providers who accept Medi-cal (and the ones that do have exorbitant waitlists) those who

indicated they had private insurance also stated that there were not enough providers who accepted their private insurance and that they were encouraged to access services via the county (utilizing Medi-Cal services). Further research should be conducted to examine the relationship between Medi-Cal vs. private insurance providers for mental health services in California and its effect of service utilization.

“If you have private insurance you have limited resources, especially if involved in the criminal justice system.”

– Family Member from Shasta County

Findings from focus groups conducted by NAMI CA would suggest, despite legislation like AB 1424, participants mentioned that family members are kept out of opportunities to be in sessions. This is then combined with frequent changes in providers, leading to both peers and family members needing to build a new relationship with a provider from scratch. Many of the participants were well versed in HIPAA information confidentiality process and how to navigate having their loved one release that confidential info to them. Despite family member expertise in this process, communication between behavioral health staff and family members was still routinely cited as a substantial barrier to supporting a loved one, findings that are supported by our stakeholder survey assessments of family member involvement in treatment.

“Mental health professionals are often not open to suggestions or innovated approaches. The HIPAA laws prevent the family from giving timely, important information. There are also long waiting lists to even get the services available such as FSP, AOT, not enough programs in general to meet the demand.”

– Family Member from NAMI CA Focus Group

Nearly half of the participants from NAMI CA’s case studies expressed distrust of the providers treating their family

members with mental illness, with a particular concern that providers are not listening to families or spending enough time with the consumer before prescribing medications. They also felt obstructed by and frustrated with government bureaucracies and health systems. Self-care, particularly for family members with conservatorship of their loved ones, was reported as lacking and even non-existent. Challenges expressed by our participants include fear for their loved ones, shame, guilt, and grief over the life they had before their loved one's mental illness. Many participants said they had been ostracized by some friends and family members because of their loved one's illness.

“ I have been stigmatized by some mental health providers who resist hearing our observations and past experiences with our son. We know our son's psychotic symptoms and his medication history of what has and hasn't worked to reduce his psychotic symptoms. However, many doctors will not consider our knowledge and experience in making their treatment decisions. Many doctors will not communicate with us at all. ”

– Family member in Fresno County

“ Challenge one is the stigma surrounding mental illness. Denial is also a challenge surrounding mental illness. Another challenge is people do not know where to go for treatment. Money for treatment is also a challenging aspect. Medicine can be quite expensive. There is also a shortage of providers to treat mental illness. ”

– Asian American peer and family member in Santa Clara County

“ You know - nobody brings you chicken soup when your son has a psychotic break. ”

– Family Member from Focus Group



COMMUNITY RECOMMENDATIONS FOR TREATMENT

Research

As mentioned previously in this report, when family members receive clinical support, in the form of information about treatment and diagnoses, they are better able to support their loved one and, ultimately, influence better outcomes for those living with mental health conditions.³⁵ To that extent, one of the most well researched evidence-based practices for supporting family members involves psychoeducation. Family psychoeducation is a process of working with family members who are supporting a person

with mental illness with the aim of improving treatment outcomes by assisting those who are closest to the person to manage the issues that can arise or which may exacerbate the illness.³⁶

While psychoeducation typically seeks to partner with family members, their loved ones, and mental health professionals, it should not be confused with family therapy. In family therapy, the object of concern is the family unit (i.e., behavioral issues between children and parents,

communication problems between spouses, etc.) and the family unit is identified as the area that needs to be changed for a more effective and healthy relationship. Psychoeducation, on the other hand, aims to improve functioning and outcomes for those living with SMI by including and educating the family of those with SMI with the understanding the family unit is an important aspect of promoting wellness and recovery for those living with mental health conditions.

One of the primary methods that NAMI CA supports family members and the mental health community is through providing psychoeducational content to family members and peers through a variety of no-cost programs across the state. These include psychoeducational programs such as Family-to-Family and Peer-to-Peer which conform to the Substance Abuse and Mental Health Services Administrations 6 core principles of evidence-based family psychoeducation principles.³⁷

“ NAMI has been a great resource for support group, information, treatment options and not feeling alone in a difficult journey. ”

– Family Member from Contra Costa County

Researchers at the University of Maryland, Department of Psychiatry conducted one of the few studies into the effects of NAMI psychoeducational programs with families.³⁸ This study is significant because it relied on random assignment, a hallmark of scientific research wherein participants are randomly assigned to either a control or an experimental group. The researchers found that the family members who partook in the Family-to-Family course, compared to family members who were placed on a service waitlist,

had significantly greater improvements in problem-focused coping, empowerment, illness knowledge, and reduced distress.

