NAMI
National Alliance on Mental Illness
California

The ANNUAL STATE of the COMMUNITIES REPORT with FAMILIES

"You are not alone"

Funded by
MHSOAC
Mental Health Services
Oversight & Accountability Commission

Year Three 19-20

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INTRODUCTION & OVERVIEW

ACKNOWLEDGMENTS

NAMI California (NAMI CA) expresses gratitude to the individuals and family members who graciously shared their knowledge, experience, and voice as part of this project. This work would not be possible without the dedication and passion of those across the state who participated in all aspects of this project to support the efforts of NAMI CA in the development of this report including the multi-disciplinary coalition that is the Family Advisory Committee, our many state and local partners, and the leadership of the local NAMI affiliates across California.

This report is the result of a strong collective state and local effort. Special acknowledgements are given to the NAMI CA Board as well as NAMI CA CEO, Jessica Cruz, for her support and expertise in this field. NAMI CA thank the many state and local leaders who supported this project, most notably the Mental Health Services Oversight and Accountability Commission as funders for this work. Thank you to the NAMI CA staff, specifically to Sofia Amezcua, Ragini Lal, Tory Martinez, and Brianna Vargas for their significant contributions to this report. This project is dedicated to the individuals and families across the state struggling with mental health and mental illness. Through continued advocacy and support, it is the hope that this ongoing work will reduce the stigma of mental illness and bring healing to all families and communities.

ABOUT NAMI CALIFORNIA

NAMI CA is a grassroots organization of families and individuals whose lives have been affected by serious mental illness. Founded in 1977, NAMI CA started as a small group of parents that turned into a national movement to inform and educate the country about mental illness and advocate for the rights and care of mentally ill family members. It is an organization that has changed the way we think about, treat and care for mental illness as the leading organization of individuals working with mutual respect to provide help, hope and health for those affected by serious mental illness.

NAMI CA has 56 local affiliates and represents 19,000 people to the California Legislature and Governor on issues of mental health and mental illness. NAMI California educates families, individuals, decision makers, professionals, and the public about the needs of communities to increase access to appropriate services and supports, resources, and education in order to create acceptance, awareness, and eradicate stigma.

In 2017, NAMI CA was awarded a contract through the Mental Health Services Oversight and Accountability Commission (MHSOAC) using funds provided by Proposition 63, or the Mental Health Services Act (MHSA). The Act establishes a one percent (1%) tax on personal income in excess of one million dollars to support and encourage system-wide change in California's public community mental health system that would foster a positive impact on the state's prevention of and response to mental illness. As part of that effort, NAMI CA was selected to enhance the participation, voice, and empowerment of family members and individuals through advocacy, education, and outreach efforts at the state and local level by ensuring that family members have a major role in the development and implementation of mental health policies and programs, as well as access to quality services and supports.

As part of this funding, NAMI CA has compiled this report to outlines the significant efforts to engage with families and individuals across the state to explore and support the needs of the many diverse communities across the state with the goal of improving services and supports for all.

NAMI California Board of Directors

NAMI California Leadership

- Jessica Cruz, MPA/HS, Chief Executive Officer
- Steven Kite, Chief Operating Officer
- Kris Amezcua, Vice President of Operations
- Angela Brand, Vice President of Strategic Engagement

ABOUT NAMI CA'S WORK

Programs

NAMI CA supports an array of state and local program trainings to supports individuals and family members in a wide variety of community settings, from churches to schools to NAMI Affiliates. With the unique understanding of people with lived experience, these programs and support groups provide outstanding free education, skills training and support. Classes and groups are offered and facilitated by trained NAMI leaders and provide invaluable support to families and individuals. Offerings include:

- NAMI Family-to-Family is a class for families, significant others, and friends of people with mental health conditions. Designated as an evidence-based program by SAMHSA, it facilitates a better understanding of mental health conditions, increases coping skills, and empowers participants to become advocates for their family members. Also available in Spanish, De Familia a Familia de NAMI.
- NAMI Peer-to-Peer is a class for adults with mental health conditions. The course is designed to encourage growth, healing, and recovery among participants. This program is also available in Spanish, De Persona a Persona de NAMI.
- Mental Health 101 (MH101) is a NAMI CA program devoted to giving individuals an opportunity to learn about mental illness through an informative presentation, short video, and personal testimonies that represent a variety of cultures, beliefs, and values. All presenters must have lived experience as peers or family member/caregivers. The goal of this program is to create a multi-generation of culturally diverse individuals that can help address the stigma associated with mental illness through education, support, and advocacy.
- NAMI Connection is a support group for people with mental health conditions. Groups meet weekly, every other week or monthly, depending on location. This program is also available in Spanish, NAMI Conexión.
- NAMI Family Support Group is a support group for family members, significant others, and friends of people with mental health conditions. Groups meet weekly, every other week or monthly, depending on location.
- The Family/Peer Support Specialist (FPSS) Webinar Training Program is devoted to providing individuals who have lived experience with a mental health condition (as a peer, family member, or sometimes both) a pathway to employment/volunteer work within the behavioral health field.
- NAMI Homefront is a 6-session educational program for families, caregivers, friends, and other loved ones of military service members and veterans with mental health conditions. It is modeled after the NAMI Family to Family course but is designed to address the unique needs and culture of this group of individuals.

NAMI CA social media post for 2020 U.S. Veterans Day

Advocacy

NAMI CA leads a robust effort to support advocacy on behalf of individuals and at the state, local and national levels to fight stigma, provide support, educate the public, and advocate for better mental care and services for all. NAMI CA works with affiliates to engage with local mental health departments, boards, and commissions to support and ensure family members are included in the development of local program planning. At the state level, NAMI CA works with legislative staff and agencies to address relevant policy issues and educate policymakers about the needs of families and individuals. NAMI CA engages communities through several activities including:

- NAMI Smarts for Advocacy Training
- MH101 for Policymakers
- Capitol Advocacy Day
- Regional Advocacy Meetings
- Community Collaboration Meetings

Team NAMI CA #votes4mentalhealth

Community Engagement

NAMI CA works across the state to engage communities, families, and individuals across the state to create awareness of mental health and mental illness. Events and activities bring together community members and other local leaders working to improve mental health care and services in California to reduce stigma among underserved communities and to increase reach into multicultural populations. Through partnerships with local affiliates and community partners, NAMI CA elevates the voice and engagement of families and provides education and awareness about the issues that impact families and communities. Activities include:

- Surveys
- Focus Groups and Community Listening Sessions
- Communications and Materials Development
- Town Halls
- Multicultural Symposium
- Youth Symposium

ABOUT THIS PROJECT

This project funded by the Mental Health Services Oversight and Accountability Commission as part of their work to support and participation of individuals and family members in the mental health system. Through these funds, NAMI CA worked closely with community members to better understand the challenges and barriers faced by individuals and their families when accessing and receiving services as well as how family members fit into the process of treatment, care, and support for individuals living with mental illness.

Year One Overview: Accessing the Mental Health Care System

Feedback gathered in Year One indicated 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. As noted in the Year One Annual State of the Community Report by NAMI CA [1]a study by Coffman and Associates 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. Concern for the impact on individuals and families, activities focused on inclusion of family members and individuals as part of the treatment plan as family members are a valuable source of information as the persons who are caring for individuals with mental illness; their insight into needs and possible solution is a key component for devising new strategies to supporting and expanding the mental health workforce. As a result, NAMI CA was able to use this feedback in their continued support and advocacy for peer certification in California, a reality achieved in 2020.

Further, many community members reported difficulties in scheduling appointments, gaining access to referral services, and following up with the County Behavioral Health Department for mental health services in the county. One participant shared:

"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 the ER or PES in crisis with list of county providers/clinics and no effort to aid with scheduling/ coordinating follow-up care. This is a huge waste of money and resources and ER/PES stays a revolving door and individuals are labeled as "frequent flyers."

- Family Member Survey Respondent.

Participants also reported difficulties with helping their loved one get the care need and the disconnect experienced with engagement with behavioral health department many sharing that family members are rarely involved in service delivery or outreach initiatives.

"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

Year Two: Accessing Barriers in Access to Treatment, Supports, and Services

Through ongoing community engagement efforts across the state, NAMI CA was able to explore the barriers and challenges faced by individuals and their families in accessing services. Building on the information gathered in the first year regarding network adequacy, discussion was focused on the additional factors that would impact an individual's ability and experience when seeking and receiving services. NAMI CA gathered feedback and recommendations to better understand individual and community perspectives on the mental health system, primary access points, and needed supports for family members when navigating the system and advocating for their loved ones.

NAMI CA also found that there are a significant number of family members caring for their loved one. Despite providing their loved ones with their most basic needs, including housing, appointment scheduling and social support, many reporting that service providers do not seek input from them as caregivers, do not include them in treatment planning, and do not feel the mental health professionals are approachable. This is especially frustrating to families when they act as their advocates and support in all scopes including financial, emotional, and physical.

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

–Family Member; Hemet, CA

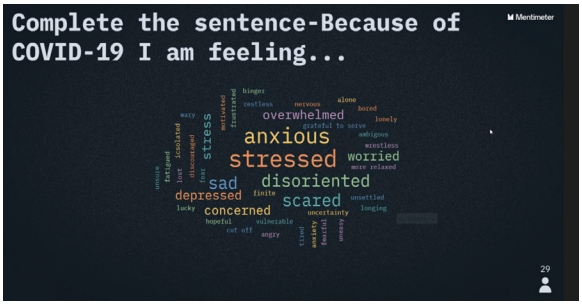
Using this information, NAMI CA was able to work with local affiliates to increase access to additional local classes and support groups for families and individuals. Additionally, NAMI CA was able to identify opportunities for more focused advocacy training in communities and counties to better support families in navigating the system and advocate for a key role in the planning of their loved one's treatment.

Year Three: Factors Impacting Access to Appropriate Services and Supports

NAMI CA focused final efforts on engaging communities across the state about issues related to the availability and efficacy of services and supports and what is needed to ensure quality access to care for all individuals and their families. Information and feedback gathered highlighted challenges faced by families when engaging with the criminal justice system, the crisis care continuum, and housing needs.

IMPACT OF COVID-19

In February 2020, California leadership issued rigorous recommendations, requirements, and state mandates in response to the worldwide pandemic outbreak of the SARS-CoV-2 (COVID-19) virus. As part of these recommendations, counties across the state closed businesses, transitioned schools to a virtual learning model, and participated in statewide lockdown to help prevent the spread of the virus. As restrictions have been lifted and modified, much of California remains in various stages of lockdown and quarantine. Emerging research by leading health experts have demonstrated the severe impact that the pandemic has had on physical health, mental health, and overall well-being. Some of these findings have concluded serious increases in call-volume for various mental health hotlines, increases in stress and symptoms of depression and anxiety disorders among the general population, and increases in symptoms of those who were already living with mental illnesses or co-occurring disorders.



