

The 2021-2022 Annual State of the Communities Report with **Families**

“You are not alone”



THIS PAGE INTENTIONALLY LEFT BLANK

Contents

Acknowledgments	5
About NAMI CA.....	6
Preface	7
Family Member Contribution to Mental Health Treatment	7
Impact of COVID-19	7
Needs of Families	8
The Criminal Justice System and Mental Health	8
Housing	8
Family Involvement in Care	9
Lanterman-Petris-Short (LPS) Act.....	9
Care Court.....	9
Family-Driven Solutions and Recommendations.....	10
Supporting the Needs and Barriers of Caregivers.....	10
Access to Care	10
Continuum of Care.....	10
Crisis Care.....	11
Insurance Cost	12
Cultural and Linguistic Competence.....	12
Anosognosia.....	12
Stigma.....	13
Conclusion	14
End Notes.....	15

THIS PAGE INTENTIONALLY LEFT BLANK

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 our members, the leadership of the local NAMI affiliates, and our many state and local partners across California.

This report is the result of a strong collective state and local effort. Special acknowledgments 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 thanks the many state and local

leaders who supported this project, most notably the Mental Health Services Oversight and Accountability Commission as the funder for this work. Thank you to the NAMI CA staff, specifically to **Sofia Amezcua, Ashlee Espinoza, Ragini Lal, Cithlaly Lopez**, and **Tory Martinez** 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 CA

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 58 local affiliates and represents 19,500 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 to create acceptance, awareness, and eradicate stigma. For many years, NAMI CA has contracted with 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 over 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 awarded funding 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 outline 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 to improve services and support for all.

Preface

FAMILY MEMBER CONTRIBUTION TO MENTAL HEALTH TREATMENT

Research throughout this project suggests that familial support is a major agent in the psychosocial development of individuals who suffer from mental health problems. Studies on family involvement in mental health treatment report that increased familial support improves patient outcomes, especially when family members are well-informed of their loved one's mental health condition and are given proper clinical guidance.¹ Psychoeducational services provide family members with information that can help them detect a mental illness and intervene, as well as assist in the elimination of stigma. Fostering a partnership between families and mental health providers would generate a treatment plan that adheres to the families' values and strengths. In cases where families are left feeling excluded from their loved one's treatment, the lack of communication between caregivers and healthcare personnel can hinder the patient's progress. More research focused on the role that family members play in a family-driven setting would attest to the importance of familial involvement in mental health treatment, improve the well-being of the patient, and provide better guidance to clinicians when developing a family-centered plan.² It is of great importance to continue to provide families with resources that will ensure they are well-equipped and educated to be involved in the care of their loved ones.

IMPACT OF COVID-19

As the U.S. transitions from pandemic to endemic, the public expresses frustration as COVID-19 continues to negatively affect the physical, financial, and mental state of many. Research by leading health experts shows that COVID-19 has increased the number of people reporting symptoms of psychological distress, depression, anxiety, or post-traumatic stress.³ The unpredictability and misinformation of the virus have caused a panic that has become an unprecedented

stressor of mental health issues. Mental health services have been in great demand but have been disrupted through the reassignment of mental health staff and the inaccessibility of its care.

Based on 2022 findings from Mental Health America and their Online Screening Program, COVID-19 had negative effects on mental health throughout the United States.⁴ For instance:

Figure 1

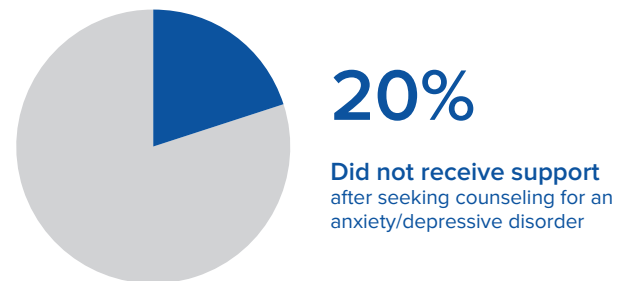


Figure 2

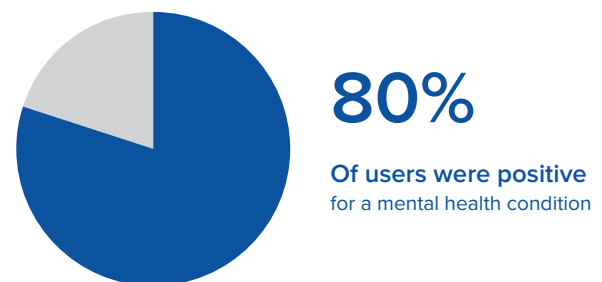
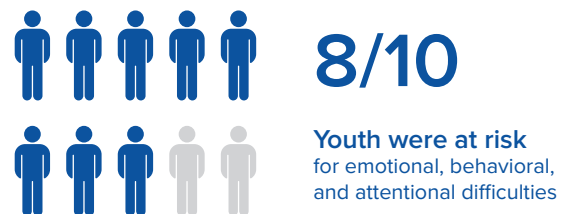


Figure 3



Needs of Families

To assist the needs of families across California, NAMI CA aims to provide supports and services to individuals and families that are affected by mental illness. Through extensive community engagement efforts, NAMI CA identified the needs of families to be related to the Criminal Justice System and Mental Health, Housing, Family Involvement in Care, Lanterman-Petris-Short (LPS) Act, and the CARE Court.

THE CRIMINAL JUSTICE SYSTEM AND MENTAL HEALTH

Considering the increase in interactions between law enforcement and peers and their families, efforts were made to improve the outcome of those exchanges. NAMI CA spearheaded legislation to improve required training for law enforcement, emergency dispatchers, and other first responders. In 2020, the Commission on Peace Officer Standards and Training (POST) agreed to partner with NAMI CA to re-write the emergency dispatchers' basic training course to include training hours that address calls that are related to mental health. Additionally, to support our Officers and their families, NAMI CA continues the NAMI COPE training program, which trains peace officers to become Peer Support Group Facilitators using the NAMI Connections Model and establishes peer support groups within law enforcement agencies. Peace Officers receive education credits for training. NAMI CA has renewed our course certification with POST for the 2021-2022 and has included dispatchers in the program.

HOUSING

Due to California's growing homeless population, there is a public need for more outreach programs that work with homeless individuals, specifically those who are hesitant or unwilling to accept help. According to recent findings, more than 52% of homeless individuals in California suffer from severe mental illness or have a drug addiction.⁵ Increasing and improving outreach programs would ensure housing and mental health services are available to them

regardless of their living conditions. Additionally, most families are unable to cover the cost of housing for their loved ones despite receiving SDI. Housing options for mentally ill individuals should be made more accessible and have support services including but not limited to, case management, clinical services, and transportation.

This year, NAMI CA supported:

- **AB 2547:** Grants housing subsidies and offers stable housing to older Californians and people with disabilities—including mental illness—who are facing or experiencing homelessness.
- **SB 1338:** CARE Court is Governor Newsom's proposal to deliver mental health and substance use disorder services to the most severely impaired Californians.

"Homeless services for our loved one living on the streets. One's that will come out on the streets to provide services."
– NAMI CA Stakeholder Survey Respondent, 2022

"We can't afford to supplement housing near the place where he could access the integrated care team that cared for him early in his illness"
– NAMI CA Stakeholder Survey Respondent, 2022

In need of "Access to affordable, clean, and safe housing"
– NAMI CA Stakeholder Survey Respondent, 2022

FAMILY INVOLVEMENT IN CARE

Families should take an active part in treatment decisions and use their relationship and unique knowledge of their loved ones to create better outcomes. This includes promoting a client- and family-centered approach that gives the individual motivation to fully participate in the planning, monitoring, and evaluation of their treatment. Further, efforts should ensure that the family has access to the information, skills, and support to make informed decisions as equal partners in treatment. Systems and supports should be developed to ensure that families of individuals living with serious mental illness can easily access mental health and related services for their loved one without being required to navigate multiple, complex, and overly bureaucratic systems.