Professor of Psychology Dr. Saki Cabrera tells the story of the special place in the family held by her



Dr. Saki Cabrera

late uncle with schizophrenia. His symptoms never struck her as strange because she always knew her uncle to be that way and they loved him for it, not just in spite of it. Saki says of the family-oriented Latino community, “we take care of our own.” This is why her mother took care of her uncle within the family rather than trying to get him admitted to a psychiatric facility. This perspective shows us how much of an important source of support family members can be and demonstrates alternatives to relying only on health systems for care.

Saki expressed that being able to share her story about her late uncle helped her feel like she was letting his legacy live on. Storytelling can be as therapeutic for the family member with lived experience as it traditionally is for peers.

NAMI CA Contribution to the Literature

The results of our stakeholder survey would suggest that family members of individuals with mental health conditions are well aware of the service capacity and utilization process with their local mental health providers. Furthermore, our research suggests that, in many cases, family members are as knowledgeable of their loved ones’ treatment barriers, staff issues, psychiatric needs, and other factors that contribute to the continuum of care for their relatives.

To begin, many family members express their support for NAMI CA psychoeducation programs. This occurs for a variety of reasons, in addition to the content of the programs. For example, survey respondents mention that support groups and educational programs are more accessible than typical mental health services and do not have similar barriers associated with long wait times or lack of personnel, despite the majority of NAMI programming facilitated by volunteers in locales and settings that are donated.

“ NAMI has helped the most of all private or public services. The classes were more informative and more interesting than the ones [our medical plan] offered. And the location was in my area (not 1-1/2 hours away). ”

– Family Member from Riverside County

One theme that emerged in our analysis of our survey data included the awareness of high staff turnover. Many family members in our survey note that the high staff turnover results in the inability for their loved ones to build trust with therapists and mental health professionals and that these staff shortages also contribute to long wait times for appointments and services. Also, many family members mention that no services exist specifically for them as family members and that rarely are they included in treatment aside from scheduling appointments or providing transportation.

Family members in both our focus groups and respondents to our stakeholder survey consistently reference difficulties in communicating with mental health professionals and hospitals. This is primarily due to HIPPA laws and regulations designed to protect patient privacy yet also result in treatment info being kept from family members and loved ones. While many family members are aware of how to go about procuring authorization for the release of protected health information under HIPPA, less family members are aware of other avenues to advocate on behalf of their loved one, such as psychiatric advanced directives or AB 1424. Future research will explore the experiences and beliefs that family members have about these programs and services in more depth.

Many of the respondents to our annual stakeholder survey mention the support they have received from family and peer support workers as being effective for their loved one. A common theme within our own research details that often times, the lack of psychiatric hospital beds and other inpatient mental health services combined with a shortage of psychiatric professionals, leaves many peers in need of mental health services, aside from prescription medications, for long period of time. Additionally, after episode of crisis, many family members report that there are not adequate plans in place for their loved on upon discharge, leaving their loved one to “fall through the cracks” and often revert back to crisis as they wait for appointments with psychiatrists that are upwards of 6 months out. Multiple family members report that when their loved ones work with peer support specialists, especially upon discharge from an involuntary hold, exhibit better functioning and are more likely to adhere to treatment during the interim wait to see a mental health professional for therapy. In a similar vein, many family members in our survey report simply not knowing what services exist or where to go, that complex bureaucratic rules effecting program eligibility often stymie

them, much less their loved ones who may be symptomatic. The inclusion of family navigators and other family support specialist would likely alleviate some of these additional barriers to service fidelity.

“Resources are extremely underfunded and difficult for the average person to find out about, to access and to understand. While components may be good, there is no coordination overall. There is no consistency in care, and the chance that an individual will fall through the cracks is very high. Long-term care is virtually non-existent, so for the chronically and severely ill, unless they have a one-on-one advocate for them, they will inevitably fall out of the system. This is very ineffective, not to mention cruel.”

– Family Member from Los Angeles County

Recommendations include setting healthy boundaries yet accepting the need to be flexible. Those who acted as caregiver to a family member with serious mental illness also described organizational tools, like a care binder with diagnoses, medications, and hospitalization history or a protocol in place to promote hygiene. Participants cite their own research and experiences as the major contributions for their ability to care for or support their loved ones. For those with a self-care plan in place, many suggested prayer, exercise, a support system, and involvement in mental health programs and advocacy. Almost all participants cited education as the most essential criteria to their ability to support and cope with their loved one.

Participants involved in NAMI attribute the majority of their knowledge and coping skills to NAMI programs. In fact, those involved with NAMI tended to express more confidence in their knowledge of mental health than those who are not. Many said they are involved in NAMI in part for their own self-care and as a support system of friends who understand when most others do not.



