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# NAMI EAST BAY NEWSLETTER

A local affiliate of the National Alliance on Mental Illness (NAMI)

September-October 2022

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## Hearing Voices Network Wednesday, September 28, 7:30 pm

The speaker and discussant at our September 28 meeting, **Cindy Marty Hadge**, is a Lead Trainer for the Wildflower Alliance and Hearing Voices Network USA, and she is an international award-winning trainer and keynote speaker. Cindy spent many years struggling with trauma, use of both prescribed and un-prescribed drugs, and distressing voices, while receiving services from a mental health system that was at times helpful but was also frequently injurious. She is now creating a life she finds worth living through the healing environment of the Wildflower Alliance, the Hearing Voices Movement, and a belief in a loving higher power. In doing so, she has found that all her struggles have value in creating space for herself and others to heal.

Cindy will share her experience of navigating her voice-hearing experience and supporting others to do the same.

### Speaker Meeting starts at 7:30 pm

The presentation will be **Zoom/online**, and attendees should preregister at our website: <https://namiastbay.org>, click on "What's New," and follow the link.

**Note:** The meeting will be available in written summary in the newsletter, and video-recorded and accessible via the What's New link on our website.

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## Support Meetings

For the duration of shelter-in-place and social-distancing orders from Alameda County, NAMI East Bay is offering online **Family Support Meetings** every Tuesday from 6 to 8 pm via Zoom. You can go to our website <https://namiastbay.org>, click on "What We Offer," and follow the link to "Online Support Groups."

**Note:** Invites to a Zoom meeting will include phone numbers, links, meeting identification, and passwords. You can join any meeting by phone and

voice only, but to participate by video you need to download the [Zoom app](#) before joining the group.

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## In Memory of Rebecca Woolis

It is with a heavy heart that we share the sad news that our friend Rebecca Woolis has passed away. Rebecca was a family therapist in Berkeley, and she wrote the excellent book, [When Someone You Love Has a Mental Illness](#). Besides holding down a successful psychotherapy practice, among other activities, Rebecca participated in the county's Crisis Intervention Training for local law enforcement and was the director of the Bonita House Wellness Center. She was a friend to NAMI East Bay and often made presentations to our group. She was also a dear personal friend, and we shall miss her dreadfully.

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## Dues Notification

As we are ending Post Office delivery of hard-copy newsletters, we can no longer rely on the address labels to let you know your membership status. You should receive a notice from the national NAMI organization when your membership expires, and you can also email our office to learn that information. We feel strongly that our services should be available to all, but we certainly appreciate your financial support. We will also provide some ongoing accessible information to non-computer-using members.

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## 988 Alameda County

988 is the new number for the existing National Suicide Prevention Lifeline (800-273-8255), where free compassionate support is available 24/7 for anyone. This number was rolled out in July and represents a nationally available help line and crisis call center. For a comprehensive overview of this service, check out [988alamedacounty.org](https://988alamedacounty.org) to see information about the process and what you can expect, the kind of help available, responses to questions such as the 911/988 difference, and to meet some staff.

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SPEAKER NOTES

## Prevention and Early Intervention in Psychosis: A Window of Opportunity to Change the Course of Serious Mental Illness

*Summarized by Thomas T. Thomas*

According to the National Institutes of Health, 100,000 youths and young adults in the U.S. experience a first episode of psychosis each year (NIH, 2013). And yet, it takes 21 months on average before someone can receive specialized treatment for early psychosis after they first begin experiencing symptoms (NIMH, 2019). Coordinated specialty care for early psychosis is a treatment model provided with evidence-based components designed for early detection, individual psychotherapy, strength-based care management, supported employment and education, judicious medication management, and peer and family support.

**Adriana Furuzawa, MA, LMFT, CPRP**, a clinical and hospital psychologist, is the director of [Felton Institute's Early Psychosis Division](#). She oversees the implementation of the (re)MIND® program (formerly known as PREP – Prevention and Recovery in Early Psychosis) offering care in five counties in the San Francisco Bay Area and Central Coast.

Started as the Family Services Institute of San Francisco 130 years ago, the institute was renamed for a dynamic director, Kitty Felton, about ten years ago when it branched out to Alameda County. It has subsequently expanded to San Mateo, Monterey, and Marin counties. Their work is funded through each county's behavioral health department and receives state and federal support.

