SUMMARY

NAMI California

National Alliance on Mental Illness

The ANNUAL STATE of the COMMUNITY REPORT on FAMILIES

"You are not alone"

Funded by MHSOAC Mental Health Services Oversight & Accountability Commission

FY 2017-2018

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 focused of mental health as a public policy issue. Through surveys, meetings, trainings and shared experiences family members play a vital mechanism in supporting loved ones living with serious mental illnesses. NAMI CA extends infinite gratitude to 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.

INTRODUCTION

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.

CALIFORNIA FAMILIES OVERVIEW

A study by the University of California at San Francisco found that one in six Californians were diagnosed with a mental health condition and 1 in 25 were diagnosed with a serious mental illness in 2014 (Coffman, Bates, Geyn, Spetz, 2018). These statistics are mirrored by other studies including the California Health Interview surveys, which report that about 1 in 12 Californians meet criteria for "mental health need" (Grant, Padilla-Frausto, Aydin, Streja, Aguilar-Gaxiola, Caldwell, 2011, & Tran, Ponce, 2016) and national data from the 2016 National Survey on Drug Use and Health found that in 2016, about 1 in 5 US adults met criteria for having any mental illness and that 1 in 24 US adults meet criteria for serious mental illness.

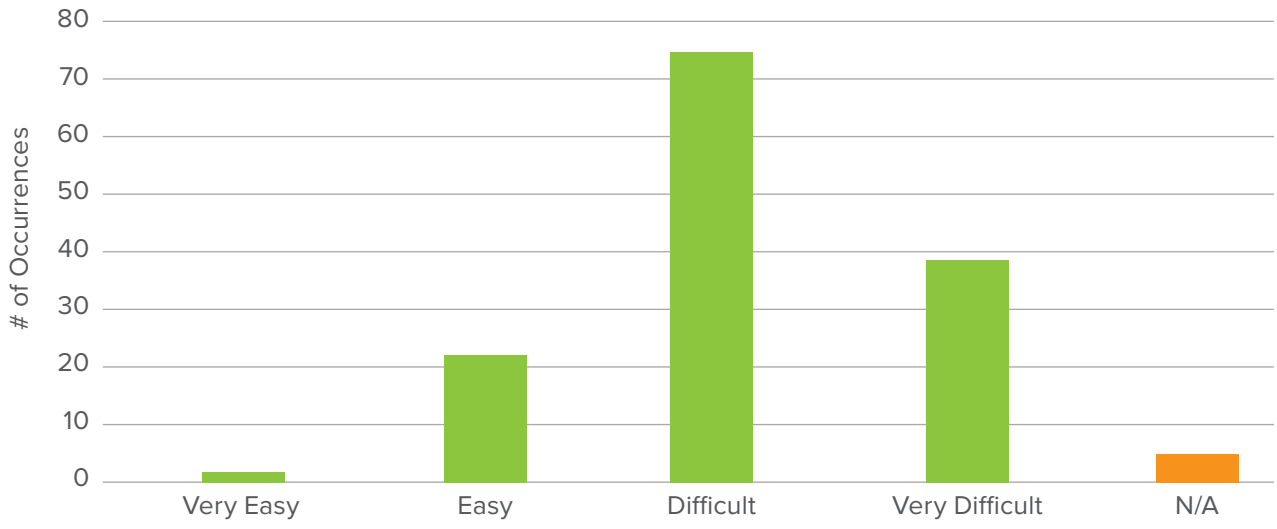
The expansion of Medi-Cal programs due to the Affordable Care Act have made mental health services available to many Californians. However, the rise in individuals available for Medi-Cal specialty mental health services has not experienced a similar growth in providers. In fact, the same study by Coffman and colleagues (2018) cited earlier in this summary, also would suggest that California's current behavioral health workforce are subject to a host of supply shortages for key behavioral health positions. For example, the researchers note 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 (Coffman, et al, 2018).

Based on our stakeholder surveys, case studies, interviews, and focus groups from Year 1, the data we collected from 34 California counties and over 150 survey respondents would suggest that:

- Family members do not perceive the PMHS to be easy to navigate and connect with services (Figure 1.1).
- Family members feel that their perspectives are not taken into account by behavioral health professionals (Figure 1.2).
- Family members are acutely aware of behavioral health staff shortages, turnover, and the lack of housing resources specific for those with mental health conditions.
- Housing is a particularly salient issue for family members, as supported by previous research as well as our own, which would suggest that family members in California bear a large burden of housing related expenses for their ill loved ones.
- Family members have an overall, neutral appraisal of county mental health crisis services. (Figure 1.3).