ROLE OF NAMI CA PROGRAMMING

NAMI's evidence-based and family-supported, education and training programs helped thousands of families through crisis for nearly 40 years in California. These programs have been utilized across the country and found to be highly effective, supported by both evaluative and anecdotal evidence. Families consistently expressed that the courses have been life-changing. NAMI CA is constantly responding to the needs of those we serve. Therefore, families participating in the following programs are asked to provide feedback through surveys and program evaluations.

“ *My level of knowledge about mental illness is very good thanks to NAMI classes and extensive reading, support groups, meetings, etc. Being educated has helped my family cope, communicate, and plan. It has caused me to become an advocate. People living with mental illness are among the most discriminated against, underserved, and misunderstood people in our community. We need every available voice to help improve their lives and speak with them and for them when they cannot.* ”

– Family member

NAMI CA in partnership with local affiliates and community-based organizations has continued their commitment and mission to serve families 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 important more than ever. That is why we continue to work with affiliates and organization to continue the offering of various programs such as Family to Family, Basics, Family supports groups and more which help with access to care.



Family Support Group Training

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 10 program trainings for family members, which in turn has trained over 100 teachers in different counties across the state that include: Kern county, Merced county, Sonoma county, Sacramento county, Solano county, Los Angeles county, and Riverside county.

Family to Family Program

NAMI Family-to-Family is a free, education program 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.

NAMI CA is constantly responding to the needs of the communities we serve. Therefore, 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** *“I’ve changed my mannerisms. I’m more mindful of my role in helping my sister.” —Family to Family participant*
- A** *“Being more compassionate towards my family member.” —Family to Family participant*
- A** *“I have better language to discuss mental illness and more confidence to advocate for my daughter.” —Family to Family participant*
- A** *“I thought I knew a lot about mental illness before my son was hospitalized but lived family experience brings a whole new level of contact with information and resources. It’s almost like you have to join the club before you really find out what’s up - and what is totally missing from our society - such as access to mental health professionals and groups of people who can help. The greatest amount of practical information I learned was from NAMI. For example the helpline folks let me know how there used to be a way to get someone to come to your home and do an assessment for people who won’t go in for care but that it had been defunded - and 3 years after my son’s first hospitalization it was funded again for a 2-3 year cycle, but it’s now gone again. Those who have been through the process had their hands on the pulse of local services - but no one outside that world hears enough about it - and it changes so often... I then took Family to Family. It provided a lot of information and personal support - but more importantly I felt like I could call anyone from my class - or drop in at any meeting and someone there could help me answer the most individualized of questions. The biggest outcome was that I felt empowered. I was told: ask and don’t take no for an answer - keep asking - don’t give up - you are the one who can make a difference in your loved ones recovery - and we have your back. I read a lot of research articles and try to share the info with my family, NAMI members, and my son. As soon as we completed Family to Family and were out of the first crisis, I started looking into volunteering at NAMI. I’m now on the Board. I have attended an advocacy workshop. I manage our FB page. I present at CIT. I focus on outreach and awareness. I try to get out information from the County, NAMI and police out to those who need it.” —Family member in Yolo County*

Family Support Groups

NAMI Support groups help families living with a loved one with a mental illness. Support groups bring families together and foster group discussion and interaction. Families are no longer isolated in supporting their loved one living with mental illness; they help one another through learned wisdom. Support groups offer a renewed

sense of hope for families who find strength in being part of a group with shared experiences. Guiding the format are four processes: The stages of Emotional Response, Guidelines, Principles of Support, and the Agenda, led by trained volunteer facilitators who are also family members of individuals living with mental health challenges.



Family Support Group Training 2018

“ I facilitate a Family Support Group once a month, and once a month I attend the group as a caregiver and a backup facilitator, so we can split the group if it gets too large. (The first year I found NAMI, I went to Family Support group twice a week except for the 12 weeks I spent taking F2F.) Since so many things about caregiving and having a mental illness are beyond my immediate control, I enjoy paying it forward by running my affiliate’s website and being an advocacy leader. **I have been able to strengthen and improve relationships with my loved ones based on skills taught in F2F and in learning the LEAP method.** I shepherded a reluctant family member into agreeing to apply to and get additional services from a regional center. I have been able to smooth the waters between family members who were repeatedly triggering each other. I have become more supportive and understanding in myriad ways. I have done my best to share these skills and my knowledge to my loved ones and others in their support networks. I have been able to persist when otherwise I would have had to give up. NAMI Family Support Group is in many ways the most valuable ongoing source. It is a continuous source of infinite knowledge about the trials and tribulations of mental illnesses.

My family’s experiences were enough to propel me into advocacy. Once I had begun to get the support I needed through NAMI, the more I had the time and the will to undertake advocacy.

The more I found out about mental illness, the more I saw what needed to be done. My affiliate had no advocacy program as such, so it was not until I began doing research online, that I began to see how many advocates there were out there and how much needs to be done. I began to see our problems weren’t just us or even mainly us, but the failure to have a robust system of access and supports in place. The connections and friendships I formed with advocates locally, regionally, and across the country became an extended part of my personal support network.