Word Cloud responses during a virtual Town Hall

The situation has negatively impacted many families including youth who have had to endure changes to their learning and socialization; it has also impacted the most vulnerable individuals living with mental illness including incarcerated individuals, unlawfully detained immigrants, and individuals experiencing homelessness.

"I would like my loved one to have more frequent and more consistent meetings (even if over the phone during COVID-19 but clinic is closed now and not answering the phones) with care providers, particularly social worker / therapist. That has not happened for more than a year. I won't be alive forever and need to have someone else in the care team. For now, I am the DeFacto social worker/case manager, but I am a parent and not a trained mental health provider."

- Families Mental Health Survey Respondent

"It's interesting that schools can involuntarily commit students to residential care in CA. Then COVID hit. I am now managing suicidal crisis management at home and de-escalating psychosis while we wait for facilities to begin to accept new patients. He will probably go out of state for the residential school placement."

- Families Mental Health Survey Respondent

Throughout the pandemic, NAMI CA aimed has worked diligently to provide additional support, resources, and guidance to those most impacted by COVID-19. Through community engagement efforts, NAMI CA has heard firsthand about the significant losses experienced by individuals and families including economic (job loss, business closures, employment cuts) as well as the loss of friends, loved ones, and family members. Further, the closures of county and community agencies left many without access to needed supports and services increasing isolation, despair, and exacerbation of mental health challengesCOVID-19 has become a reality in our lives for our communities, both personally and professionally.

While NAMI CA was also impacted by the COVID-19 pandemic, the agency was able to shift quickly, providing supports and services through the state office as well as through many local affiliates in a virtual space.

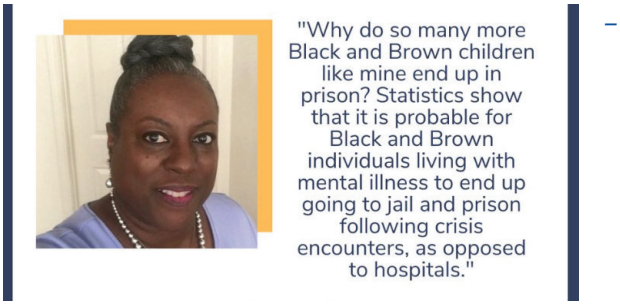
IMPACT OF RACIAL TRAUMA ON FAMILIES

Further impacting the lives of individuals and families is the current state of race and social justice issues, including Black Lives Matter and impacts of the long-standing legacy of systemic racism in response to recent and more frequent incidents of repeated deaths. The violence and racial trauma experienced by Black, Indigenous, and People of Color (BIPOC) furthered by systemic racism has had a considerable impact on individuals, communities, and populations both physically and mentally. Racism permeates through many systems: law, criminal justice, health, education, mental healthcare, and more; public health experts and mental health leadership, including NAMI CA, support efforts to classify racism as a public health crisis and must be recognized and addressed as such.

The impacts of trauma can be detrimental and can put individuals and entire communities at a higher risk for mental illnesses and co-occurring disorders. Previous Annual State of the Communities Reports issued by NAMI CA have demonstrated a higher rate of discrimination among BIPOC responses in surveys, focus groups, and interviews.

"We understand that we must take steps to right wrongs and demand equality and justice. We must work together to protect our loved ones and fellow Californians impacted by racial discrimination and violence. We must continue to advocate at the local and state level for systematic change and take on long-rooted racial disparities and structural inequities."

– Jessica Cruz, NAMI CA CEO, Statement on Systematic Racism and the Quest for Justice



Anita Fisher, NAMI San Diego, While We're at It: Let's Fix the Systemic Racism in the Mental Health System

YEAR THREE AT A GLANCE

Through the final year of this project, NAMI CA worked closely with local and state partners to continue efforts to create conversation, gather feedback and information, and design activities and events to meet the needs of families and individuals.

EXPANDED NAMI CA PROGRAMS & TRAININGS

Throughout this project, NAMI CA has offered resources for program training at both the state and local level. Notably, state trainings prepare individuals to become local program leaders and facilitators, training for trainers that can thereby increasing the capacity of local affiliates to offer more classes and support groups to individuals and families. In the final year of the project, NAMI CA trained 133 new program leaders. Additionally, local affiliates conducted more than 100 classes and support groups reaching more than 1500 individuals and family members.

As a result of COVID-19, NAMI CA and local NAMI affiliates have made the remarkable transition to the virtual space, shifting classes and support group to online platforms, regional implementations of their NAMI Programs and moved them to an online platform. With the support of NAMI National, state and local affiliates were provided with the support and guidance to ensure that during the pandemic, families and individuals still had access to the supports and services offered by their local affiliates.

POLICY PRIORITIES & LEGISLATIVE FOCUS

To ensure a comprehensive statewide advocacy strategy, NAMI CA partners with members and local affiliates to collect feedback and information on the issues and experiences impacting families and individuals impacted by serious mental illness. Information is gathered through ongoing community engagement, including surveys, focus groups, listening sessions, and advocacy meetings to support an advocacy platform guided by families and individuals across the state. In 2019-2020, NAMI CA worked closely with members and advocates to explore issues related to housing, criminal justice, crisis care, peer certification, telehealth, LPS conservatorship, IMD waivers, and proposed revisions to the MHSA. Additionally, NAMI CA engaged in conversation about issues of race and social justice as well as the impact of COVID-19 on families, individuals, and youth.

The priority sponsor bill for NAMI CA in 2020 was Assembly Bill 3242 introduced by Assembly Member Irwin. Signed into law, this bill authorizes the use of telehealth to conduct and complete needed examinations, assessments, or evaluations as it relates to the involuntary commitment and treatment of individuals under the Lanterman-Petris-Short (LPS) Act. As counties continue to manage the COVID-19 pandemic, telehealth has become critical component to providing safe, timely, and reliable evaluations for individuals across the state resulting in less egregious wait times for evaluation and less overcrowding in hospital emergency departments. Another legislative victory celebrated by NAMI CA included the passage of Senate Bill 803, introduced by Senator Beall, enabling California to expand the behavioral health workforce by allowing certification of Peer Support Specialists. With the passage of SB 803, California will now be in line with the 48 other states that already recognize peers' value as a critical part of the behavioral health workforce. As the state continues to face the challenges brought on by the COVID-19 pandemic, California will now be ready to utilize the unique role that peers and families play in our state's behavioral health recovery through the development of a statewide scope of practice, standardized curriculum, training and supervision standards, and certification protocol for peer support services. NAMI CA also supported the National Suicide Hotline Designation Act, which was approved by the Senate earlier this year.

NAMI CA social media post for Suicide Awareness

NAMI CA also published an Advocacy Toolkit, which provides individuals with the knowledge to become more involved in advocacy efforts and mental health policies. It offers advocacy tips and suggestions and links folks to additional resources and how to take action at the state and national level by getting updates, signing petitions, letters, and more. This year was a big voting year for many individuals. NAMI CA shared information across platforms to encourage individuals to vote, vote early, and #vote4mentalhealth. Given that advocacy efforts are centered around peers and family members storytelling; the toolkit also provided various free resources on how to tell a compelling story. (Toolkit: https://namica.org/advocacy-toolkit/)

NAMI CA will continue outreach in the community and to organizations who might support individuals and families impacted by mental illness. NAMI CA wants every individual and family to have the tools available to them at the local and state level to advocate for a better coordinated public mental health system.

CULTURAL COMPETENCE TRAININGS

Family members expressed that more culturally and linguistically appropriate education for all involved in the mental health care system would help their families to better navigate the mental health system. To address this key factor and aim to improve the experiences of diverse families with mental illness, NAMI CA conducted several trainings for cultural and linguistic responsiveness through a three-part series. The Cultural and Linguistic Competence Training Series created by and facilitated in partnership with the University of CA, Davis (UCD) Center for Reducing Health Disparities begins this conversation around what it means to be culturally responsive and meaningfully engage all communities. These webinar-based and in-person trainings were created to enhance NAMI affiliate and community partners' capacity to better serve diverse racial/ethnic and underserved communities. The curriculum includes characteristics of culturally diverse audiences relevant to learning, strategies to characterize learning needs, pitfalls and strategies to engaging culturally diverse audiences, key terminology in cultural competence, mental health disparities, unconscious bias and its impact on diverse communities, strategies for reducing mental health. To assist local affiliates and partner organizations in beginning to address the mental health disparities that exist among communities from diverse racial, ethnic, a cultural background (I.e. Latinx, LGBTQ, Veteran, etc.) NAMI CA developed a toolkit to help increase and improve diversity (Toolkit: https://namica.org/blog/cultural-linguistic-responsiveness-toolkit-webinar-training/)

REGIONAL ADVOCACY MEETINGS

Regional Advocacy Meetings provide NAMI with an opportunity to engage with local communities to explore the specific issues impacting families and individuals. In partnership with local behavioral health and NAMI affiliates, NAMI CA brings together family members, loved ones, caregivers, peers, and community members to discuss the current mental health system in their region.

Coachella Valley Regional Meeting

Further, these meetings provide an opportunity to engage local individuals and families, identify relevant topics and issues impacting communities, and design strategies on the local level to meet the needs of individuals and families in roundtable dialogue addressing some of the most pressing issues at the community level with the goal of forming long lasting partnerships dedicated to creating system change. As a result of COVID-19, only one in-person regional meeting was held in Coachella Valley. 86 community members and decision makers gathered to discuss issues related to housing and criminal justice, including representatives of the local Board of Supervisors.

TOWN HALLS

As a result of COVID-19, the remaining slate of regional advocacy meetings were reimagined as virtual events planned to reach a broader statewide audience. The resulting Town Halls provided a unique opportunity for NAMI CA to connect local individuals and communities to state level agencies and entities tasked with oversight and support of California's complex mental health system to foster a better understanding of how the system works together and which agency is responsible for which component of the system.

NAMI CA hosted five virtual Town Halls featuring leadership from the California Department of Health Care Services, Department of State Hospitals, The California State Association of Counties, the California Alliance for Child and Family Services, and the California Association of Local Boards and Commissions. The leadership from each of these organizations focused their presentations around the various needs of communities across the state, discussed the impact of COVID-19, and shared what their organizations are working on to advance mental health needs of families and individuals at the state and local levels and engaged in a Q&A session with participants. This online platform allowed a wider attendance from across the state; something not available before the COVID-19 pandemic and allowed NAMI CA to host a public forum with no limit on number of attendees. Over 400 individuals participated in the Town Hall events with favorable feedback shared with NAMI CA.

