The ANNUAL STATE of the COMMUNITIES REPORT with FAMILIES

“You are not alone”

Year Two 18-19
# TABLE OF CONTENTS

Acknowledgements ........................................................................................................... 3  
Preface ................................................................................................................................ 4  
Methodology ....................................................................................................................... 4  
NAMI CA Findings .............................................................................................................. 5  
Family Member Contribution to Mental Health Treatment ............................................... 7  
Family Member Experiences ............................................................................................... 7  
Difficulty Working with School System ............................................................................ 7  
Lack of Education for Families ........................................................................................... 7  
Lack of Prevention and Early Intervention (PEI) ................................................................. 7  
Interventions & Treatment Modalities .............................................................................. 8  
  Collaborative Care & Peer Support ................................................................................. 8  
  NAMI CA Findings ........................................................................................................... 8  
Role of NAMI CA Programming & Advocacy Efforts ......................................................... 9  
Family-Informed Recommendations ................................................................................... 9  
  Access to Treatment .......................................................................................................... 9  
  Housing .............................................................................................................................. 9  
  Crisis Services ................................................................................................................... 10  
  Criminal Justice and Forensic Issues .............................................................................. 10  
  Family Involvement in Treatment .................................................................................. 11  
  Complete and Comprehensive Services for All Ages ..................................................... 11  
End Notes ............................................................................................................................. 12
NAMI California (NAMI CA) appreciates the tremendous commitment and compassion from family members leading groups, teaching classes and sharing experiences of family members and loved ones throughout the state. By utilizing and empowering the family members and loved ones that support individuals living with mental illness each step of the way, we can create better mental health outcomes for all. Community leaders impact lives through shared dialogue, education, and advocacy with the shared focus of mental health as a public policy issue. Through evaluations, surveys, meetings, trainings and shared experiences, family members play a vital mechanism in supporting loved ones living with serious mental illnesses. NAMI CA extends infinite gratitude to families of individuals with lived experience throughout the state; this report is not possible without your collaboration, honesty, and involvement in this cause. We would also like to thank Proposition 63 Mental Health Services Act and 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. These funds 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.
The family unit currently acts as one of the most important agents for providing psychosocial support for individuals with mental health conditions. Research would also suggest that patient outcomes improve when family members are provided with the information, clinical guidance, and support they request.\(^1\) Through NAMI CA focus groups, families have continued to take part in as much of their loved one’s treatment as they can. Families fill in the blanks for providers, they provide physical, financial, and emotional support for their loved ones with serious mental illness.

In Year 1 of the three-year project funded by MHSA, it was found that despite the increase in covered services by the Affordable Care Act, the number of available providers did not increase enough to make the new coverage very effective, rather, it caused longer wait times, overburdened systems, and lack of job growth in the field of psychiatry. In fact, a study by Coffman and associates\(^2\) found that by 2028, the current pool of mental health providers would decrease by 34%; California (CA) will have 50% fewer psychiatrists and 28% less psychologists than will be needed.
Similar to Year 1, NAMI CA conducted a variety of information gathering processes in Year 2, to gather information on the experiences and needs of consumers and family members navigating the public mental health system. NAMI CA used a variety of data collection processes such as communications with the Advisory Committee, qualitative interviews, case studies, focus groups, and community gathering sessions. In addition, we collected feedback and evaluation responses from various family members throughout the state who participated in advocacy events, programs, and trainings. NAMI CA administered a statewide survey among public mental health providers and the NAMI CA network (members, affiliates, partner organizations) seeking to understand the experiences of family members navigating the public mental health system. NAMI CA collected responses from 259 individuals who identify as family members or loved ones of individuals living with mental illness from May 2019 through July 2019. Individuals from 40 of CA’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.

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

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

**Family Member Contribution to Mental Health Support**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Disagree/Strongly Disagree</th>
<th>Agree/Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I provide support for my loved one’s most basic needs, including housing, appointment scheduling, social support, etc</td>
<td>8%</td>
<td>92%</td>
</tr>
<tr>
<td>My loved one’s mental health care professionals often seek my input and advice regarding my loved one’s wellness and recovery.</td>
<td>14%</td>
<td>86%</td>
</tr>
<tr>
<td>I feel that the mental health team that works with my loved one is approachable and that they try to inform me of my loved one’s recovery as much as possible and as much as they are legally allowed to share.</td>
<td>7%</td>
<td>93%</td>
</tr>
<tr>
<td>I feel informed and knowledgeable about my loved one’s treatment plan, schedule, provider network, and wellness goals.</td>
<td>10%</td>
<td>90%</td>
</tr>
</tbody>
</table>

Figure 1
If you needed to, could you schedule an appointment with a medical health professional (e.g. therapist, counselor, LMFT, LCSW, etc.), for yourself or a loved one, within the month?