”
– Family member and peer in Los Angeles County



Basics Program Training 2018

Basics Program

NAMI Basics is a free education program for families with children and adolescents living with mental illness. The curriculum introduces the stages of emotional reactions of the family to mental illness from crisis to acceptance, offers insights to understand the lived experience of the child/teen, and includes current information on a variety of mental illnesses. It is covered in 6 classes, taught by trained teachers who are parents or caregivers with individuals who developed symptoms of mental illness before the age of 13.

Homefront Program

NAMI Homefront is a free, 6-session educational program for families, caregivers and friends of military service members and veterans with mental health conditions. Based on the nationally recognized NAMI Family-to-Family program, NAMI Homefront is designed to address the unique needs of family, caregivers and friends of those who have served or are currently serving our country. The program is taught by trained family members of service members/veterans living with mental health conditions.

A Riverside County graduate from the Homefront Teach Training program expressed the following:

As a 26-year retired Navy Senior Chief and a NAMI F2F Teacher, the NAMI Homefront Teacher Training was a blessing and a long time coming. I am delighted that I am now in a position to offer free educational classes to the families and loved ones of Veterans, faced with mental health challenges, in

an effort to educate and empower Veteran families and loved ones. I feel very much empowered as a result of this training and look forward to teaching the FIRST EVER NAMI Homefront course at the VA Ambulatory Care Center in Redlands CA. This will be a first in my county (Riverside) and neighboring San Bernardino County. The VA offers a whole host of options for mental health services for the Veterans but not so much for their families and loved ones. This course will serve to bridge that gap in service and I am proud of NAMI National and California for recognizing the need for NAMI Homefront and for their efforts in making this course possible in our communities.

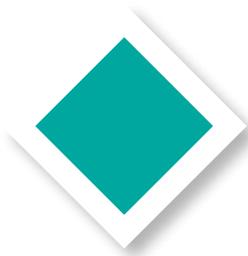
Mental Health 101 Program

NAMI CA also responds to the needs of cultures and communities to make sure we are reaching all families in need. The Mental Health 101 Program is devoted to giving individuals in marginalized communities an opportunity to learn about mental illness through an informative presentation, short video, and personal testimonies that represent a variety of cultural, beliefs, and values. The goal of Mental Health 101 is to create a multigeneration of culturally diverse individuals that can help address the stigma associated with mental illness through education, support and advocacy.

NAMI CA is constantly responding to the needs of our target population. 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 the MH101 presentations and answered the following question: “In your opinion, what was the strongest part of the presentation?”

“The real-life experiences shared. Makes it less stigmatized and more relatable. You feel better about your own situations after hearing other stories.”

– MH101 Participant



NAMI AFFILIATE HIGHLIGHT – FAMILY VOLUNTEER SUPPORT NETWORK OF NAMI CONTRA COSTA

The Family Volunteer Support Network of NAMI Contra Costa’s mission is to empower families through direct support before, during, and after times of mental health crises by discovering community, cultural, and family strengths and resources and advocating for those living with mental illness to gain access to them all. The network will function and offer support to Central, East, West and South sections of Contra Costa County. Local community-based organizations, parents, youth, leaders and coordinators came together for the kick-off event to celebrate the highly anticipated family support network and community resource.

towards helpful resources. The volunteers can provide services at all stages, whether individuals are in crisis or not.



The Family Volunteer Support Network Ribbon Cutting Ceremony (August 2018 in Concord, CA)



The Family Volunteer Support Network supporting Central, East West and South sections of Contra Costa County.

The Family Volunteer Support Network (*The Family Network*) is a group of trained volunteers who provide support to family members and loved ones of individuals experiencing mental health challenges.

The Network helps to navigate the complicated mental health care system and to overcome barriers to linkage of services by listening, educating, and then guiding families

The Todos a Santos Plaza location in Concord, CA will serve as the hub and training location for the Family Volunteer Support Network. The opportunity will expose individuals and family members to relevant trainings and resources. Support will touch the entire Contra Costa County. The Family Network will include family support groups, social events, and volunteer recognition. This is a brand new, MHSA-funded, program that adds to the 30-year legacy of NAMI Contra Costa’s work to raise awareness, educate, and advocate for mental health care services for consumers and their families. Being built from the ground up, this program will develop a volunteer base that will deliver essential services to families facing a variety of challenges common to emerging mental health care needs.

The community program planning process identifies current and ongoing mental health service needs. This process provides direction for MHSA funds to address expressed unmet needs. It also informs planning and evaluation efforts

that can influence how and where MHSA resources can be directed in the future.