"I feel more confidence and resolve navigating the issues of co-occurring situation in trying to support, work with, regarding my grandson's Illness. Actually, I can do more to benefit him and others by understanding the big picture. And then deciding where I can best fit in to assist. I am, in many ways, released from trying to change him. The 'wishing', the "worrying", the 'sadness," etc. doesn't go away. But there is an acceptance that this is what it is "for now." Tomorrow is another day and maybe I can be part of those who help bring that change around. So, thank you all so much. I value the presentations, the education, all of you and your work and knowledge!"

- San Diego County, California State Association of Counties Town Hall Attendee

CAPITOL ADVOCACY DAY

Each year, NAMI CA hosts the Spring State Capitol Day where individuals and family members travel to the State Capitol to engage in discussion and advocacy activities with NAMI CA leadership and legislative staff. Advocacy Day has provided a platform for passionate advocates to engage with lawmakers on important policies aimed at improving the quality of life for people with mental illness.

The COVID-19 pandemic had a significant impact on the legislative session in 2020. With the closures of the Capitol building as well as the significant demand on policy makers to focus on the pandemic, the budget impacts, and the state's response to counties, the legislative cycle was extended, and policy priorities were shifted.

NAMI CA revised the plan for Advocacy Day and hosted a virtual event, attracting 123 participants from all over the state; many as first time attendees. The event featured a keynote by Senator John Moorlach who discussed his involvement with NAMI CA and the relationships that built with constituents that identify as family members and caregivers of those with mental illness. He urged participants to continue their advocacy at every level, highlighting instances when family advocacy has moved the needle forward for the public mental health care system in CA. He also answered questions from attendees and empowered them to share their stories with decision-makers. Additional speakers included Assembly Member Susan Eggman and CA Secretary of State, Alex Padilla. Breakouts were conducted where participants met with state legislators and their teams to discuss their personal experiences and advocate for peer and family support, suicide awareness, and improvements to family involvement within the continuum of care.

2020 Virtual Capitol Advocacy Day

Participants reported feeling more confident in their ability to advocate for themselves or others regarding mental health and that they would recommend the event to other individuals or stakeholders in mental health. Many reported their satisfaction with the online platform and that it allowed them the opportunity to meet with advocates from across the state; for some the online platform made it possible to attend this annual event for the first time.

"I was led to believe I have a unique, but similar, precious story, and I have new hope that my voice will be heard."

-Anonymous, 2020 Virtual Advocacy Day Attendee

"Hearing from both Republican and Democratic legislators & ability to give personal experience that connects to the bills. THANKS."

– Anonymous, 2020 Virtual Advocacy Day Attendee

THE ROLE OF FAMILY MEMBERS

The family unit currently acts as one of the most important agents for providing psychosocial support for individuals with mental health conditions. Further, research indicates that patient outcomes improve when family members are provided with the information, clinical guidance, and support they request. Through the advocacy and support of organizations like NAMI CA and local NAMI affiliates, families are provided the opportunity to access an array of support to ensure that they are equipped and educated to participate in the care and treatment of their loved one.

With the passage of Proposition 63, known as the Mental Health Services Act (MHSA), the mental health system in California began a long overdue shift from a medical model to recovery-oriented services for mental health treatment. A critical component of this shift included a recovery-oriented services model that holds consumer and family member participation as one of its core values. This includes concepts of recovery and resilience integrated with service experiences for clients and families for improved outcomes. Services should engage clients, consumers, and families in all aspects of the mental health system, including planning, policy development, service delivery and evaluation. [2]

MHSA Code of Regulations defines a client or consumer as “an individual of any age who is receiving or has received mental health services” and a family member as “any individual who is now or was in the past the primary caregiver for an individual with a serious mental health condition who accessed services, particularly public services, for that condition…families can include biological, adoptive, grand or foster parents, siblings, other kinship caregivers, friends, and others.

The role of family member support in the treatment of mental health conditions can significantly improve outcomes for both the consumer and family member. Qualitative research tells us that family members, friends and other individuals involved in the patient’s support network can be important sources of collateral information about the reason for evaluation, the patient’s current symptoms and behavior, and history, including trauma exposure and psychiatric treatment. Communicating with family members or other caretakers can be particularly important when the patient requires assistance or supervision because of impaired function, unstable behavior, or neurocognitive impairment. The American Psychiatric Association (APA) ultimately recommends that an assessment, clinical procedure, or treatment plan must be made by the psychiatrist in light of the psychiatric evaluation, other clinical data, and the diagnostic and treatment options available. Such recommendations should be made in collaboration with the patient and family, whenever possible, and incorporate the patient’s personal and sociocultural preferences and values in order to enhance the therapeutic alliance, adherence to treatment, and treatment outcomes. Additional research indicates that family participation prevents relapse, decreases negative symptoms, and improves social and occupational functioning. [3]

Through this project, NAMI CA has worked closely with family members from the across the state to better understand the complex mental health needs of their loved ones and how family involvement shapes experiences, recovery, and service delivery. Ongoing engagement has identified that access to treatment planning, information about medications prescribed, and hospitalization information have remained critical issues for family members.

Family members are a key component to the care of support for many individuals, many reporting that they provide their loved ones with their most basic needs, including housing, appointment scheduling, and social support. However, many often report that service providers do not seek input from families or caregivers, do not include them in treatment planning, and do not feel the mental health professionals are approachable. Further, many family members have shared feelings of being unwanted in the process of trying to help their loved ones through their crises and recovery periods. This is especially frustrating to families when they act as their advocates and support in all scopes including financial, emotional, and physical. [3]

METHODOLOGY

As with prior year efforts, NAMI CA continued to engage with families and individuals in communities across the state to gather information on their experiences and needs when navigating the public mental health system. NAMI CA used a variety of data collection processes including communications with the Advisory Committee, qualitative interviews, stakeholder surveys, case studies, and focus groups to obtain information from multiple, diverse perspectives.

ADVISORY COMMITTEE

The NAMI California Family Advisory Committee consists of nine members that identify as either consumers or family members/loved ones of those with mental health conditions. Of these members, six were family members and three were consumers and family members. The Advisory Committee helps assure that data collected reflect local concerns from the standpoint of individuals, providers, county, and community-based agencies with perspectives serving the unique issues of family members and caregivers with lived experience. Feedback helped NAMI CA obtain this data in a manner that truly allows family stakeholders to voice their concerns about the challenges of accessing mental health for their loved ones.

FOCUS GROUPS

NAMI CA conducted additional focus groups with family members during the final year of this project. In-person groups took place in Coachella Valley, Yolo and Kern County. While the COVID-19 pandemic required a shift to virtual focus groups, NAMI CA was able to increase the participation of individuals through online platforms to conduct additional groups. As a result, feedback was gathered from family members from additional regions of the state.

Kern County Families Focus Group with leadership presentation of TAY programs

STAKEHOLDER SURVEYS

NAMI CA administered an annual statewide survey in support of this project as an ongoing opportunity to seek information about the unique experiences of family members navigating the public mental health system. The surveys were available in English, Spanish, Simplified Chinese, and Arabic. NAMI CA collected responses from 727 individuals across 45 counties who identify as family members of individual with mental health conditions. Questions utilized a variety of designs from Likert-style scale questions, rank order, and open-ended formats.

- 86% of respondents identified as female
- 73% of respondents were over the age of 55
- 30% of respondents identified with various backgrounds
  - LGBTQ
  - Veteran
  - Homelessness
  - Current or former foster youth
  - Immigrant (independent of documentation)
- 7% stated an income less than 20,000 while 26% stated they made 100,000 or more.
- 70% of respondents were college graduates
- 66% of respondents identified as White/Caucasian/ European