Figure 1.1

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, etc.



"Complicated system all services are not available in some areas, people with non-Medi-Cal insurance have difficulty accessing services."

— **Family member survey respondent**

"There is no map. I had to join NAMI to get information about what services are available and how to access those services. There is no follow up by county mental health and a gap between our psychiatric care facility and county services post release from treatment."

— **Family member survey respondent**

"Fragmented services, narrow scope so people with complex needs are shuffled from one clinic to another, multiple providers do not communicate with each other rather than having coordinated care in a single location. People are discharged from ER or PES in crisis with list of county providers/clinics and no effort to assist with scheduling/ coordinating follow-up care. This is a huge waste of money and resources as ER/PES remains a revolving door and individuals are labeled as "frequent flyers"

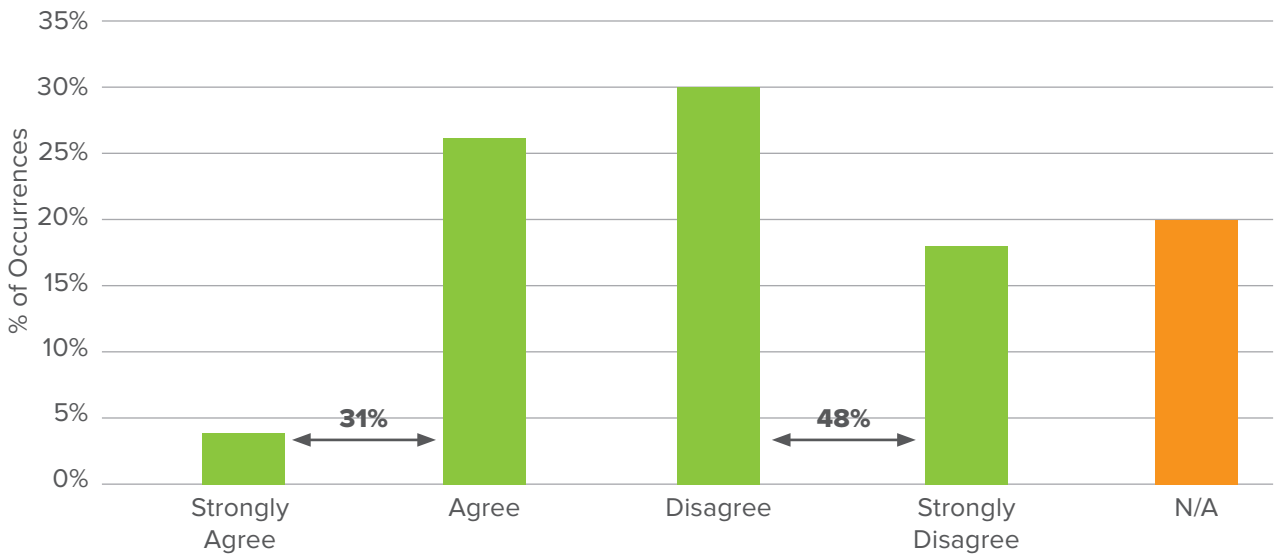
— **Family member survey respondent**

"Wait list for psychiatrist is 8 month and we have above the national average ratio psychiatrists. Even telepsych has multi month wait lists. Terrible transition process from in patient psych to after care from hospitals and jails. This is the greatest area of opportunity for improvement. H&HS or MH professionals need role in that process."

— **Family member survey respondent**

Figure 1.2

Please rate your agreement with the following statement:"My county's behavioral health department utilizes 'Family member voice' in service delivery or outreach initiatives." (N = 139)



"County H&HS only treats SMI and turns those with SMI away when they also have a TBI or serious neurological disorder...they are known for "picking and choosing" their clientele. Families have had to fight to get their loved ones treatment - this is particularly true in South Lake Tahoe where the manager frequently turns away those that would otherwise be accepted by other counties. Long waits for appointments; and long-waits specifically for psychiatrists along with insufficient level of family involvement welcome."