Felton's (re)MIND® programs for prevention and recovery in early psychosis were first implemented in 2007 in partnership with UC San Francisco. "We were always a community mental health program walking hand in hand with research," Furuzawa said. Felton Institute is nationally recognized for bridging the gap between science and community-based services. "Usually it takes twenty years for innovation in a university setting to reach the community," she said.

California pioneered this model as one of eight centers in the U.S. They use research data to "tell the story of the work that will help us find sustainability."

The Covid-19 pandemic tested some of the protocols involving in-person interviewing, and the institute had to find new ways to interact with clients. "But data showed us we could continue to deliver services," Furuzawa said.

The idea of early intervention was borrowed from physical health in treatment of conditions like high blood pressure and diabetes. The causes of serious mental illness are not always clear and include a variety of factors. If they are caught early, it may be possible to delay the onset of psychosis, reduce the numbers and length of hospitalizations, and reduce the burden to the person, the family, and society.

Schizophrenia affects about 2.5 million Americans. In 2013, the average time lag between onset of psychosis and start of treatment in the U.S. was one to three years; now it's about a year and a half. The World Health Organization standard is three months or less—and some countries actually achieve that.

When asked about psychosis, most people believe it involves being untethered, mixing reality and fantasy, or is connected with dreams. They think it is something severe, out of control, part of major mental disorders, a break with reality as perceived by most people, and like falling off a cliff, never to return. But psychosis is an umbrella term and represents a spectrum that is part of the normal human experience.

At one end of the spectrum are the transitory sensations, like misinterpreting a shadow for a shape or feeling the phantom buzz of the cell phone in your pocket when it really isn't ringing. This advances to catching sight of or hearing the voice of a deceased loved one during a period of grief—which may be culturally appropriate. Culture is a background against which some of these experiences need to be tested. Further down the spectrum would be hearing non-distressing voices or sounds. And at the far end is the full-blown diagnosis of a psychosis, where the person can't determine if he or she is dreaming or awake and may be aware of, as Freud would put it, "a part of the mind that is normally hidden from us."

Psychosis may involve experiences that are added to reality, those that are removed from reality, or experiences that are confused with reality. Still, the diagnosis is not a cliff you permanently fall over but a

condition from which you can recover. It is in the early stages, the prodrome between faint symptoms and the full-blown state, that the person may be at high risk but still have insight into the experience. The person may be struggling with the experience but still able to catch him- or herself.

Factors that contribute to developing a psychosis include life experiences, stress, trauma, sleep deprivation, and substance abuse. Genetics may also create a predisposition for biology and the environment to create conditions for psychosis.

Positive symptoms of psychosis may relate to perceptions: hearing or seeing things that others don't; smelling, tasting, or feeling unusual sensations; and increased sensitivity to light and sound. The person may exhibit unusual thinking or beliefs that only make sense to them, confusion about reality and imagination, believing song lyrics or television programs have special messages for them. They may feel suspicious and be preoccupied with the supernatural.

Negative symptoms include losing qualities that make us connected and motivated, losing pleasure in activities, having reduced emotions and expression, lack of will, less verbal ability, and rigid posture. The person may be disorganized in their communication, unable to get a point across or understand a conversation, ramble, or exhibit unpredictable behavior.

Functional impairments include difficulty with school or work, lacking personal goals, and losing friends, relationships, and social contacts. There may be cognitive impairments like memory loss, slowed thought processes, trouble planning ahead or solving problems, and impulsivity. The person may exhibit mood swings, feel sadness or emptiness, have disrupted sleep patterns, distraction and restlessness, and anxiety. Seventy-five percent of people with psychosis experience depression.

The question to ask is whether the symptoms are significant and impact the individual's ability to care for him- or herself. Psychosis does not always mean treatment is required. But you want to catch it early and address it.