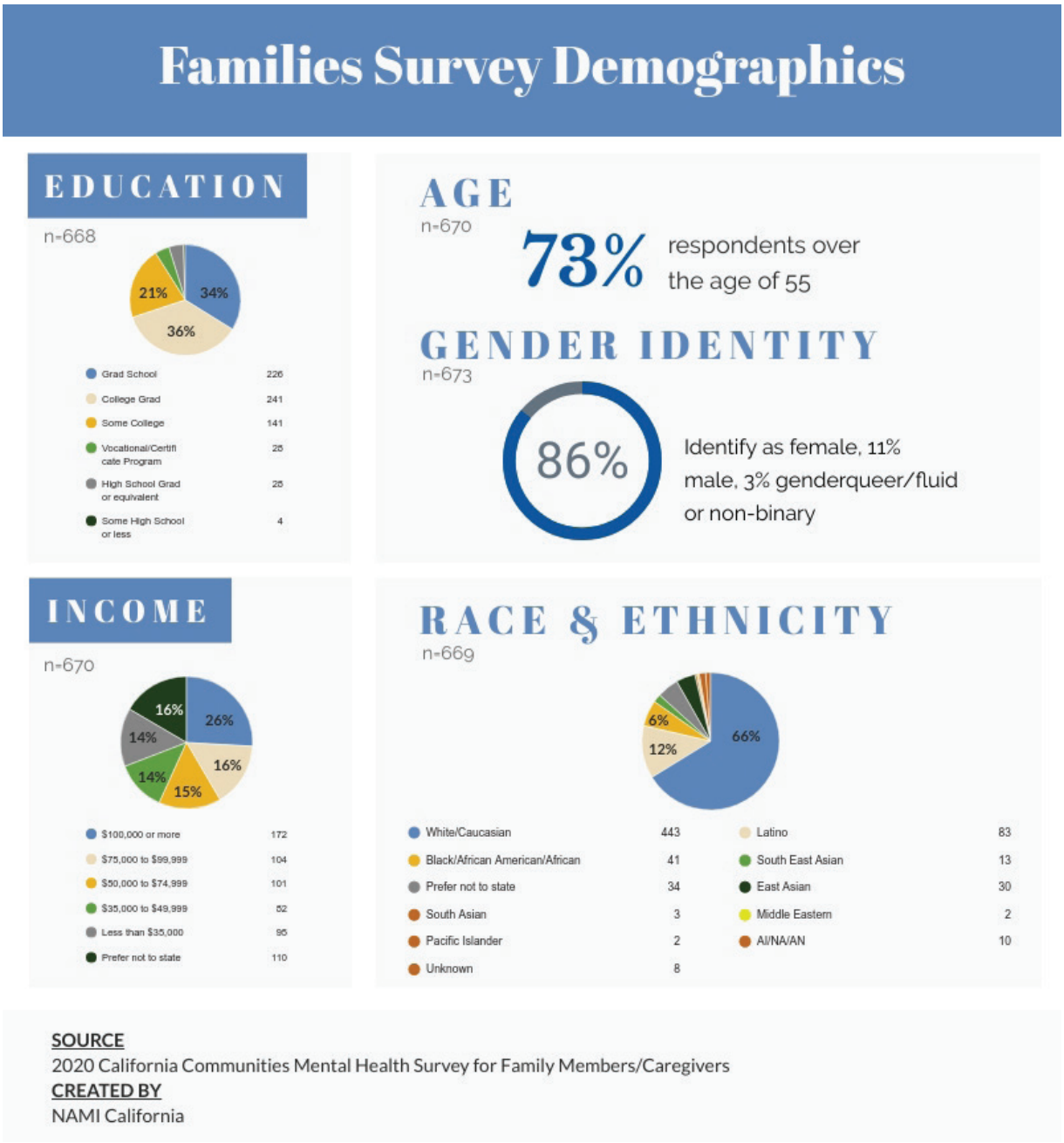

Families Survey Demographics
EDUCATION
n-668
21%
34%
36%
Grad School 226
College Grad 241
Some College 141
Vocational/Certification Program 25
High School Grad or equivalent 25
Some High School or less 4
AGE
n-670
73% respondents over the age of 55
GENDER IDENTITY
n-673
86%
Identify as female, 11% male, 3% genderqueer/fluid or non-binary
INCOME
n-670
16%
26%
14%
16%
14%
15%
$100,000 or more 172
$75,000 to $99,999 104
$50,000 to $74,999 101
$35,000 to $49,999 52
Less than $35,000 95
Prefer not to state 110
RACE & ETHNICITY
n-669
6%
12%
66%
White/Caucasian 443
Black/African American/African 41
Prefer not to state 34
South Asian 3
Pacific Islander 2
Unknown 8
Latino 83
South East Asian 13
East Asian 30
Middle Eastern 2
AI/NA/AN 10
SOURCE
2020 California Communities Mental Health Survey for Family Members/Caregivers
CREATED BY
NAMI California

Figure 1

FINDINGS

POPULATION OVERVIEW

Family Member Contribution to Mental Health Treatment

Ongoing research throughout this project indicates that the role of family member support in the treatment of mental health conditions can significantly improve outcomes for both the consumer and family member.

Additionally, family members, friends and other individuals involved in the individual's support network can be important sources of collateral information during an intake or evaluation, including overview of current symptoms and behavior, medical history, trauma exposure and prior treatment. Communicating with family members or other caretakers can be particularly important when the patient requires assistance or supervision because of impaired function, unstable behavior, or neurocognitive impairment. The American Psychiatric Association (APA) ultimately recommends that an assessment, clinical procedure, or treatment plan must be made by the psychiatrist considering the psychiatric evaluation, other clinical data, and the diagnostic and treatment options available. Such recommendations should be made in collaboration with the patient and family, whenever possible, and incorporate the patient's personal and sociocultural preferences and values to enhance the therapeutic alliance, adherence to treatment, and treatment outcomes. [2]

Previous reports have highlighted World Health Organization estimates that deinstitutionalization has resulted in 50% to 90% of individuals who utilize mental health services now reside with their family.[1] Further, nearly 77% of families have some sort of role in the treatment planning process.[4] NAMI CA and local NAMI affiliates strive to provide support to relatives and caregivers. It is a continuous effort to assure families they have the support system they need as they are caring all aspects of their loved one's experience. As the number of families involved in the treatment planning process increases, it is vital to continue to build and foster trusting relationships with families and improve collaboration between the family member the support systems and the care teams. According to SAMHSA programs, organizations, and systems all help to strengthen family engagement within the mental health system. [2]

An important aspect for families is to have support not only from organizations and treatment teams but from others who have navigated the mental health system for their own families and can assist as a peer support specialist. NAMI CA has been actively engaged in advocacy efforts to further support peer certification and the use of peers and family members as a sustainable strategy to increasing network adequacy through meaningful employment of peers and family members in the public mental health system. Through program efforts, NAMI CA trained 116 new Family/Peer Support Specialist who were certified to enter the public mental health field, working in several supportive settings.

Mental Health Stigma

Mental health stigma is the negative way in which people think about and view persons with mental illnesses. This stigma creates fear, rejection, avoidance, and discrimination toward persons with mental illness. [2]Public stigma causes society to question the safety and competency of those with mental illnesses. Research show that stigmatizing beliefs "sets the context in which individuals in the community respond to the onset of mental health problems, clinicians respond to individuals who come in for treatment, and public policy is crafted." [4]

As noted by the WHO, "the single most important barrier to overcome in the community is the stigma and associated discrimination towards person suffering from mental and behavioral disorders. [1]

Additionally, while some individuals might not be aware that they have a mental illness, fear of the stigma of a diagnosis is closely associated with barriers to treatment.[3]

A study completed by the RAND Corporation on stigma, discrimination and well-being among adults experiencing mental health challenges found:

- More than 2 in 3 respondents would, or probably hide a mental health problem from coworkers or classmates, and more than 1 in 3 would hide it from family or friends

- 1 in 5 respondents indicated that they might delay treatment out of fear of letting others know about a mental health problem; with nearly all of them indicating that they would eventually seek care.
- Treatment in the US overall is a concern as the average delay for those seeking treatment for mood disorders is 6-8 years and 9-23 years for anxiety disorders
- In 2013, 59% of respondents with serious psychological distress had obtained mental health treatment
- 1 in 10 Californians reported that they would delay or not obtain treatment if needed due to stigma.
- 4 out of 5 survey respondents agree that a person with a mental illness will eventually recover.[3]

Further data demonstrates that 1 in 3 people would hide their mental health challenges from family and friends, a classification referred to as "social network stigma" – when an individual is more concerned with how their families and friends perceive mental health and mental health treatments vs. the public. [4] Stigma can be a powerful influence and as a result, ensuring individuals that it is in their best interest to reach out for help is challenging.

Access to Mental Healthcare

Many individuals and families have expressed difficulties in accessing care for themselves or a loved one. This is due, in part, to a decline in the behavioral health workforce. As a result, individuals have difficulty accessing the medication and care that they need. Further, existing mental health professionals are reporting high rates of fatigue and burnout. About 45% of psychiatrists are above 60 years of age, thus the decline in providers continues to raise concerns for access to care. The hardest hit communities will be minorities in the Central Valley and Inland Empire, where the number of qualified providers is the lowest. Only around 55% of psychiatrists accept private insurance and even fewer now accept Medi-Cal insurance. [3] This lack of access disproportionately impacts many of California's most vulnerable communities already struggling with poverty and other environmental and economic stressors such as homelessness, criminal justice involvement, or substance use disorders. As part of broader efforts to address the decline in mental health professionals, studies are underway to explore the efficacy of utilizing primary healthcare providers, training them on basic psychotherapy techniques and prescribing pharmaceutical treatments for common psychiatric disorders to support increased access to mental health care in the US.[3]

Another challenge is the lack of available psychiatry beds in California. There are currently five state hospitals with a total of 6,078 beds.[5] However, these facilities are not generally available to the public. According to a report by the California Hospital Association, CA operates 29 hospitals licensed as freestanding Acute Psychiatric Hospitals (APH) and 28 county-based Psychiatric Health Facilities (PHF). While recommendations state that there should be 50 beds for every 100,000 people to meet population requirements for forensic, child, and adult psychiatric services,[3] when viewed collectively, total psychiatric beds in CA appear to average lower, at 32 beds per 100,000 people. However, when removing the beds available in state hospitals, in the context of "publicly available" beds, the number decreases further to about 17 beds per 100,000 people.

Throughout this project, NAMI CA has observed an increase in rates and statistics regarding youth mental health issues, including:

- 32% of high school students (grades 9-12) report they felt sad or hopeless almost every day for 2 or more weeks in a row so that they stopped doing some usual activities.
- 13% of youth (ages 12-17) reported they had at least one major depressive episode in the previous 12 months.
- 17% of high school students report they have seriously considered attempting suicide within the last 12 months. 9% of students report they attempted suicide 1 or more times and 3% reported their suicide attempt resulted in an injury, poisoning, or overdose that needed to be treated by a doctor.
- Approximately 89,000 adolescents aged 12–17 with MDE (30 .5% of all adolescents with MDE) per year from 2010 to 2014 received treatment for their depression within the year prior to being surveyed.[3]

Through ongoing engagement with families, parents have expressed frustration that while they want to help their children, they do not feel equipped enough to support their children and feel that they need more education and training. Parents feel there should be more materials readily available to them to best support their children at all ages, including elementary aged youth. These challenges in accessing care has only been exacerbated by COVID-19. As more individuals seek treatment and support during this time, further barriers exist in the limitations of in-person office visits, provider availability and access to technology as part of engaging in the transition to telehealth.

New Interventions and Treatment Modalities

The use of psychoeducation through family programs can significantly support those caring for a loved one with mental illness.[1] NAMI CA supports family members and individuals by providing a full slate of community education, including Family to Family, Peer to Peer, and the Family Support Groups to family members and individuals across the state. These NAMI programs are recognized by SAMHSA, the Substance Abuse and Mental Health Services Administrations as an evidence-based family support program. Ongoing evaluation efforts demonstrated that families experienced significantly greater improvements in problem-focused coping, empowerment, illness knowledge, and reduced distress.[3] Further survey results indicate that families were grateful for opportunities to learn how to support their loved one outside of scheduling appointments and transporting them to their appointments.

Further work in year two explored the importance of the coordinated relationship between the individual and their provider teams. The mental health team should consist of mental health coordinators, family physicians, and psychiatrists. 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]

Studies have shown that co-located services, both psychiatric and non-psychiatric, significantly improved wait times for services[3]in that shared care sites offered services more than 40 days sooner and helped to reduce the wait time at non-shared care sites.