LANTERMAN-PETRIS-SHORT (LPS) ACT

In California, there are critical treatments that fall short; much to do with the lack of policy requiring health plans and insurers to cover the needs of individuals that are placed on hold and follow-up care thereafter. Currently, there is no mandated standard of care after a 5150 hold; however, a prompt follow-up after discharge from a psychiatric hospitalization with an outpatient MH provider is critical to patient outcome.

This year, NAMI CA supported:

- **AB 1859:** Requires health plans and health insurers to approve medically necessary treatment of a mental health or substance use disorder for individuals involuntarily detained under the Lanterman-Petris-Short (LPS) Act (a “5150 hold”).
 - Governor Newsom vetoed, claiming provisions would be unenforceable and lead to undue confusion.
- **SB 929:** Addresses a data shortfall that exists on what services are provided to those under various LPS Act holds and their outcomes.
 - Governor Newsom signed into law on September 25, 2022.

CARE COURT

For serious cases of untreated schizophrenia or other untreated psychotic disorders, family members, friends, first responders, and behavioral health workers can now seek the support of the CARE Court. CARE Court (SB 1338) is designed to support individuals that are unlikely to survive without the supervision of others or who become a threat to themselves or others. Signed into law on September 14, 2022, CARE Court intends on providing housing and treatment to people experiencing severe mental illness and homelessness.

NAMI CA was engaged at each point in the legislative process, testifying at committee hearings, meeting with the Governor, delivering over **300 support** letters from members, and working with the Administration on amendments to ensure family involvement in the CARE Court process. NAMI CA will be at the table throughout the implementation process. Leadership in the Legislature has asked that we report back to them on how it is being implemented in each of our counties.

Family-Driven Solutions + Recommendations

Families across California often encounter barriers in the public mental health system that makes it difficult to access care. To close the gaps in the mental health care system and provide families with critical services, NAMI CA's efforts focused on identifying and understanding the challenges faced by families to successfully contribute towards finding solutions by providing insightful and relevant information, resources, and services.

SUPPORTING THE NEEDS AND BARRIERS OF CAREGIVERS

Family members play a crucial role for many living with mental health and can connect those in need with treatment, resources, and services; however, most family members and caregivers report having difficulty accessing care. Approximately 39% of NAMI CA stakeholder survey respondents reported rarely or never receiving adequate support as caregivers of their loved one(s), while less than 5% of respondents reported always receiving the support they need. Due to California's fragmented mental health system and the inaccessibility to its care, NAMI CA strives to provide guidance and resources to thousands of Californians who are struggling with structural barriers related to Access to Care, Continuum of Care, Crisis Care, Insurance/Cost, Cultural Linguistic Competence, Anosognosia, and Stigma.

ACCESS TO CARE

California does not have a centralized mental health care system nor an oversight body that is tasked with ensuring equitable access and service delivery. Rather, the responsibility lies within multiple agencies, service delivery, and accessibility from county to county. This means that many families end up navigating a county-based system that often does not have the

necessary services and support for their loved ones. Further, many families are not aware of the structure of the mental health system and are not equipped to effectively navigate their loved one's care. Due to COVID-19, many patients and their families had to transition and adjust to telehealth services. To educate Californians on telehealth and its care, NAMI CA hosted Alliance for Patient Access (AFPA) at the March 2022 Town Hall Forum, "Balancing in Person and Telehealth Care." AFPA provided information regarding the background and future of mental health telehealth services and discussed an in-depth perspective on finding a balance between telehealth and in-person care for mental health treatment.