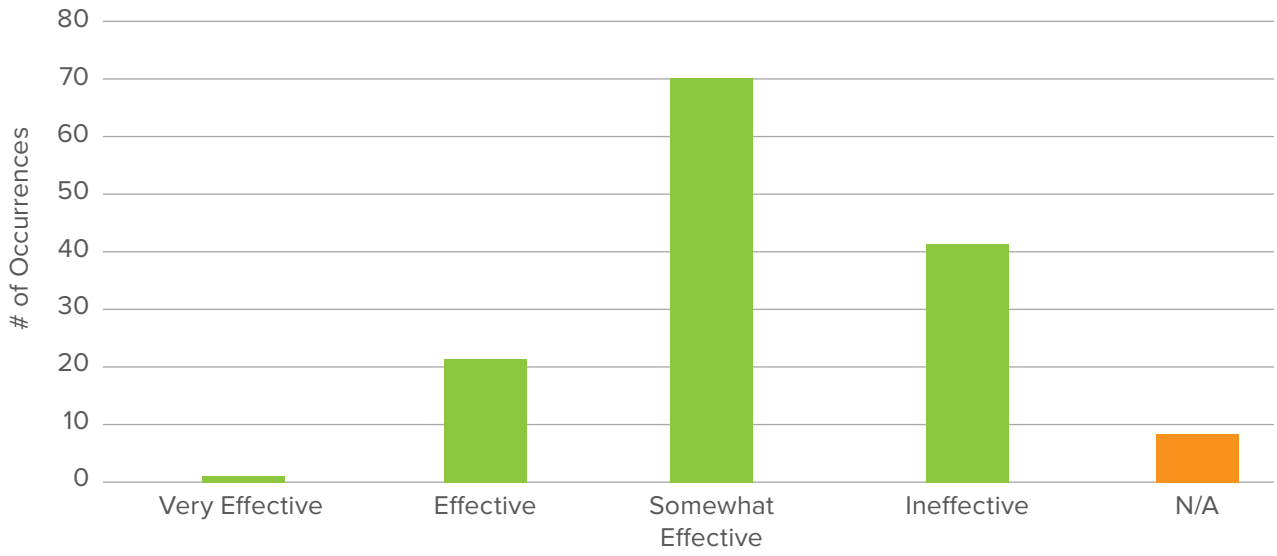
— **Family member survey respondent**

"I can accept having a son with a serious disability. But to add insult to injury, I do not find the mental health care system to be sympathetic to what family members go through. In many cases, the mental health providers, government bureaucracies and insurance companies obstruct the vital information, participation and assistance that family members could provide if they were only allowed to be more a part of the recovery model and mental health team. Being disappointed by the mental health care system has been almost more upsetting than my son's diagnosis. As one example, three years ago he was accepted into the TAY-FSP program (Transitional Age Youth-Full Service Partnership), which is partly funded by MHSA. The FSP motto is "whatever it takes" which implies they are there to help the most difficult and needy clients. Meanwhile, they dropped my son as a client exactly two years ago, right when my son became homeless and the most vulnerable he had ever been."

— **Excerpt from Family member interview**

Figure 1.3

How would you rate the effectiveness of your county's crisis response services for mental health emergencies? (N = 140)



"*Crisis intervention is overwhelmed. I've had to call law-enforcement for mental health issues with unfortunate consequences for my loved one"*

— **Family member survey respondent**

"Often the crisis team cannot find appropriate placements so they allow folk to go home once the individual is tired. Intakes are hard to access."

— **Family member survey respondent**

"Police have traumatized my son- he no longer trusts them. They have been very abusive, not giving him time to respond, knocking him to the ground and threatening him. They even [tazered] him on one occasion because he wouldn't get on the ground. Police yell and demand, they should be trained to work with the mentally ill in their community, not assume MI are dangerous."

— **Family member survey respondent**

"Improving but again looks better on paper than in real life. PMRT teams are only available for limited evening hours and not at all for late night early morning. PMRT response times are calculated from time dispatched, but the reality is that the request for PMRT may have originated many hours or even a day or more before. Who to call, when to call, and what to ask for is a mystery for most clients and family members. Police agency responses are improving with training, but are still inadequate with most officers still waiting to receiving the full training."