The (re)MIND<sup>®</sup> program, which deals with schizophrenia and associated conditions, and the BEAM program, which deals with bipolar, depression, and mood disorders, are available in Alameda County for residents who qualify. They must be age 15 to 24, have access to Medi-Cal or be eligible for it, have

experienced the onset of psychotic or bipolar symptoms within in the past two years, and have symptoms that are not caused by substance abuse. The programs include:

- **Assessment** – This involves a clinical interview for DSM-5 symptoms and disorders if the patient has had a first break, or a structured interview for psychosis-risk syndrome if without a first break.
- **Therapy and Case Management** – The person is generally given Cognitive Behavioral Therapy for Psychosis (CBTp) and motivational interviewing, along with case management for symptoms.
- **Medication Management** – For early prevention, the approach to medication may be different from that for serious mental illness, where the goal is to reduce symptoms. In early intervention, the goal is to prescribe and monitor effectiveness at the lowest dose necessary and if possible to prescribe only one medication (monotherapy), rather than a mix or “cocktail” designed to gain immediate effect. Clients are informed of the risks and benefits with each medication and share in making decisions.
- **Support for Education and Employment** – The program will assist the client in finding opportunities for education and employment, as well as accessing accommodations.
- **Family and Peer Support** – The program works with young clients to help them build their “team” of support. It works on family education. An innovation that the Felton Institute helped develop is peer support among clients.

The Felton Institute's programs are centered on recovery. This includes recognizing the signs and symptoms of relapse and taking action quickly and appropriately. The client is encouraged to have goals beyond the immediate relief of symptoms, which may include in their work or schooling, acquiring hobbies, or living independently. Clients are also encouraged to build friendships and relationships and to connect with their families.

“Hope is our best ally against stigma,” Adriana Furuzawa said in conclusion. “Science is on our side, too.”

The full presentation recording is available on the [NAMI East Bay](http://www.namieastbay.org) website under What's New. Past Speaker Notes articles are available online at [www.thomasthomas.com/NAMI.htm](http://www.thomasthomas.com/NAMI.htm).

### Musing on Changes

Rather than do some self-indulgent musing in this issue, I need to alert readers to some upcoming changes at NAMI East Bay. Due to circumstances beyond my control, I am stepping down/back/side-ways from affiliate leadership. Because ours is primarily an all-volunteer organization, this has not provoked a clamor of folks desiring to step forward. Where is that coup when we need one? Accordingly, after some Board discussions and soul searching, we're suggesting some 2023 changes to a model which has been in place since 1981.

- **Newsletter** – Our every-other-month, six-page newsletter will be re-imagined. We will no longer be writing, printing, labeling, and mailing out a hard copy. It will all be online and consist primarily of alerts and announcements through our Mailchimp service, and we promise not to overburden your inbox. If you are presently receiving this newsletter in paper form and can change to electronic, let us know your email address. If you are a paid member with no computer access nor skill set, let us know and we will mail out a monthly sheet. What you're reading today will be the second-to-last paper edition. Recordings of speaker meetings will be available online and links will be sent out.
- **Support Groups** – The weekly Support Group will continue online, and we hope to expand our offerings in this area.
- **Speaker Meetings** – Our every-other-month Speaker Meetings will continue. We will be adding an online, content-focused discussion group on the fourth Wednesday of the in-between months. So keep each month's fourth Wednesday evening open for something NAMI.
- **Board of Directors** – When I was raising my kids in the '70s, much of our life was run by the co-op model, with a babysitting co-op, produce-buying co-op, cheese-buying co-op, preschool co-op. It worked when everyone took a share of the work and helped out. Accordingly, we are going to expand the number of our Board of Directors and extend an invite for you to join us. Rather than have one person holding onto and using the resource file, we are asking that Board members each pick some small area of resource knowledge and become our resident specialist. Our Board

meets once a month online for an information sharing and problem solving session, and it's a friendly group of compatible, experienced family members along with those with lived experience. Pre-pandemic, we even got together at social events. Think about joining our group.

- **Organizational Support Help** – We are currently looking for someone who is responsive, time-flexible, and comfortable with the tech world of website updating, Zoom, and bulk-mail processing to be available to us a few hours a month, paid or as a volunteer. We are so lucky to have an office manager/director in Sally Pugh, who handles phone calls, mail, and membership processing. Her role will be expanded.

So ... actions we need from each of you before January 2023 include:

1. If you are currently receiving our hard-copy newsletter, let us know your email address, since we will not be sending information to your home address, or
2. If you are not comfortable with receiving material online and you are a paid member, let us know and confirm your home mailing address.
3. Consider how you can help us out during this time of change. Would you like to join our Board? Could you take on some specific small area of resources to research and be our liaison specialist? Are you someone—or do you know someone—who is tech savvy and who can give us, paid or not, a few hours of help a month?

We look forward to continuing the good work of NAMI East Bay for the past 41 years through this time of change.