For that reason, it is important to highlight and foster collaborations between County Behavioral Health and the community. Partnerships are imperative to effectively address the mental health needs of populations served. In Contra Costa County, the local NAMI Affiliate (*NAMI Contra Costa*) worked diligently to express family member concerns at various stakeholder meetings throughout a period of years. We would like to share this as a model to help address mental health needs while leveraging resources and available funds.



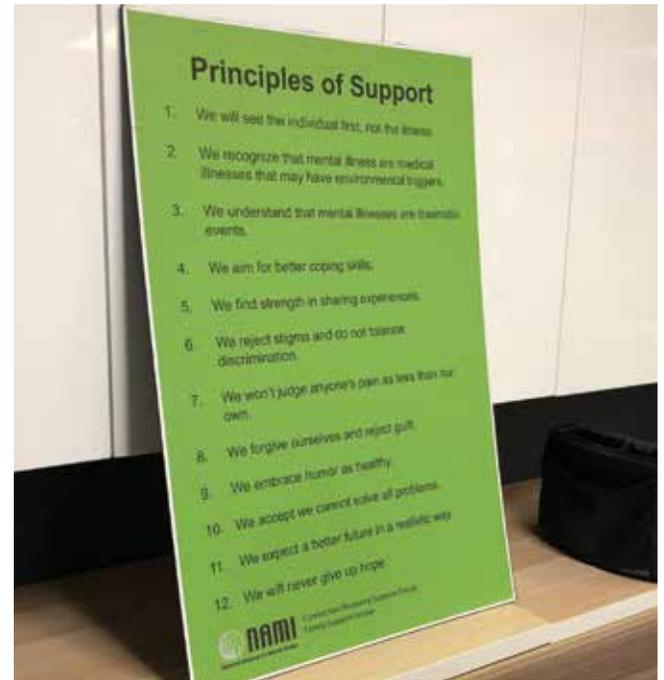
Warren Hayes, MHS Program Manager, Contra Costa Behavioral Health Services shares the vision and hopes behind the Family Volunteer Support Network.

As a result, the county prioritized family concerns regarding lack of mental health resources and supports. Through the community planning process, Contra Costa County Behavioral Health Department will fund and support a Family Volunteer Support Network in Contra Costa County. This is important to highlight given the need to strengthen interactions between county behavioral health staff and family members of individuals impacted by serious mental illness. We must continue to build relationships, and this is one huge resource that will provide pathways to services and supports. We must continue to collaborate and communicate to improve outcomes for all. If we are not sharing our experiences and working to improve the mental health care delivery system, then individuals are less likely to live a life of hope and recovery.

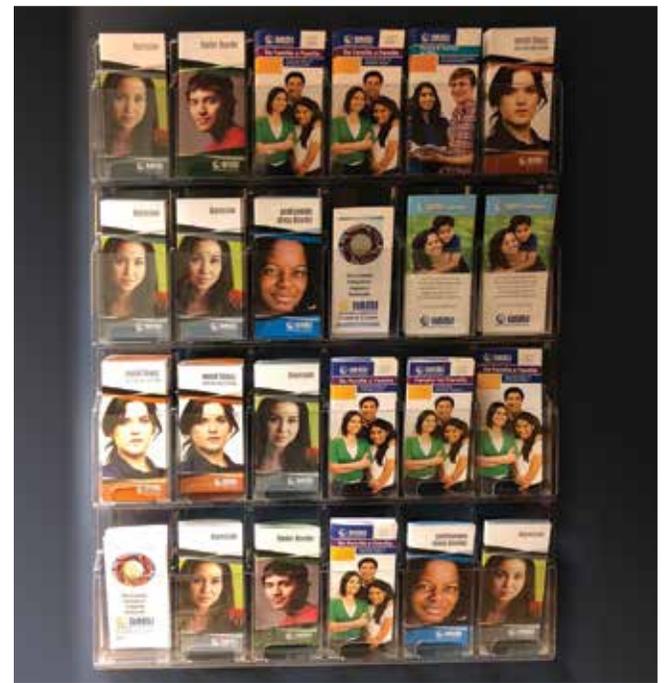
Services provided include:

- Teaching and promoting coping skills and self-care
- Providing support
- Assistance with finding the right services at the right time
 - o Culturally and linguistically appropriate services

- Assistance in navigating systems such as programs and insurance
- Educate and link to resources to address specific needs



Principles of support covered through the Connection Recovery Support Group-Family Support Group.



Within the space located in Concord, CA NAMI Contra Costa displays mental health resources and information.



STATE AND LOCAL ADVOCACY EFFORT

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 112 responses from membership, who listed the following five priority areas as most important: (1) access to treatment; (2) housing; (3) crisis services; (4) criminal justice; (5) family involvement in treatment. Many of the priority areas were reflected in both NAMI CA focus groups and regional meetings, as well as in state legislative efforts.