Peer support has also been a successful strategy to addressing dwindling access to mental health services and a shortage of providers. The use of trained peer specialists can support the current gaps in services, access to triage and treatment and expedite service delivery. Peer support can include peer-run support groups, peer-led advocacy organizations, and peer involvement in mental health treatment programs in services in the public mental health system. Peer support has shown to bring the following outcomes to service delivery: dedication and commitment to work; ability to use their stories and lived experiences to inspire hope; ability to guide people in accessing community resources and services; demonstrate to the team, family members, and others that people do recover; and many other outcomes listed in Year 2. Many seek a safe place where they can feel comfortable in a low-demand environment. Peer support provides that sanctuary.[3]

LITERATURE REVIEW

The Criminal Justice System and Mental Health

"People with mental illness are falling through the cracks of this country's social safety net and landing in the criminal justice system at an alarming rate."[6] Our criminal justice system houses Mental Health Courts which are built to focus on the individual and treatment to restore health and to reduce the number of times an individual is incarcerated. [6] The administrative office of the court's facts sheet states that out of 11 million people that are arrested across the US at least 600,000 have acute mental illness and 7 million have co-occurring disorders.[7] Among inmates that are incarcerated with mental illness, around half have been booked on a nonviolent crime and offenders with mental health challenges are three times more likely to have had prior records than those without mental health challenges. [6] These statistics are alarming. Primarily the goal is to keep individuals with mental illness out of the criminal justice system unless necessary. In a clinical interview done by the State of Federal Correctional Facilities it was found that 49% of inmates reported manic episodes and major depression including hypersomnia and insomnia and 24% reported a psychotic disorder consisting of hallucinations.[8]

As programs like the mental health courts and mobile crisis units are created, NAMI CA has opportunities to reduce the weight on the criminal justice system and improve the treatment plans for individual's with mental health challenges.

Family members and Loved Ones Interaction with Police during Crisis

Often families interact with law enforcement during a loved one's crisis. During a crisis, the police are often the first ones to be called.[9] Increasingly, across the state, law enforcement agencies are training police with skills to interact with an individual with mental health challenges. Mobile crisis teams which consist of police and health care providers are created to provide a response team that is trained in mental health, can help mitigate a crisis, or can make sound decisions on the behalf of the individuals they encounter.[9] Police currently play the role of gatekeeper and must decide if the individual is placed in the criminal justice system.[7] Officers must make the determination that the individual was involved in a criminal act and that act was a higher priority at the time then the status of their mental health needs in which they could be placed into the mental health system.[9] Families struggle to get

the appropriate care for their loved ones when they are arrested for petty crimes that resulted from a mental health diagnosis or co-occurring substance use disorders.[9] Crimes such as being a public nuisance, urinating in public, and sleeping on the street.[9] These petty crimes cause individuals to get stuck in the criminal system only to worsen their situation.[9] Officers have also been known to choose jail to get someone with SMI off the streets and in a safe place for the night, when they know there are not enough psychiatric beds for them to go to under the mental health system's due to lack of resources. The American Psychiatric Associations states, "The nation's largest mental health warehouses are the jails in major metropolitan areas, not hospitals, producing more persons with mental illness in jails than in mental health institutions."[8]

It is a battle of funds and resources between both systems.[3] As jails are filled more and more with people that need mental health care, more funds are needed to support that system. Yet, we also need to fund the mental health system and create resources needed to prevent jails from being overpopulated and assure mental health care is timely provided.[2] Therefore, the continuous effort to train officers and build mobile crisis teams are critical, to ensure trained officers will have the knowledge, resource guides, and skills needed to make such determinations.

Juvenile and Criminal Justice System

Many juveniles that have entered the criminal justice system and 45.5 % of those youth were identified as having a mental health disorder in which 27% of those suffered from serious mental illness.[6] There are multiple challenges surrounding the needs of youth and programs containing early interventions are key once mental health needs are recognized, especially to keep juveniles out of the system before they end up in an adult detention center.[6] It is important to remember when working with juveniles that they need a system of support. These children interact with schools, their parents, mental health providers, and even probation officers, which means there must be collaboration when working with a juvenile[6] with mental health challenges before and after incarceration.

Homelessness and Mental Health

Issues of homelessness and mental health go hand and hand. In October 2019, Los Angeles conducted a county-wide point-in-time count to collect data and conduct interviews with nearly 4000 individuals experiencing homelessness.[10] The data was studied by multiple agencies to identify linkage between mental health and homelessness, though the results were varied, likely due to difference in agency related guidelines.[10] The results ranged from 29% to 78% of LA's unsheltered population living with mental illness. Out of those results, LAHSA, LAT, and UCLA all recorded a rate of 75% or higher, from the data.[10] Many individuals are at risk of homelessness due to a mental health crisis, often because of lack of discharge planning after they are released from a hospital or other institution.[11] SAMSHA states that "transitional or supportive housing and homeless shelters can help stabilize people with mental health issues and substance use disorder who are experiencing homelessness". [11] Sheltered living is critical to successfully keep individuals off the streets. Early intervention is another way to address the escalating issue of homelessness within the mental health community.[11] According to SAMSHA "research shown intervention to prevent homelessness are more cost effective than addressing issues after someone is already homeless".[11]

Conservatorship

A conservatorship is applied when a person's psychiatric conditions prevent them from providing basic needs, like clothes, food, and shelter. A conservator, or guardian, helps the individual obtain treatment, basic needs, and will act as their advocate to protect their individual rights. In order to establish a conservatorship, a family member, friend, or public official must petition the court and demonstrate that the individual cannot care for themselves. They must have proof that the person they seek to get a conservatorship cannot manage their own financial affairs or make sound decisions on their personal care. A court-appointed investigator will be appointed to review the case. A hearing is then conducted to review the case and allow for all parties to participate. Family members may be notified and have a chance to speak on why they believe that their loved one should or should not be under a conservatorship. The individual must appear at the hearing, unless medically unable to do so. A judge will determine the whether the conservatorship is necessary.[12]

Conservatorship can be costly and time-consuming for many families. Families must pay not only for the attorney, but all other court and case related fees. Conservatorship can have significant benefits to supporting the safety and security for the individual as well as ensuring that there is a neutral party to consider multiple perspectives and viewpoints during any dispute over care. While this is a process that can take considerable time and money, it can be a necessary step to maintain the needs of a loved one.[12]

THE NEEDS OF FAMILY MEMBERS

In the final year of this project, NAMI CA identified that in addition to the need for effectively accessing appropriate services and supports, families often experience challenges within the system as it relates to engagement with criminal justice system, housing needs, available crisis care. Through additional engagement on these issues, community members shared their experiences as well as strategies and practices outlining various points of potential intervention for mental health services and supports.

Prevention and Early Intervention

Phase one is the earliest intervention exists at the level of prevention through community-based partnerships (schools, etc.). This may include emotional well-being courses in elementary school and early resilience and empowerment programs youth.

Figure 2

Phase 2, or early intervention before the on-set of symptoms, requires that individuals be aware of warning signs. It also involves mental health education for all so that individuals know when someone is at higher risk for mental illness (considering family history, adverse childhood experiences, etc.).

Phase 3, early intervention at the immediate on-set of symptoms, requires that individuals be aware of early symptoms of mental illnesses and know immediate next steps and readily available resources. According to the WHO, mental health conditions start by age 14 in 50% of those afflicted.

During Phase 4 symptoms may go untreated for a variety of reasons. In diverse communities, this could be due to cultural stigma, fear of discrimination, lack of understanding, lack of culturally appropriate care, etc. At this point, symptoms may begin to interfere with someone's daily life activities or routine (e.g., work, school). If individuals do not receive care by this point, it sometimes escalates to moments of crisis.

Phase 5 includes the need for crisis care. Crises vary from person to person, but may involve encounters with law enforcement, the juvenile or criminal justice system, self-harm, or psychiatric holds. After crisis, a clear issue comes to light, maybe even a first-time diagnosis where someone may or may not be linked to care or treatment. At this time, family, primary care providers, mental health providers, lawyers, and more may become involved. There is also opportunity for continued engagement and intervention during treatment when an individual is receiving care and following a treatment plan that consists of unique components. The treatment team may or may not be incorporating whole-person care. Finally, through recovery, individuals need continued mental health support and services. Here individuals are balancing the pillars of recovery - health, home, purpose, or community.

Criminal Justice System and Mental Health

As many families and individuals reported interaction with law enforcement and the criminal justice system, efforts were made to further explore the nature of those interactions and the outcome of those experiences. NAMI CA heard from many peers and family member/caregivers that the criminalization of mental illness, specifically SMI, has been one of the hardest things to deal with during times of crisis which are already difficult on the person experiencing it and those closest to them.

"Being arrested was a step backwards and very hard to deal with."
- Online Focus Group Participant

"People with mental illnesses should not be put in jail."
- Online Focus Group Participant

"Once you have judges, it's looking at mental health as the intent of criminalization."
- Online Focus Group Participant

In the statewide survey, NAMI CA posed questions on this topic:

- 79% of survey respondents reported experience accessing crisis services.
- 75% reported interaction with law enforcement during crisis.
- 40% reported that law enforcement present was trained in mental health care
- 28% reported that there was no trained crisis response

Focus group participants shared similar experiences to what was gleaned from the statewide survey. Many shared their sentiments regarding that these critical moments of crisis should not be escalated to the point of arrest or juvenile and criminal justice systems. Instead, they expressed the desire that their loved ones be immediately linked to mental health care and treatment during crisis.

"My daughter was out on the streets. She called me. I was in another state. I had to call the police to take her to the hospitals."
- Online Focus Group Participant

"Training is a continuum. There could or should have been a clinician, so he did not have to be transported and then assessed in jail. Jail should never have entered it." -
Families Mental Health Survey Respondent

"If there was an understanding that actions which resulted were because of a reaction to a mental health problem. There was no opportunity to describe the illness and get appropriate help. It took years to unravel the issue and still causes family pain as well as ongoing misunderstanding."
- Families Mental Health Survey Respondent

Many of our participants and respondents also shared their valuable ideas on how crisis experiences could be improved and mitigated for those with mental illness and SMI. Many of these solutions already exist and work across many CA counties, but there is a lack of standardization for CIT teams and training across the board.