"6-month waitlist to see a psychiatrist; lack of clarity about access to care due to emphasis on 'meeting criteria'..."

– NAMI CA Stakeholder Survey Respondent, 2022

CONTINUUM OF CARE

A continuum care model provides patients with guidance over an extended period and ensures the patient's needs are well comprehended by providers. The concept of continuum care is not a service provided by all systems. A fragmented system fails to oversee a patient's progress through the various transitions in their life, which can impact patient progress. Thus, patients and their families would greatly benefit from better access to case management, as it would help them overcome systematic barriers and provide them with guidance over an extended period. Case managers work directly with the patient to formulate a treatment plan that is tailored to their needs. They assess a patient's

strengths, support system, and other factors to have a comprehensive understanding of their needs and also provide patients with wraparound care.

Solutions to support Continuum of Care:
 "wrap-around services that ensure success"
 – NAMI CA Stakeholder Survey Respondent, 2022

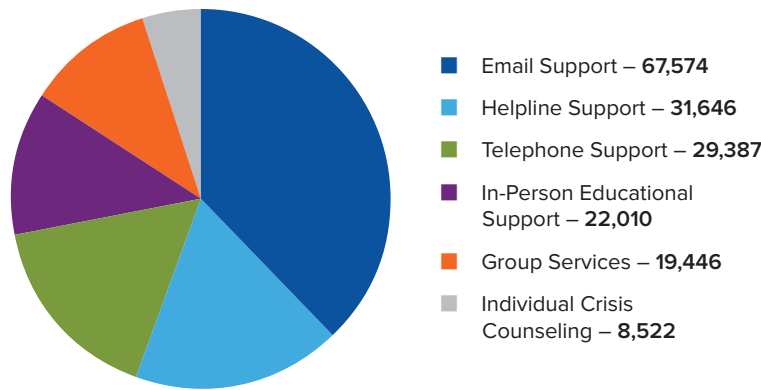
CRISIS CARE

On September 29, 2022, Governor Newsom signed Assembly Bill 988, which enacted the Miles Hall Lifeline and Suicide Prevention Act to establish 9-8-8 centers in California to connect individuals experiencing a behavioral health crisis with mental health services. Through the implementation of the 3-digit dialing code, individuals experiencing a mental health crisis can receive crisis intervention

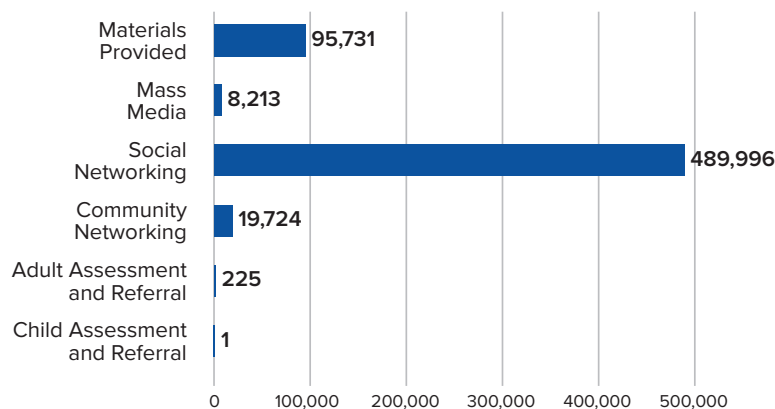
and support 24/7 and be connected to trained crisis counselors who will resolve their urgent needs on the phone or by text. NAMI CA co-sponsored the state's implementation of 988 and continues advocating for mobile crisis teams in every community.

Through the efforts of NAMI CA and seven NAMI Affiliate partners, a total of 178,585 individuals and families were served with a total effort of 613,890 various efforts and contact provided to peers, families, and communities. NAMI California is a proud supporter of CalHOPE, the state's crisis response program to help members of our communities impacted by the pandemic. In 2020, the program was greatly expanded to address the unique need for mental health support during the COVID-19 crisis. In partnership with local NAMI affiliates, NAMI CA strives to offer safe, secure, and culturally sensitive emotional support for all Californians who have been impacted by COVID-19.

