
NAMI EAST BAY NEWSLETTER

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

November-December 2022

Wellness Centers

Wednesday, November 16, 7:30 pm

A sometimes hidden gem among county services are the Wellness Centers or Hubs. Scattered throughout the county are six sites which offer welcoming, accessible, and supportive community spaces for individuals with a wide range of mental health needs. The sites have the goals of building community, encouraging independent skills, and providing support through groups and activities.

Bay Area Community Services (BACS, www.bayareacs.org) offers four hubs: Hedco, Towne House, South County, and Valley. Bonita House (www.bonitahouse.org) has two sites: the Berkeley Wellness Center and Casa Ubuntu Creative Wellness Center.

We are pleased to have the directors of wellness programs from each agency speak with us on Wednesday evening. **LeAnne Rozner** from Bonita House is a Licensed Marriage and Family Therapist. **Clarise Burton** is from BACS and she or a representative will be joining us. The speakers will be describing their programs and respond to questions.

At our January 25, 2023, Speaker Meeting, the presenter will be Rachel Pruchno, PhD, author of *Beyond Madness, The Pain and Possibilities of Serious Mental Illness*. She is an Endowed Professor of Medicine at Rowan University and director of research at the New Jersey Institute for Successful Aging. The book is endorsed by E. Fuller Torrey, MD, author of *Surviving Schizophrenia*. Rachel lives in Massachusetts; so rather than have her stay up late, we will be taping her talk earlier that day. If you read the book and would like to participate in the Q&A and discussion portion, let us know and we will send you the Zoom link for her talk.

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.

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.

CARE Court Becomes Law

After it was passed overwhelmingly in the state legislature, the Community Assistance, Recovery and Empowerment (CARE) Court was signed into law on September 14 by Governor Gavin Newsom.

The governor described the new program this way: "CARE Court connects a person struggling with untreated mental illness—and often also substance use challenges with a court-ordered Care Plan for up to 24 months. Each plan is managed by a care team in the community and can include clinically prescribed, individualized interventions with several supportive services, medication, and a housing plan. The client-centered approach also includes a public defender and supporter to help make self-directed care decisions in addition to their full clinical team."

CARE Court will focus on several thousand of California's most desperately ill citizens and is limited to people suffering from severe untreated mental illness, such as schizophrenia, schizoaffective disorder, and other psychotic illnesses. Although the law has been promoted as a fix for homelessness, the vast majority of people now living on the streets will be unaffected.

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SPEAKER NOTES

Hearing Voices Network

Summarized by Thomas T. Thomas

Cindy Marty Hadge, who spoke at our September 28 meeting, is Lead Trainer for the peers-led [Wildflower Alliance](#) in Western Massachusetts and for the [Hearing Voices Network USA](#),¹ where she is an internationally award-winning trainer and a keynote speaker. Cindy spent many years struggling with trauma, use of both prescribed and unprescribed 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.

Hadge began by describing a hypothetical “Patient A,” a middle-aged woman who lived alone, isolated herself and was afraid to go outside; depended on her adult children and food deliveries for sustenance; smoked cigarettes, drank, and watched TV; had no regular doctor or medical services; was unable to communicate; and tended to self-harm.

She then asked the audience what they thought the patient’s diagnosis was. Several people suggested depression and a thought disorder. And the prognosis? They said it depended on the patient’s internal and external condition. And what could the family do? Help her get meds and try to fix things. But one member also said that what works is gentleness, kindness, and “being present.”

Cindy Hadge then described her own experience. She was born at home with a cleft palate and hustled off to a hospital before her mother saw her. She had several intense surgeries and still was not the perfect baby, so she never got to bond with her mother. She recalled one Christmas in a hospital charity ward, where she saw a woman coming down the hall distributing presents and had her first vision, of an angel, and of “a loving mother who could protect me from evil.”

Her own mother had a drinking problem, for which doctors at the time prescribed Valium, and that made things worse. The woman took her own anger out on her daughter. Hadge started hearing a voice at age twelve, and it said that either she or her mother had to go. In response to the voice, Cindy internalized the conflict and began to injure herself.

Hadge engaged in magical thinking, believing that “If I am good enough, everything will be okay.” When her mother once hit her in the back of the head, Hadge thought she should have seen the blow coming. When she did hit back, she felt shame and guilt. “My parents were not nurturing people,” she said, “and I was a needy kid.” It would take thirty years for a therapist to finally explain that the voice was telling her to stand up for herself. “Instead, I was blind to myself, tried not to be me, not to remember, and broke into pieces.”