Advocates who attended the Regional Meeting in Kern County pose for a group photo (May 2018).

Advocacy Capacity

Through both focus groups and regional meetings, it became apparent that individuals around the state are hungry for training on how to advocate for themselves and others at both the local and state level. Over the course of three regional meetings in Contra Costa, Kern, and Santa Cruz Counties, 123 advocates were trained utilizing the NAMI Smarts for Advocacy curriculum.

NAMI Smarts for Advocacy is a hands-on advocacy training program that helps individuals and families transform their passion and lived experience into skillful grassroots advocacy. This curriculum is taught as a series of three 1-2 hour modules or as a single full-day training. Modules are designed to teach individuals how to: tell a compelling and inspiring story that makes an “ask” in 90 seconds; create an effective email, elevator speech, and phone call; and engage successfully in meetings with elected officials.

“ I learned anyone can be an advocate for mental health. ”

Regional Meeting attendee

The 123 individuals trained in NAMI Smarts were all trained by two trainers who, until July 2018, were the only individuals able to teach the curriculum across the state. Data from our post-presentation evaluations would suggest that, after completing the NAMI Smarts training, participants



Advocates who attended the Regional Meeting in Kern County pose for a group photo (May 2018).



Brenda Scott leads family members in a NAMI Smarts module.

express significant improvements in their knowledge and confidence to engage in advocacy related activities.

In July 2018, 30 advocates came together in Sacramento to be trained to teach the NAMI Smarts curriculum. In increasing our NAMI Smarts teacher roster from 2 to 32, we hope to drastically expand the number of advocates taught in 2018 and 2019, thereby bringing robust advocacy to all levels of the mental health decision-making process.



Newly trained NAMI Smarts Advocates representing 17 counties in California (July 2018).

Local Advocacy

As part of NAMI CA's effort to build local-level advocacy capacity, several NAMI local affiliates were funded to undertake a series of local advocacy activities, including building a local advocacy calendar, create a mental health resource guide for the community, engaging with key local decision-makers, and hosting collaboration meetings and

advocacy events with local decision-makers.

Some notable accomplishments that emerged from these partnerships include:

- NAMI El Dorado partnered with a local hospital, Barton Health, along with other community partners to develop a service guide with a variety of NAMI and non-NAMI behavioral health resources. In addition, NAMI El Dorado's warm line is on the inside cover. Thousands of these guides were produced and distributed across the county at various locations, including in fifteen mental health kiosks across the county.
- NAMI Long Beach engaged in a collaboration event with the Long Beach Unified School District Community Action Council (made up of Superintendents, Special Education Director and Special Education Administrators and Program Specialists and Special Ed Teachers and Parents of kids with special needs). At this event of 100 participants, two NAMI members shared their lived experiences and gave presentations on NAMI Programs and ways to engage. From this event, a collaborative relationship with the local Superintendent was formed around the development of NAMI On Campus High School Programs.
- NAMI Marin hosted a collaboration event with UC Berkley on the impacts of sleep on mental and emotional health.
- NAMI Sacramento conducted a variety of activities as described below:

Local Profile: Sacramento

Sacramento, like many large cities, is a magnet for people because of the services provided. Sacramento is one of the most diverse cities in California and serving the mental health needs of such a diverse community is no easy task. To meet the needs, NAMI Sacramento creates collaborations with service organizations to provide quality services. Always struggling with funding, NAMI Sacramento is trying to have a big impact with few resources.

As the state capitol, Sacramento attracts many passionate activists. NAMI Sacramento wants to tap in to that passion to better serve individuals and communities while assuring that all NAMI personnel and volunteers dealing with people with mental illness are qualified providers of NAMI services. The demand is high.

Currently, NAMI Sacramento is seeing a growth of peer support groups and an expansion of family support. A family support group has just begun in Mandarin.

On a daily basis, NAMI Sacramento hears from the community. The goal is to change the current intervention/support system from reactive to proactive. Recent national tragedies raised the awareness of suicide through celebrity social media. Unfortunately, two recent suicides of 16-year-olds in Sacramento occurred without any widespread or even local concern.

NAMI Sacramento is formulating public presentations focusing on suicide awareness with “survivors.” Some local college campuses will have these presentations during National Suicide Prevention Week in September. One role NAMI Sacramento has is to help individuals and the community deal with impact of trauma.

Recent volatile incidents in Sacramento, emphasize the need for positive interaction between law enforcement and the community. In order to reduce or eliminate trauma, NAMI Sacramento works to improve the current crisis intervention situation. To serve this variety of public needs, NAMI Sacramento maintains a strong presence in

crisis intervention training, working with local law enforcement and other stakeholders to build a robust CIT program.