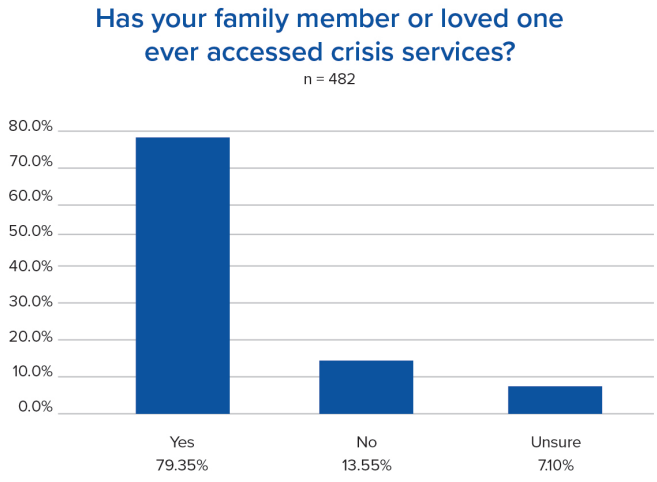


Figure 3

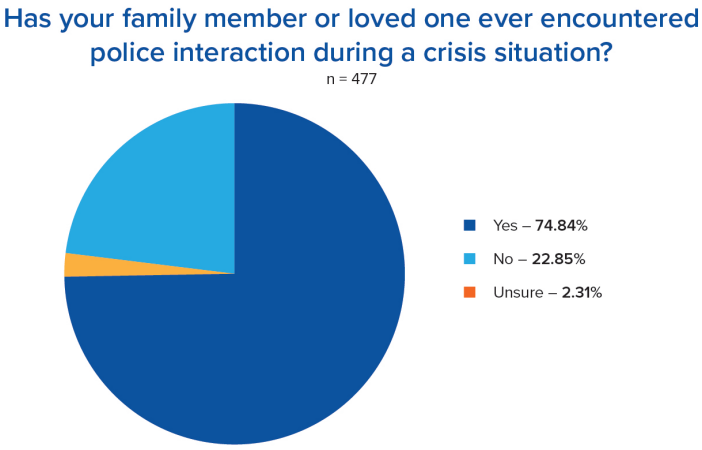


Figure 4

"I called 911 asking for [Crisis Intervention Teams] because my son was manic and had [Congestive Heart Failure]. When the Daly City police car arrived, I was giving them AB1424 form and requested them to bring my son to PES Mills Peninsula or San Mateo General Hospital. He is bipolar and had cardiomyopathy with ejection fraction less than 20%. The male officer did not get the form from me and told the female officer to 'get her inside the house, her son can speak for himself.' If the responding policemen were CIT trained, I believe they would have listened to my input. They brought my son to Seton Medical Center where his CHF was treated but mental illness was not addressed." *- Families Mental Health Survey Respondent*		
"A couple of times during episodes or has gone missing what was most helpful was providing as much information like requesting a crisis trained or CIT officer and stressing that my son is nonviolent, he does not have violent tendencies but if he is disheveled this is how my son who is African American may present to you when you approach him or try to speak to him." *- Kern County Focus Group Participant*	"A trained mental health worker would've been very helpful. I do not fault the police because they have no adequate training in mental health situations. Our sons encounter with the police would have worsened had I not been present. Trained mental health teams should intervene in crisis situations not the police." *- Families Mental Health Survey Respondent*	"Our loved one had MANY 5150 encounters with police, and we were able to witness improved communication and service over the years ...still it would be more comforting to have these encounters led by Social Workers instead of uniformed officers." *- Families Mental Health Survey Respondent*

Table 1

Housing

Housing was highlighted as a key issue in the last year of this project. Additionally, NAMI CA receives daily inquiries and calls regarding available housing and supports for loved ones. Secure housing is recognized as such by many leading mental health organizations and agencies and research professionals as a key component of supporting recovery. 1% of survey respondents said they experienced homelessness (n=694). Family members supporting a loved one, especially an adult child with mental illness, shared a deep concern regarding the lack of secure supportive housing.

"Housing and group sessions. My daughter was in a 6-month residential program, then released to a homeless shelter, after 6 weeks there, she had no option other than moving in with a friend."

- Families Mental Health Survey Respondent

"It is also important to increase housing and employment opportunities in the community, and to promote the anti-stigmatization."

- Families Mental Health Survey Respondent

"Over the 15 years we have been involved in MH, services have improved except for housing and outpatient programs for co-occurring disorders."

- Families Mental Health Survey Respondent

Furthermore, to support our literature findings, there is a housing crisis in CA that is creating severe challenges for our state residents and puts those living with any mental illness and SMI at much higher risk. NAMI CA engaged in many conversations with state and local leaders including legislators. Senator Scott Wiener shared that in a state of 40 million CA is only building 100,000 housing units; this is creating a profound deficit of 2.5 to 3.5 million houses. Respondents and participants across the survey and NAMI events elaborated on the association they have witnessed between lack of housing and increased exposure to law enforcement and the juvenile and criminal justice systems.

"There are still many peers who are homeless or in criminal justice system that need more services. Need more housing and less interaction with the Criminal Justice system."

- Families Mental Health Survey Respondent

"There is a critical need for expanded IMD and residential services for long term support for people with SMI to get them out of incarceration and homelessness and into treatment and care. Also, mobile psychiatric crisis response teams are critical services that need to be expanded."

- Families Mental Health Survey Respondent

"MHSA needs to have a plan for when someone fails out of the county programs, so they don't become homeless or incarcerated. We do need more tracking of those in the funded MHSA programs as if someone fails out of a MHSA funded program, they should not become homeless or incarcerated."

- MHSA Focus Group Participant

Participants also discussed the basic and critical needs among individuals living with mental illness, especially those living with serious mental illness, noting stable housing is one of the key factors independent living and ensuring the recovery of their loved ones. This data is also supported by the SAMHSA key pillars of recovery.

"Housing is part of treatment."
- MHSA Focus Group Participant

"There is not enough support for seriously mentally ill who are homeless."
- MHSA Focus Group Participant

"Supportive housing for mental health clients so they can live independently. County support services to supplement the supported housing."
- Families Mental Health Survey Respondent

Family Involvement in Crisis and Care

One of the tenets and subsequent requirements of the MHSA is the meaningful participation of consumers, family members, youth, and community stakeholders in the decision-making process at the state and local level. In communities, this is done through the Community Planning Process (CPP) which provides an opportunity for communities to weigh in on the development and implementation of local mental health programs and services. However, despite this requirement, 49% of survey respondents were not aware of the opportunities to be involved in the CPP and only 14% reported opportunity to engage in the CPP at the county level.

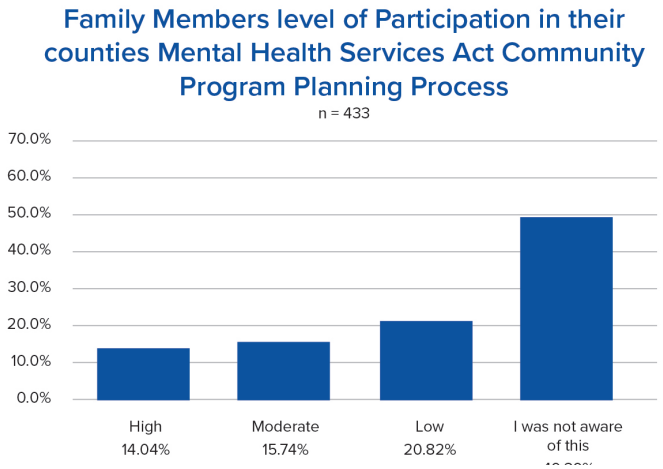


Figure 2

Health Insurance Portability and Accountability Act (HIPAA)

Family members also shared concerns related to the Health Insurance Portability and Accountability Act (HIPAA) as a barrier to engaging with their loved one's care during the most crucial times.

"If there is no HIPAA waiver, you don't even get to know what the diagnosis is or what the treatment is."
- Online Focus Group Participant.

"When HIPAA laws are thrown right in front of us, all of sudden we can't be part of that conversation."
- Online Focus Group Participant.

"Family members are pushed out of the treatment and we are the ones who know our family members best."
- Online Focus Group Participant.

To ensure support for families and individuals, a HIPAA Waiver of Authorization, allows an individual's health information to be used or disclosed to a third party. When surveyed about HIPAA and HIPAA waivers, 40% of respondents reported having an established waiver with their loved ones.

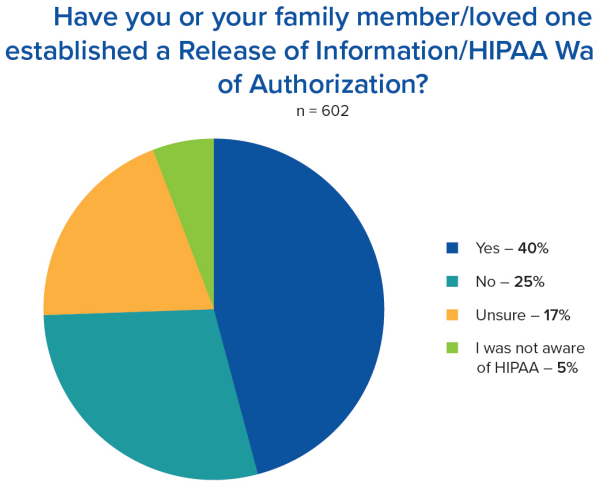


Figure 3

Further, some families have indicated that while recognizing the benefits and protections of the Act, it can also cause difficulties during crisis. While family members can often provide timely and critical information to crisis and response teams, challenges with HIPAA can impact their ability to act quickly. Families would benefit from additional education on HIPAA, HIPAA waivers, and how to communicate with care teams, especially during crisis times.

Caregiver Services and Supports

In the final year of this project, NAMI CA asked family members about how they access supports and resources as a caregiver. In support of families, NAMI CA gathered this information, to understand how to better offer services and supports for those providing care for their loved ones.

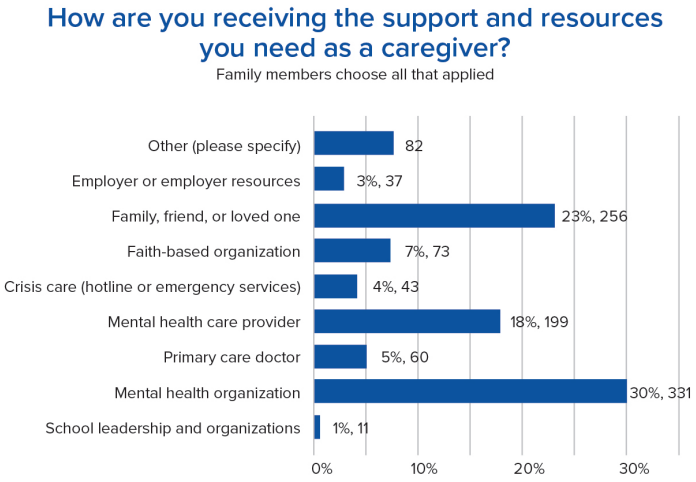


Figure 4

Despite the challenges and demands of caregiving, many respondents reported not receiving needed supports.

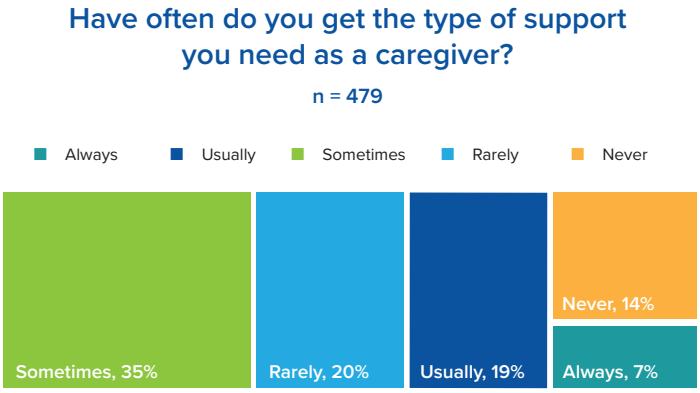


Figure 5

Conservatorship

Families often struggle with supporting a loved one who requires a high level of care but is non-compliant in treatment. Often, families may seek Conservatorship as a strategy to enabling them to work directly with their loved one's doctor to achieve recovery treatment for their loved one. For many families, conservatorship is the only option they have when there is a need to escalate treatment for their loved one to ensure the safety and care they need.