![Figure 2]

Access to Services

- Primary mental health services (i.e., therapy sessions with licensed mental health professionals, enrollment in outpatient facilities, availability of psychiatric services, etc) in my county are convenient to access and easy to enroll in.

- My county's crisis services are responsive and effective.

- Myself or my loved one utilizes Peer or Family Support services (i.e., non-clinical peer support specialist group meetings, Family Advocate services, etc.)

![Figure 3]
Family Member Contribution to Mental Health Treatment

Based on survey results, NAMI CA found that there is a high number of family members providing care for their loved one. In fact, 94% of respondents identified as a family member or loved one of someone with a mental health condition; 71% of respondents indicated that they provide their loved ones with their most basic needs, including housing, appointment scheduling, and social support. Despite the large number of respondents that are primary caregivers for their loved one, the majority of them feel that service providers do not seek input from caregivers, do not include them in treatment planning, and do not feel the mental health professionals are approachable (Figure 1).

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

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

– Family Member, Monterey, CA

Data collected from stakeholders indicates that just over half of the respondents would be able to schedule an appointment with a mental health professional within 30 days (Figure 2). In addition to scheduling appointments, other barriers to accessing care included transportation issues, stigma and/or discrimination from care providers and family members, access to childcare to go to the appointments, lack of time, cost, and lack of insurance.

Family Member Experiences

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

Difficulty Working with School System

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

– Family Member, Focus Group

Lack of Education for Families

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

– Family Member, Rural Area

Lack of Prevention and Early Intervention (PEI)

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

– Family Member, Orange County Focus Group
INTERVENTIONS & TREATMENT MODALITIES

Collaborative Care & Peer Support

While collaborative care may seem like common sense to most, the reality is that there isn’t always collaboration between providers when it comes to mental healthcare. The mental health team should consist of mental health coordinators (MHCs), family physicians, and psychiatrists. In addition, all primary care team members can be involved, including nurses, nurse practitioners, dietitians, and auxiliary staff. In most cases, primary care physicians are not in contact with their patient’s mental health team or any other providers they may be working with.³

NAMI California’s data indicates that there is very little collaboration, despite the overwhelming evidence of its efficacy. With dwindling access to mental health services, the field is relying more on the work of Peer Support Specialists, to help lessen the gap, to triage, and get more people immediate services. As previously discussed in the definitions section, peer support is a recovery-oriented treatment model in which individuals provide mental health services in a clinical setting who have received formal peer support provider training and/or certification; as well as having their own lived experience and recovery of a mental health condition.⁴

NAMI CA Findings

Our findings suggest that families respond well and feel more respected and integrated with the help of peer support style programs and trainings for them in their roles as family members. Additionally, there is a clear desire from our participants to have coordinated and holistic teams assisting individuals with mental illness and them as a family unit. This includes the teams outlines above.

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

“There are typically 7-16 people. We talk about finding services but also talk about the more emotional things”
– Family Support Group Facilitator NAMI El Dorado County

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

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

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

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

NAMI considers Family to include friends, teachers, neighbors, coworkers and others in the community. Even if the “family member” isn’t completely involved in the care of the person struggling they can still benefit from outside support. The interest in NAMI Family Programs primarily arises from families who reach out to their local NAMI affiliate for support. It often happens when the family doesn’t know where else to turn for help. The local Affiliate connects individuals to the NAMI Family classes and Support Groups that are being offered in their area. The NAMI CA state office attempts to supports families in numerous ways (Figure 4).

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

FAMILY-INFORMED RECOMMENDATIONS

Access to Treatment

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

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

Housing

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

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

Crisis Services

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

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

Criminal Justice and Forensic Issues

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

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

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

- Promote a client- and family-centered approach that gives the consumer encouragement to participate fully in planning, monitoring, and evaluating treatment; and gives the family the information, skills, and support to make informed decisions as equal partners in treatment (provided the consumer wants his or her family to be engaged in the process).

- Ensure that families of children living with serious mental illness can easily access mental health and related services for their child without being required to navigate multiple, complex, and overly bureaucratic systems.

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

– Family Member, Orange County

Complete and Comprehensive Services for All Ages

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

- Promote policies that help identify mental health issues in children, intervene with clinically approved services, and prevent mental illness from going undiagnosed.

- Ensure that schools provide and sustain key mental health services, supports, and appropriate accommodations. Encourage schools to maintain close connections with community mental health and primary health care systems.

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