— **Family member survey respondent**

RECOMMENDATIONS

The stakeholder surveys, focus groups, case studies, and interviews collected by NAMI CA as part of the Annual State of the Community report allowed NAMI CA to understand the unique challenges and barriers effecting the family member of individuals with MH conditions in California. This data and research also yielded a number of potential avenues that state and local policy makers can explore in efforts to provide better MH care and support those who utilize the Public Mental Health System.

Expand Peer Support capacity in the state California

- NAMI CA recommends that specific focus be given to promoting Family Support Specialists to assist family members with effective approaches to advocate and care appropriately for their loved ones.
- The expansion of the Peer support services can also enable those who live with MH conditions, oftentimes individuals who have little to no employment history and experience systematic wage depression (Kessler, et al. 2008), are beneficial in supporting Peers to achieve success in line with the Recovery model and its values by empowering Peers to develop goals, skills, and an income.
- Peer support professionals can provide important and necessary services in between crisis episodes or therapeutic visits. Family members we heard from cited long wait times between appointments, when looking for new providers, and upon step-down from locked facility or involuntary holds. Peer and family support professionals can provide the necessary transition services in interim wait for licensed or specialized MH care.
    i. As noted earlier in this report, and by many other agencies, California is experiencing a shortage of certain MH professionals. In comparison, a report by Resource Development Associates in partnership with the Office of Statewide Health Planning and Development (2017) found that non-prescribing, non-licensed MH professionals (i.e., case workers, non-licensed counselors), the category that Peer support professionals would fall under, are the fastest growing provider type in California based on data from 2010 tracked through 2015.
    ii. It is well within the capacity of the State of CA to expand Peer Support services as an immediate, cost effective solution to access and step-down care deficiencies while long-term solutions are developed for workforce supply issues pertaining to other MH specialties.

Housing

- Due to a variety of external factors influencing California's housing market and housing affordability, the intersecting identity of being an individual with a MH condition creates unique barriers to finding secure housing for Peers and presents as a specific issue for family members who worry for their loved ones housing status.
- While ballot initiatives, such as Proposition 2, are useful in fueling programs and services that provide secure housing for those living with serious mental illness this will likely not detract from
    i. The majority of individuals with a debilitating and serious MH condition will likely still depend on their loved one for housing assistance and support and;
    ii. Other systemic barriers, most notably NIMBY-ism, are issues that exist at local and municipal levels and can be difficult to "legislate" away.
        - These systemic local issues can be addressed by empowering family members and peers to participate in the local community planning process involving MHSA funds and programming.

We also need to support stakeholders with opportunities and resources to advocate at city council and Board of Supervisor meetings.

a. Certain community-based organizations, such as NAMI CA, already focus on training peers and family members in influencing legislative processes. The State of California or MHSOAC can further support these organizations to train family members and peers in local advocacy and community planning participation, which in turn can lead to the expansion of housing facilities for those with MH conditions at local levels across the state.

- NAMI CA would suggest further exploration into what targeted programs (i.e., financial assistance, educational assistance, service-linkage, etc.) most positively impact family members who provide housing assistance to their loved one.

Crisis Intervention Services

- As figure 1.3 demonstrated earlier, our research findings would suggest that family members largely view their local county services as only moderately effective.
- Increasingly, local police forces and sheriffs are interacting with individuals who have MH conditions.

i. Crisis Intervention Training may similarly reduce negative interactions between law enforcement and individuals experiencing a MH crisis. This results in safer outcomes for individuals with MH conditions and increases the likelihood that individuals with MH conditions are more likely to be diverted to MH programs opposed to jails.

Expand Psychoeducational Programming

- Family psychoeducation is an evidence based practice endorsed by SAMHSA (2009) that shows strong program validity across multiple MH diagnoses, domains, and group composition settings. For further reading, please refer to Dixon and colleagues (2001).
- By expanding community resources and CBOs that provide psychoeducational programs and services to Peers and family members. The increased access to educational programming, social groups and networks, and training can be beneficial for participant mental health, coping, and outlook.

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To view the full Annual State of the Community Report from Year 1 please visit:

https://namica.org/wp-content/uploads/2018/11/2018-AnnualStateofCommunityReport_Families-compressed.pdf

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