"Family members should be encouraged and helped to become conservators of their family members if needed. It is almost impossible to become a conservator, the time spent, the difficulty to meet the requirements takes time away from supporting your family member. Is it better to have a stranger with no knowledge of the many years of your family members background as the conservator or is it better for the caring family to serve in that role? The family does not want to deprive their ill member of their rights but rather to protect, help & hope that they will improve & become more independent."

- Mental Health Survey Respondent

"He has no mental health treatment team. It is a phrase we hear but we have never been able to receive. His care is from his psychiatrist and us, his parents and his brother. Many years ago, he attended a habilitative day treatment program which was closed due to lack of funding. Within the last 2 years a new adult treatment program was announced & he was to join but funding ended. We tried to integrate him into the county mental-health program. Social workers in the program wanted him evaluated by the psychiatrist. Able to access the psychiatrist, an intern did see him twice and then nothing happened. Both our son and us would like to be involved in his treatment plan but so far it has been unsuccessful. When our son is well, he wants us to be 100% involved. When he is disabled to the point where he cannot even speak to the psychiatrist, then he does not want anyone to help him. This is the time when he would need a conservatorship. Unfortunately, the way the system is set up, conservatorship could not be achieved in a timely manner. Without committing a crime or harming himself or others nothing can be done to help him." -

Mental Health Survey Respondent

In all NAMI CA communications with family members of loved ones who experience schizophrenia, bi-polar disorder, schizoaffective disorder, clinical depression, obsessive compulsive disorder and chronic alcoholism, many families struggle to provide enough proof to the courts that there is a great need for a conservatorship, largely due to the requirements of being considered "gravely disabled" under the law. Gravely disabled means the individual with mental illness cannot take care of his/her basic needs for food, clothing, and/or shelter. However, under current state law, if another person provides for their food, clothing or shelter, or if a person can get food or clothing from the shelters, then they do not meet the criteria for being considered gravely disabled. Homelessness also does not qualify someone as being gravely disabled.[13]

"Lack of the County Public Guardian's Office to manage high caseloads."

- LPS Focus Group Participant

"The whole framework needs to be reformed. People should not be forced to disintegrate to point of danger to self or others before they get medical care."

- LPS Focus Group Participant

"The legal standard should not be the criminal standard of 'beyond a reasonable doubt.' It should be 'clear and convincing evidence.'"

- LPS Focus Group Participant

"Our family members mental illness deteriorated but because she was under our roof and we had been providing room and board then she was automatically not 'gravely disabled' so even though she was not functioning at all, she couldn't do chores, warm up her food, do laundry, take showers…and if we were to put her on the street then we would be at fault because we hadn't given her proper notice to move out so we would have to wait 30 more days…So she was only 'gravely disabled' when the 30-day notice was up and she had not gone into treatment. She still had a car, and no one would believe she didn't have the capacity to drive so she drives off and comes back daily asking for food and a shower. Still not considered gravely disabled because she is driving and there are food wrappers in the car. So, by the end of December finally she's labeled 'gravely disabled' because she's lying in the middle of the street to get run over. And the dilemma for me is the signs of becoming gravely disabled were happening all the way back in October."

- LPS Focus Group Participant

Families have expressed concern that their loved one must be at risk for suicide or become involved in the criminal justice system just to receive care. There are key signs/red flags that family members can look for, in support of their loved one getting the help they need. [13]

- Delusional conversations expressing the need for knifes or other items to protect themselves
- Walking in front of cars in the street and they are oblivious to the vehicles
- Obsession with the idea of others wanting to kill them
- Leaving gas burners on after cooking
- Losing weight because they are afraid the food may contaminate them

The process of conservatorship is a supportive option to help ensure the safety of individuals and preservation of their rights.

FAMILY-INFORMED RECOMMENDATIONS

Throughout this project, NAMI CA has worked with communities to not only better understand the needs of families and individuals, but to identify strategies and supports to meet those needs through NAMI CA programming, advocacy, and community education. Some of the challenges, systemic in nature, provide an opportunity for NAMI CA to work closely with state and local partners to explore the current landscape of available supports and services and advocate for necessary changes to ensure quality access to care for all communities.

Respite Care

Caring for a family member or loved one is a demanding job. Respite care provides temporary relief for a caregiver, enabling them to take a break from the daily demands of caring for a loved. Respite can help to relieve stress, restore energy, and promote balance. However, while important, many family members do not know about available respite supports. When asked about respite supports and resources, only 30% responded that they receive that support from a mental health organization (like NAMI) while 23% said they seek support from another family member, friend or loved one.

"We have respite care services for disabilities but not for behavioral health and as a caregiver we can only do so much"

- Coachella Valley Focus Group Respondent

"I live in Alameda County. One of the contracted service providers (STARS) has been very helpful in preventing caregiver burnout. They provide a case manager and a peer support counselor that will come to us. That interaction with my son happens out in the community and gives us a little break and room to breathe."

- TAY [Transitional Age Youth] Focus Group Participant

To ensure support of families and caregivers, NAMI CA works with partner organizations and local NAMI affiliates to provide the necessary information, including communication about the benefits of respite as well as how to seek available community-based respite services. Additionally, through NAMI programming, families can

receive support through local classes, support groups, and community activities designed to support families and caregivers when caring for their loved one.

Family and Peer Support Specialist / Peer Certification

Navigating the mental health care system can be challenging. Often, families and individuals will seek the help of someone who has been through the process to learn how to understand the mental health system, identifying resources, and how to navigate before, during, and after a crisis.

"Families need support on finding access to care, treatment centers, housing, crisis intervention, guidance, and resources for their loved ones."

- Families Mental Health Survey Respondent

Family and Peer Support Specialists are individuals trained and employed in the public mental health system. They use their own personal experience in order to personalize care and assist families in understanding of services, utilizing referrals and providing support. These individuals also serve an important role as they can help decrease the workforce shortage.

NAMI affiliates support training and support of peers and families (FPSS training)

NAMI CA provides support and training for family members who are seeking roles as Family and Peer Support Specialists through ongoing efforts funded by OSHPD. To date NAMI CA trained more than 100 individuals to enter the public mental health workforce. Further, NAMI CA has been a strong partner at the state level in advocating for a statewide peer certification program that would establish a formal peer certification process across the state, further signaling the critical role that family members and peer play in mental health and service delivery systems.

Mobile Crisis Units

Mental health crisis response services are a critical component to the mental health service system. These teams can intervene wherever the crisis is occurring, often working closely with law enforcement and first responders, crisis hotlines and hospital staff. Mobile crisis teams can conduct pre-screening assessments, support de-escalation to help divert individuals from jails and hospitals, prevent hospitalization and connect individuals and their families with local, community-based programs and services. While many counties have active Mobile Crisis Units, there is still a need for increasing the availability and operation of these critical response teams.

"Improved mobile outreach and wellness check services to encourage participation and continuity in treatment."

- Families Mental Health Survey Respondent

Many local NAMI affiliates work with their local mobile crisis teams to provide family support during crisis and provide training to law enforcement on how to work with and support families during crisis. Additionally, using funds provided by SB 82, The Investment in Mental Health Wellness Act of 2013, counties have been able to increase crisis triage programs, often in partnership with their local NAMI affiliate. Also, several local NAMI affiliates operate phone lines to support individuals and families in crisis, helping to connect those in need to local services and supports.

Continuum of Care: Post-Crisis and 5150 Release

One of the most challenging times for families and their loved ones is after a crisis and subsequent 5150 medical hold. Many family members report that when their loved one is released after a 5150 hold, it can be done at all hours of the day or night and often with no established plan for a continuum of care.

"Often feel like there is no help out there for those that are chronically suffering from mental health. 51-50's are an OK option in a crisis but what about after?"

- Families Mental Health Survey Respondent

Families have reported that policy and procedures set across all counties would create a consistent continuum of care to ensure stabilized care, supports, and resources for families to ensure access to care for their loved one prior to release.

While many NAMI affiliates work directly with families and individuals, access to supports and information can vary by county and community making it difficult for NAMI affiliates to connect local families. Through current partnerships with Kaiser Permanente and the Department of State Hospitals, NAMI CA is looking to expand program offerings to support families in need as part of a larger strategy by community partners to address gaps in the crisis continuum of care and support families struggling with repeated hospitalizations and criminal justice diversion. Further, NAMI CA is working to better understand the needs of counties in developing a more responsive system across the state.

Increasing Mental Health Care Education Across CA

Education can provide tools and supports to communities to support stigma reduction, create awareness about mental health and mental illness, and inform communities about available resources and programs. As family members and individuals seek information about their loved one, it is just as important to ensure that all sectors of the system receive information, including providers, professionals, faith-based organizations, schools, decision makers, legislative staff, law enforcement, and those tasked with support for the systems.

"Education is key I wish I had these services before my son was diagnosed. No one teaches about mental illness or early intervention...WHY???? We need more educational programs to the community at large to learn about mental illness and stigma."

- Families Mental Health Survey Respondent

NAMI CA offers a wide breadth of education on mental Illness and provides tools for families, individuals, peers, youth, students, educators, and decision makers. Materials have been developed for multiple audiences and in multiple languages to better help communities understand what is happening, navigate the system, become an advocate for themselves or their loved one. NAMI CA and local NAMI affiliates offer a full array of programs including local education classes and support groups that can be done in person or online, advocacy training for those ready to engage with decision makers, and education-based supports to address student and youth mental health needs.

As education is needed across all sectors, NAMI CA partners with state and local agencies and organizations to support efforts to provide education on stigma reduction, advocacy, awareness of what mental health and mental illness is (and isn't) as well as how family members and peers can provide support for counties, providers, and agencies as a key part of the mental health workforce.

Meet Families Where They Are

Every family and individual experience a diagnosis differently. Understandings, situations, and journeys with mental health and mental illness vary. When working with families and individuals, there are a spectrum of experiences that can include crisis, trauma, discrimination, and suffering. While some individuals have a network of support, some may be alone and trying to navigate the system with little to no information. Others may know to reach out during a catastrophic event while some are just learning to cope with a new diagnosis.