—Liz Rebensdorf, President, NAMI East Bay

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### Family to Family Classes

As we move into a period of transition for the affiliate (see above), we are putting our offerings of the popular eight-week Family to Family class on hold for a while. We suggest you check the websites of the Family Education and Resource Center (<https://FERC.org>) and NAMI Contra Costa ([www.namicontracosta.org](http://www.namicontracosta.org)) for information about planned class offerings.

### A Personal Story

*Editor's Note: This poignant piece was posted on Facebook by a regular member of our NAMI East Bay support group. It sums up so well the sad perspective family members share as they love and try to support their ill family member.*

Just going over all of the birthday wishes sent to me last week. Thank you to you guys near and far and old and new who texted or posted here. I appreciate being in your thoughts on what was my 48th year around the sun.

This year was bittersweet. As many of you know, especially those who have noticed our fourth wheel missing in our family photos for the past few months now. (Thanks so much for reaching in and checking to see what was up, and for those of you brave enough to get involved, you know who you are.)

A quick update for those of you that are unaware: My beloved best friend for 35 years, partner for the past 30, and co-parent for the past 12, has been suffering from severe mental illness issues. He was diagnosed with Bipolar 1 in November 2021 and tried to self-medicate with non-therapeutic drugs and this has led him to a place where we are no longer able to see eye to eye or heart to heart. In order to keep our family safe physically and emotionally, we haven't been able to connect with him and have no idea where he is or what he is doing. He has lost his phone multiple times and we are exhausted waiting and trying to reason.

The pandemic (and perhaps his broken arm last year) has added much more to whatever trauma he has endured in his life even before we knew each other. While that had not been a significant part of our connection, it has led him to not be able to share feelings or deal with them in a healthy way for a long time and he just lost it, as we all may have experienced at one time or another. I thought that the lifestyle we had been living with its minor ups and downs was normal, then being successful at raising these two blessings of children was helping us break cycles of past family habits and trauma; however

there are some deeper things there that not I nor our children can help him navigate.

Please keep him and our extended family in your thoughts. If you happen to see him wandering the streets of Oakland (which have been his home for the past nine months, by his choice), feel free to say hi or just walk by. I know it's confusing because you're like, "Wait, what? Do I say hi or do I walk the other way?" He's in a different world at the moment and the children and I have unfortunately come to the realization that until he decides to get the help he needs, all we can do is continue to educate ourselves about the signs, symptoms, and treatment for mental illness and substance abuse, pray that he can recover someday, and keep attending our therapy sessions and support groups.

I can't say what our future will hold, but I can say that I have had great models of single parents to help guide me and an amazing community of people who have been supporting us with important things that matter more now—phone calls, groceries, dinners, walks, and more. Every bit has helped us stay grounded.

Most of all, thanks to my new community and family of loved ones with mental illness and substance abuse issues. My NarAnon and NAMI support groups for loved ones that are struggling are really helping us understand what is going on. I didn't CAUSE it, I can't CONTROL it, I can't CURE it, and I can't CONCEAL it anymore, so I'm being transparent with this as I am with the rest of my life.

Thanks for reading, big ups to the friends, old and new, for holding us up to be able to hold it down and here is to new beginnings. Now we wait ...

It's a lot to handle and even harder to believe still. There are so many things that have been hard to witness and understand at this time. This too shall pass—and this is why we continue to pray and ask all of our spiritual guides for strength, protection, and courage.

Do the work, educate yourself, speak up, recognize and work on your shortcomings, and stay connected.



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Please check your mailing label. If the code "22" is over your name on the right side of the label, your dues are current through 2022. If your mailing label indicates a previous year, or nothing at all, your dues are not current.

We urge you to mail your 2022 dues now. And if you can afford to add a bit more, please do so. Your \$40 NAMI East Bay membership gives you our newsletter six times a year, the quarterly "Connection" from NAMI-California, and the NAMI-National "Advocate." NAMI East Bay is nonprofit [501(c)3] and your dues and contributions are tax deductible.

Family Membership, \$60 per year     Open Door Membership, \$5 per year

Make checks payable to "NAMI EAST BAY" and mail to NAMI East Bay, 980 Stannage Avenue, Albany, California 94706

Contact me for Family to Family Education Class

Name: \_\_\_\_\_ Phone No.: \_\_\_\_\_

Address: \_\_\_\_\_

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I'd like to volunteer:  In the Office     Grant Writing     Membership Committee  
 Hospitality Committee     Labeling Newsletters     Computer Committee