Recently NAMI Sacramento has heard from high school students at a surprising rate. These students are asking for help in dealing with family members, siblings, parents, or friends with mental illness. NAMI programs are adult-focused and there is a growing need to address the concerns of the younger community members. Again, family inclusion and support are critical. NAMI Sacramento continues to grow and serve all communities and sees the unmet needs of other audiences.

Statewide Advocacy

In order to provide membership an opportunity to effect change at all levels of decision-making, NAMI CA hosts and participates in advocacy days at the capitol. In February, NAMI advocates joined with advocates from the Connection Coalition to meet with legislative offices on a variety of bills, including SB 1125 (discussed more below). These opportunities serve as a powerful way for individuals to contribute to the statewide narrative about mental health and ultimately help shape critical mental health policy.



Advocates pose with Assembly Member Heath Flora during a legislative advocacy meeting (May 2018).



ISSUES

Involuntary Treatment

California has a large population of vulnerable individuals living with a severe mental illness or substance use disorder who are unable to seek treatment or care for themselves. Many of these individuals are often homeless or living below the poverty line. In Los Angeles County alone, over 800 homeless individuals died on the street in 2017.

While the need to provide care is critical, the California Legislature has a long history of trying to find a balance between the safety of individuals who can't care for themselves and their civil rights and liberties. With this concern in mind, California has tried to pass new laws that respect this balance. This year,

California has tried to create more options to protect and treat individuals who are unable to care for themselves. These groups include individuals who are homeless, living with a severe mental illness, or a Substance Use Disorder. Prior to this year, California already enacted the Lanterman-Petris-Short act and Laura's Law, as a way of providing involuntary treatment to those in need. However, a large portion of the population is not considered eligible under these laws and fall through the cracks in terms of care and service.

AB 1971, a bill introduced by Assembly Member Santiago, creates a pilot program in Los Angeles County that expands the definition of "gravely disabled" under California law. Expanding this definition would allow the state to provide urgent medical care to individuals who are not able to seek it out themselves, due to mental illness. Additionally, SB 1045, a bill introduced by Senator Wiener, creates a new type of conservatorship focusing on individuals living with

a co-occurring condition of a serious mental illness and a substance use disorder.

NAMI CA has collected and sent support letters on behalf of our membership and the NAMI CA state office. Members of the advocacy department attended hearings and tracked the development of these bills paying close attention to issues of funding, capacity, and any discussions on how to best protect civil liberties.

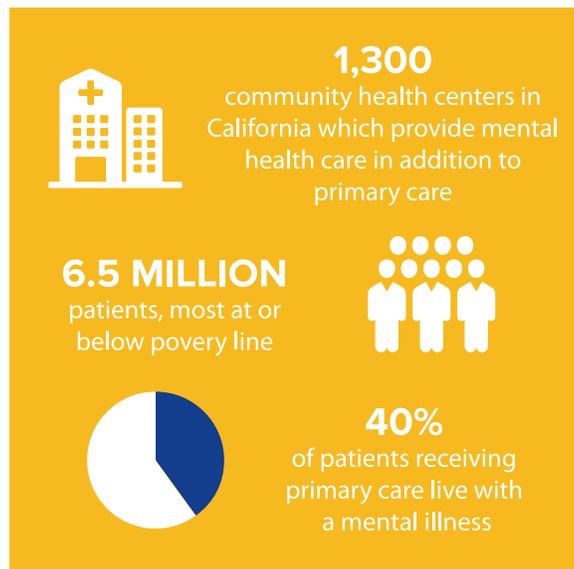
Expanding Access to Care

One of the most critical issues in advocating for improving mental health care is integrating access for underserved populations. There are 1300 community health centers in

California which provide mental health care in addition to primary care and other basic services. These centers provide services in more rural areas; it is estimated that these centers serve up to 6.5 million patients, most of them living at or below the poverty line. Research shows that up to 40% of patients receiving primary care live with a mental illness. Prior to 2017, community health centers would not provide insurance coverage for patients for two visits on the same day. Meaning that patients receiving primary care would have to come back a different day to receive mental health care. This

created an undue financial barrier for patients of community centers.

In response, the California Legislature created SB 1125, a bill that would allow same day visits for both primary care and mental health care to be covered by insurance. Approximately 20% of support letters received by NAMI CA were regarding SB 1125.





MOVING FORWARD FOR CALIFORNIAN FAMILIES

14 years after the passage of the Mental Health Services Act, substantial challenges still loom large for Californian families seeking mental health care. An aging psychiatric workforce, considerable growth of Medi-Cal beneficiaries due to the ACA expansion, and an aging group of family members who provide an incalculable amount of support to their loved ones. These challenges of the PMHS in California will also exist alongside and in tandem with challenges that will face all Californians, but those living with SPMI disproportionately, including the mounting state pension crisis, the search for affordable housing, the effects that climate change and overall aging workforce will place on the social service providers of the state.