What many families and individuals have in common is a shared understanding that in order to have the most impact when providing resources, coping skills, or outreach opportunities, it is important to use active listening skills and to meet and support families and individuals where they are. This means that systems and supports help someone where they are on their journey, not where the system or entity thinks they should be. Personalized care that is recovery driven that considers a person's own situation, capacity, and needs.

NAMI CA and local NAMI affiliates understand the demands of caregiving and the 24/7 needs of individuals and their families. To support their ongoing needs, many NAMI affiliates offer access to NAMI-run warm/hotlines, resources for 24/7 access and care, online support groups and education classes that are available to anyone, anywhere and offered every day. As NAMI programs are run by and for family members and peers, individuals seeking supports can be met with someone who knows and understand how challenging this can be for families.

30-second survey shared on social media

POSITIVE EXPERIENCES FOR FAMILIES IN THE MENTAL HEALTH CARE SYSTEM

NAMI CA gathered extensive feedback from family members regarding what has been beneficial for them and their loved ones. The following table outlines community-defined strategies to improve the mental health landscape for diverse communities, especially as individuals and their families seek services.

RESPITE FOR FAMILIES	
	"I live in Alameda County. One of the contracted service providers (STARS) has been very helpful in preventing caregiver burnout. They provide a case manager and a peer support counselor that will come to us. That interaction with my son happens out in the community and gives us a little break and room to breathe." *- TAY [Transitional Age Youth] Focus Group Participant*
EDUCATION AND SUPPORT FOR NAVIGATING THE SYSTEM	
	"NAMI has provided me with educational information and resources for my family member that I did not have access to previously. They are welcoming and supportive, which I have yet to find anywhere else, including my brother's own psychiatrist or my own therapist." *- Families Mental Health Respondent* "Children have supervision and families have education, 'Family camp by Stanford Psychiatric and Fellowship students for specific psychiatric disorders.' The families go with them and optional breakout sessions. Group activities for children and parents who can interact and learn information. A session was about how to get siblings get along, had speaker from someone who jumped from golden gate bridge to speak about experience. Safe space was offered." *- Families Focus Group Participant*
PREVENTION & EARLY INTERVENTION	
	"We were able to access Kickstart Early Intervention Psychosis Program. Kickstart has the most comprehensive service program - individual counseling, family therapy, multi-family therapy & problem solving, medication treatment, school support, occupational support, mindfulness & other useful support classes. The only service we did not have access to through Kickstart was a high level psychiatrist to get a true diagnosis. The personnel at Kickstart were able to get my child through 2 and 1/2 years of self-harm, running away, multiple psychotic breaks & being expelled from school due to the stigma from educational administration. She has not had a psychotic episode in almost 5 years now due to their ability to teach her & our family how to identify triggers and how to have long term coping strategies. My daughter still suffers anxiety and depression, but she now can cope as they arise." *- Families Mental Health Survey Respondent* "By accessing early intervention my family member was able to learn communication skills and coping mechanisms to deal with anxiety and depression as an adult." *- Families Mental Health Survey Respondent*
CRISIS INTERVENTION TEAMS	
	"Napa County has been adequate and responsive with crisis intervention, board and care facilities in the past when we needed them. NAMI Solano County is available to Napa residents." *-Families Mental Health Survey Respondent* "San Francisco's Mobile Crisis team is wonderful. They were a great help when family member was in crisis." *-Families Mental Health Survey Respondent* "Having someone from the crisis team respond to the emergency or having the social worker respond to the emergency call before the crisis, or a visit from a social worker to do an assessment." *-Families Mental Health Survey Respondent*

CONCLUSION

Through this project, NAMI CA worked with families and individuals across the state to increase understanding of the needs of families and the importance of family involvement in the overall design and implementation of mental health programs, supports, and services. While NAMI CA has been working with families for more than 40 years, the landscape of the system has changed greatly over time. It is critical that agencies and entities take the time to hear from families and individuals to ensure the relevant and timely issues that impact families are identified early and often.

These findings will have important implications for further mental health research and the development of effective and innovative interventions to addressing the complex needs of individuals living with mental illness and the families that are caring for them. These findings also provide a roadmap for continued advocacy on behalf of families as priorities and policies can be developed in response to the needs of those across the state.

NAMI CA will continue to work directly with families and individuals to support the development of programs and services that meet families where they are, can be accessed by those in need, and bring comfort and support to those across the state that are caring for a loved one living with mental illness. NAMI CA will continue to share these findings to create positive change, advocate for expansion of and increased access to available services and supports, as well as identify strategies to improve the lives of individuals and families across the state.

APPENDIX A

DEFINITIONS

Any Mental Illness (AMI): a mental, behavioral, or emotional disorder. AMI can vary in impact, ranging from no impairment to mild, moderate, and even severe impairment.[2,3]

California Department of Health Care Services (DHCS): is the backbone of California's health care safety net, helping millions of low-income and disabled Californians each day. DHCS oversees the Mental Health Services Division (MHSD), which administers several mental health programs for children, youth, adults, and older adults.[4]

Conservator of the person: A person appointed by the court to make decisions about personal matters for the conservatee, including decisions about medical care, food, clothing, where the person will live (In some states there are rules about placing someone in a locked mental institution against his or her will). The conservator must file reports to the court once a year.[12]

Conservator for the estate, conservator for finance: A conservator that handles the financial and legal affairs of the conservatee. The conservator has the power to collect all the conservatee's assets, pay bills, make investments, etc. The conservator must seek court supervision for major transactions, such as purchase or sale of property, borrowing money, or gifting of assets. The conservator must give a financial record of all expenditures to the court once a year.[12]

LPS Conservatorship (Lanterman-Petris-Short Act): This form of conservatorship is for an individual who has been found to be "gravely disabled" and can be used to involuntarily commit him/her to a mental institution. It is designed for people with serious mental disorders or who are impaired by chronic alcoholism or drug abuse. An LPS conservatorship, unlike a probate conservatorship, must be initiated by the county government—a spouse or other relative cannot petition for an LPS conservatorship.[12]

Crisis Intervention Teams and Mobile Units: These teams are trained to work with individuals with mental illness and have both police and medical personnel on the team, in efforts to reduce the number of individuals that are placed in the criminal justice system and to be able to provide them the care they need.[6]

Consumer: an individual of any age who is receiving or has received mental health services. Some consumers and agencies alike also use the terms 'client,' 'survivor patients,' or 'ex-patients' (cite)

Department of Mental Health (DMH): From 2004 until 2012, the California Department of Mental Health (DMH) was the primary state agency responsible for overseeing the implementation of the MHSA. In 2012, a change in state law dissolved DMH and transferred the majority of its MHSA duties to the Department of Health Care Services (DHCS).[3]

Family Member: any individual who is now or ever was in the past the primary caregiver for a child or youth with a serious mental health condition who accessed services, particularly public services, for that condition. Families can include biological, adoptive, grand- or foster parents, siblings, or other kinship caregivers, friends, and others. [3]

Lived Experience: a person who is employed in a role that requires them to identify as being or having been a mental health consumer or caregiver. [3]

Mental Health Services Act (MHSA): also known as Proposition 63, is a law that was approved by California voters and took effect on January 1, 2005. MHSA establishes a 1% tax on personal income over $1 million to expand mental health care in California.[14]

ental Health Services Oversight and Accountability Commission (MHOAC): the role of the MHSOAC is to oversee the implementation of the Mental Health Services Act (MHSA). The MHSOAC is also responsible for developing strategies to overcome stigma. At any time, the MHSOAC may advise the Governor or the Legislature on mental health policy. [15]

Peer Support A recovery-oriented treatment model in which individuals provide mental health services in a clinical setting who have received formal peer support provider training and/or certification; as well as having their own lived experience and recovery of a mental health condition. [3]

Public Mental Health System (PMHS): Publicly funded mental health programs/services and entities that are administered by the California Department of Health Care Services, or a California county. PMHS does not include programs and/or services administered by federal, state, county or private correctional entities or programs or services provided in correctional facilities (9 CCR § 3200.253). [3]

Recovery: "A process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential.[3]

SAMHSA (Substance Abuse and Mental Health Services Administration): the agency within the U. S. Department of Health and Human Services that leads public health efforts to advance the behavioral health of the nation. SAMHSA's mission is to reduce the impact of substance abuse and mental illness on America's communities.[11]

Serious Mental Illness (SMI): is defined as a mental, behavioral, or emotional disorder resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities. The burden of mental illnesses is particularly concentrated among those who experience disability due to SMI.[3]

Stakeholder: an individual or group which has an interest in or is affected by a nonprofit organization and its services. Examples of stakeholders include. [3]

- **Beneficiaries:** People who use the services provided by the nonprofit organization.
    - Donors and Funding Sources: Those who help fund the operations of the nonprofit organization.
    - Community: The surrounding community has a stake in how well a nonprofit organization completes its mission and objectives.
    - Employees and Volunteers: Provides vital services to keep the nonprofit running.
    - Federal, State, and County Administrations: Government entities require nonprofit organizations to provide various reports in exchange for funding, tax exemption, and tax deductions.

APPENDIX B

YEAR 3 STAKEHOLDER FAMILIES FOCUS GROUPS QUESTIONS

The following questions were developed, with feedback from our Advisory Committee members, for use in NAMI CA Year 3 focus groups.

1. **Family Caregivers/Advocate Support Roles** - Family members and caregivers of their loved one(s) with a mental health condition experience high rates of burn out.
    a. What supports and/or programs would be useful in reducing caregiver/advocate burn out?
    b. Prior focus groups discussed “whole family” case management. What would that look like for your family and in what ways would it help to prevent caregiver burn out?
2. **Service Accessibility** - Previous research has shown that providers of professional mental health services are becoming fewer and more difficult to access.
    a. What solutions could ease some of the issues in accessing mental health care for individuals and families?
    b. Has your family used alternative methods to accessing treatment (i.e., telepsychiatry, suicide prevention hotline, traveling outside of community to access services)?
        i. If yes, please describe your experience.
3. **Early Intervention** - Early intervention for teens and young adults can reduce the impacts of mental health conditions on the family.
    a. What types of early intervention services are available in your community? Has your family utilized these services?
    b. How has the school system handled the mental health concern of your students?
4. **Public Mental Health** – Individuals with mental illness experience encounters with law enforcement at higher rates. Currently, policies and trainings are trying to improve these interactions..
    a. Has your family member ever been arrested during a crisis? If yes, describe the process (i.e., legal assistance, outcome of court case, etc.)
    b. What mental health services/treatments do you know of that were provided throughout the process?

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