Graph 1: Number of individuals served through various service types



Graph 2: Various other services provided to reach peers, families, & communities



INSURANCE COST

In 2020, California's Mental Health Parity Act was amended to address the roadblocks many individuals face when trying to find behavioral health providers that will accept their insurance. This law requires state-regulated health plans to provide coverage for all treatments related to mental health conditions and substance abuse disorders. Despite these legislative efforts, 43% of individuals seeking behavioral health services are still unable to secure appointments with providers that will accept their health insurance plan.⁶ The COVID-19 pandemic revealed the lack of providers that offer telehealth care and accept Medi-Cal coverage. This year, NAMI CA hosted a Town Hall Forum where Kantor & Kantor LLP representatives presented on "Navigating Mental Health Insurance." Their team educated patients and their families about health insurance policies and the different ways to receive insurance benefits to cover the costs of mental health treatments.

"As a 'poor' person on disability, using Medi-cal there is a lack of continuum of quality care with a qualified psychiatrist assigned, lack of WRAP services to treat person that is easily accessible..."
– NAMI CA Stakeholder Survey Respondent, 2022

CULTURAL AND LINGUISTIC COMPETENCE

Disparities in access to mental healthcare have proved detrimental to the diverse communities of California. BIPOC (Black, Indigenous, and People of Color) often encounter barriers in accessing their needed care, primarily due to a lack of healthcare insurance, racially diverse mental healthcare workers, and culturally competent providers. The Bureau of Labor Statistics reported that 88% of mental health counselors in the U.S. workforce were white, revealing an underrepresentation of BIPOC.⁷ The lack of cultural and linguistic competence among mental health providers can result in the misdiagnosis and underdiagnosis of

BIPOC. Thus, marginalized communities are often left feeling unsupported and alienated. Over the years, we've heard from NAMI Affiliates, community partners, consumers, and families about the challenges and lack of resources for diverse communities and we have responded to the need. NAMI California's Annual Multicultural Symposiums are hosted to bring together community leaders from across our state to discuss existing problems and find solutions to increase resources, ensure access, and promote culturally appropriate programs in diverse communities.

"Language Barrier. Services are not familiar in the community, especially for non-speaking English family members. [Non-speaking English family members] are isolated and have trouble alone."
– NAMI CA Stakeholder Survey Respondent, 2022

ANOSOGNOSIA

Anosognosia is a symptom of severe mental illness that is experienced when an individual is unable to understand and perceive their illness. Without being aware of the illness, refusing treatment appears rational, no matter how clear the need for treatment might be to others. The rate of those with SMIs who experience anosognosia is high, with "40% of individuals suffer with bipolar disorder and, by some estimates, as high as 98% of those are diagnosis of schizophrenia."⁸ It is common for people with anosognosia to disagree with family over treatment since they do not view it as necessary, which can result in their poor adherence to treatment or avoidance of their treatment altogether. Families experience barriers while trying to support their loved ones who have anosognosia, as it impedes families from properly caring for their loved ones. Through NAMI CA's local affiliates, family support groups are offered to family and community members who have loved ones with mental health conditions, including anosognosia. These support groups are led by family members who understand first-hand the challenges

of caring for a mentally ill family member and teach families coping skills and tips on how to communicate with their loved ones.

"Anosognosia that "no one" seems to want to deal with."