Families Regional meeting in Santa Cruz, CA

Summary of research findings

The information gathering process conducted by NAMI CA led to a variety of suggestions and findings based on the many voices and perspectives represented by California's family members.

- Expanding access to intermediate services, programs, facilities that can provide necessary services (group counseling, psychiatric prescription refills/pickups, meetings/appointments that occur at non-regular business hours, expanding the opportunities for short term crisis and supportive housing, Peer support specialist services) that are necessary to “fill the gap” wherein peers wait to meet with mental health professionals
- Re-evaluation of the strategies and methods that include family members in the recovery plan for peers (i.e., trainings/presentations to mental health staff on the current research surrounding family involvement in recovery, specific messaging and targeting campaigns directed at family members to increase the awareness of family advocates programs and other means of family involvement in treatment, an analysis of potential policy changes directed at HIPPA privacy laws designed to make family member perspective easier to include
- Explore the expansion of Family Support Specialists for family members in order to:
 - Provide assistance to family members as they attempt to navigate and understand the variety of service providers, treatment options, share best practices for advocating for a loved one,
 - Provide info regarding the HIPPA privacy laws and how they effect being active in a loved ones treatment
 - Share knowledge about such programs as Psychiatric Advanced Directives and AB 1424 with family members

Plans for NAMI programs

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 family members and loved ones. In Year 2, one of our primary goals in Programming is to reach rural or underserved populations in the state of California and support them in the implementation of programs such as Family to Family classes, Family Support Groups, Basic Classes, Homefront, Mental Health 101, and more. To reach that goal, NAMI CA will be outreaching and partnering with NAMI Affiliates, community-based organizations 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 barriers to access, community recommendation for treatment, among others by engaging

with participants as they enter and leave classes and trainings. We hope to be able to expand the family voice 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 family members to share their stories and the impact that classes and trainings have had in their counties. Those unique needs are important for all organization, Mental health Departments, stakeholders and overall people that



MHSA Panel discussion with staff from the Kern County Behavioral Health Department.

serve families, 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 family members across the state.

Year 2 Research Avenues

In Year 2, through Program Trainings and Support, NAMI CA would like to capture the experiences after family members/ loved ones attend a Family Program 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 Sonoma County was supported by NAMI CA to provide a local training to train new Family Support Group Facilitators in the area during a time of budget deficits due to the wild fires that emerged in 2018. Due to this training,

there were free programs to support family members affected by the tragedy that came to their county. We hope to be able to understand further how other counties like Sonoma County require support during times where resources are limited and how to go about planning to be there for them and other organizations who serve families in the long term.

Advocacy Goals for Year 2

In Year 2, NAMI’s advocacy department will continue to build statewide advocacy capacity. We will host a NAMI Smarts teacher training in both Los Angeles and the northernmost counties of the state to increase the racial/ethnic and geographic diversity of our NAMI Smarts teachers. We will scale up and continue to support the number of NAMI Smarts classes being taught by our newly-trained teachers.

We hope to leverage this increased capacity of teachers and advocates to engage more robustly with the local planning process. Many decisions regarding how MHSA dollars are spent occur at the local level, decided by mental/ behavioral health boards and boards of supervisors. These entities have a built-in citizen feedback process. While this process has some guidance on structure, the process can vary significantly enough from county to county to make learning how to engage a barrier to participation.

A key piece of NAMI CA’s advocacy in the upcoming year will focus on developing a clear understanding of how the local advocacy process occurs and how local advocates can be most successful in that process. This is a large undertaking that will hopefully be supported by affiliates and local behavioral health departments.

This information, once gathered, will be used to provide information to affiliates on their local process for consumer and family member involvement; and create direct channels to behavioral health board meetings and other stakeholder opportunities after regional meetings and other trainings. Ideally, we’ll layer this effort over regional meetings and NAMI Smarts for Advocacy classes so that we can quickly move advocates from learning how to share their story to sharing their story with elected and local government officials. By connecting local advocates to the local decision-making process, we are working to ensure that all voices are involved in shaping our state’s mental health landscape.



CONCLUSION

As NAMI CA prepares for the next Annual State of the Community Report, we will continue to develop innovative approaches to solicit feedback from the thousands of family members who support their loved ones journey to recovery. NAMI CA would like to bring as many voices to the conversation as possible about providing the highest level of mental health care for Californian families and their loved ones. To that end, NAMI CA encourages all interested parties to contact our state office.

Throughout this report, NAMI CA makes reference to a variety of articles, internally conducted surveys, and a host of other sources. Furthermore, 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 hidden behind costs related to a lack of open access to research journals. To that extent, 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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