- NAMI CA Stakeholder Survey Respondent, 2022

STIGMA

Stigma, as it relates to mental health, deters individuals from seeking mental health services due to self-stigma, public stigma, or both. Self-stigma invokes shame in people who are experiencing a mental health condition, while public stigma stems from stereotypes about those who have a mental illness. Cultural stigma causes many BIPOC communities to associate mental illness with shame and embarrassment, abnormality, and weakness.⁹ Additionally, toxic masculinity hinders men from

speaking about their feelings and seeking mental health support, resulting in detrimental consequences.¹⁰ LGBTQ+ individuals experience mental illness at a higher rate due to public stigma and are likely to experience strong rejection from family and friends.¹¹ To aid in the elimination of stigma, NAMI CA affiliates offer programs such as Mental Health 101 and NAMI In Our Own Voice (IOOV), which are informational outreach programs on recovery that provide presentations and testimonies from people who have struggled with mental health disorders. Through these programs, NAMI CA aims to change the attitudes and assumptions made about people with mental health conditions and offer different audiences the opportunity to listen to various perspectives on a highly misunderstood topic.

"There is still stigma attached to mental illness and no one in my circle of friends and family want to deal with it."

- NAMI CA Stakeholder Survey Respondent, 2022

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. Agencies and entities must 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 address 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 and NAMI CA affiliates consist of passionate teams who continue to work towards improving mental health support and services across California through their direct engagement with individuals, families, and caregivers who are affected by the challenges of mental illness. NAMI CA will continue to share these findings to ensure families and community members have the information, updates, and resources they need to properly care for their loved ones. Through collaborative efforts, NAMI CA strives to create positive change, shape public policy, promote better access to care, and elevate the voices of thousands of individuals and families across California.

End Notes

1. LEGGATT M. Families and mental health workers: the need for partnership. *World Psychiatry* 2002; 1: 52.
2. Maybery D, Jaffe IC, Cuff R, et al. Mental health service engagement with family and carers: what practices are fundamental? *BMC Health Serv Res* 2021; 21. DOI:10.1186/S12913-021-07104-W.
3. The impact of COVID-19 on mental health cannot be made light of. 2022; published online June 16. <https://www.who.int/news-room/feature-stories/detail/the-impact-of-covid-19-on-mental-health-cannot-be-made-light-of> (accessed Nov 2, 2022).
4. Mental Health and COVID-19: Two Years After the Pandemic, Mental Health Concerns Continue to Increase | Mental Health America. <https://mhanational.org/mental-health-and-covid-19-two-years-after-pandemic> (accessed Oct 30, 2022).
5. Aubry T, Goering P, Veldhuizen S, et al. A multiple-city rct of housing first with assertive community treatment for homeless canadians with serious mental illness. *Psychiatric Services* 2016; 67: 275–81.
6. Marashi S. New DHCS behavioral health assessment identifies disparities, stakeholders give recommendations to improve services - State of Reform | State of Reform. 2022; published online Jan 20. <https://stateofreform.com/featured/2022/01/dhcs-behavioral-health-assessment-data-services/> (accessed Oct 30, 2022).
7. Employed persons by detailed occupation, sex, race, and Hispanic or Latino ethnicity. <https://www.bls.gov/cps/cpsaat11.htm> (accessed Oct 30, 2022).
8. Lockard T. Anosognosia: A Big Word for a Surprising Condition | NAMI: National Alliance on Mental Illness. 2022; published online Aug 22. <https://nami.org/Blogs/NAMI-Blog/August-2022/Anosognosia-A-Big-Word-for-a-Surprising-Condition> (accessed Oct 30, 2022).
9. Misra S, Jackson VW, Chong J, et al. Systematic Review of Cultural Aspects of Stigma and Mental Illness among Racial and Ethnic Minority Groups in the United States: Implications for Interventions. *Am J Community Psychol* 2021; 68: 486–512.
10. Chatmon BN. Males and Mental Health Stigma. *Am J Mens Health* 2020; 14. DOI:10.1177/1557988320949322.
11. Stigma and Discrimination Affects Gay and Bisexual Men’s Health | CDC. <https://www.cdc.gov/msmhealth/stigma-and-discrimination.htm> (accessed Oct 30, 2022).



www.NAMICA.org • (916) 567-0163 • nami.california@namica.org