When she did get psychiatric help, she learned that the clinical setting mirrored the trauma experience. The voices instruct you not to tell what happened, and the clinical setting says if you tell you will lose your rights. The voices say people won’t believe you, and the clinician says your experiences are not real. The voices say that someone is trying to kill you, and the clinician calls you paranoid and prescribes medication.² The voices say you should be grateful to have it this good, and the clinician says to accept and be happy with a limited life. The clinician told Hadge she was doing well so long as she was not getting into trouble. And so Cindy Hadge became the hypothetical patient as described above, isolated and alone.

She eventually found support for her experience from the peers at the Wildflower Alliance and the Hearing Voices Network. Instead of finding the right pill to fix the problem, their aim was to find inner strength and for her to become an “expert of her experience,” to understand the origin and meaning of what the voice was saying. The group asked if she heard the voice all the time, and when she answered yes, they encouraged her to keep a notepad and record the time and the context of the experience. She began to see it was not always present and was repeating messages she had heard earlier in her life. “The voice

¹ It was in leader training that she met our own NAMI East Bay board member Ed Herzog, who is a founder of the [Bay Area Hearing Voices Network](#). The group helps people who hear voices, have visions, or have unusual experiences or beliefs.

² Cindy Hadge noted that she is not anti-medication. But a person might not want to take it for the rest of her life and might want other tools in the toolbox.

lost power when I could see it was coming from outside sources and the message was not true about me.”

The point, Hadge said, is that there is a human being in there, and they have a story and have value. And that things go better when you have a counselor who believes in you rather than someone trying to scare you into submission.

Hearing voices is actually common, and about 2.5% of people hear voices at some point in their lives, often after a loved one has passed or echoing some negative message they have heard earlier. Sometimes the voice is a spiritual guide or protector, sometimes it is religiously or culturally related.

“The voices often start after a major life event, such as a trauma or emergency,” Hadge said. “If the voice has a particular age, say, sounding like a six-year-old, that might indicate an event at age six.”

She offered general strategies for the person who hears voices or has visions. First, acknowledge that the experience is real and meaningful. Then, do not feel obligated to do what the voices say. Just because you don’t see or hear what others do, that doesn’t mean the experience isn’t real. Talk to others with similar experiences and learn to manage and integrate the experience into your life. Be curious about where your feelings and your fears may be coming from. And finally, talk about this in a safe space free from judgment, fear, and pathologizing.

When you are doing better and feeling stronger, then practice saying no. Set limits, listen selectively to the voices, and communicate more often and talk back to the voices. Use fewer distracting techniques, which might help you through a difficult moment but keep you from becoming an expert of the experience.

“Many frameworks work well,” she said, “except the ‘medical model,’ because it says that you are the problem and doesn’t allow you to get better.”

Hadge offered tools for a person to build power in relationship to the voices:

- Test the power of the voices and the extent of their knowledge.
- Practice saying no to the voices.
- Discover that you are not alone in hearing voices.
- Identify your inner strength and build on it.

For family and friends of a person who is hearing voices, having visions, or having unusual experiences and beliefs, she offered the following advice:

- **Validate the person’s feelings.** For example, “It

sounds hard, and I would be scared if a voice was getting angry at me.” Be respectful of the person’s experience.

- **Be curious about the experience.** “Does the voice sound familiar to you? Do you know who is yelling at you? Have you heard them before?” And interact with the voice if possible, such as, “Can I talk to the voice? What are you so angry about? Please stop yelling at my friend.” Help the person organize their own experience.
- **Express your own vulnerability.** “In my life, it’s been difficult to deal with angry people and negative feedback.”
- **Offer a sense of community.** “Would you like to talk with people who have similar experiences?”

Healing interactively includes building trust, mirroring back strength, and encouraging a person’s situational awareness. “And remember that family members can have feelings, too,” Hadge said. Fear is contagious, but hope is also contagious.

Q. Where can we find books and support groups for family members?

A. The Bay Area Hearing Voices Network offers a once-a-month [support group](#) and training for family members.

Q. It seems that family abuse is a strong source of the hearing voices phenomenon. Perhaps the answer lies in addressing parental and sexual abuse of kids.

A. Trauma is not always abuse. Depending on the sensitivity of the child, it can be traumatizing to go to a new school or to have an emergency that results in surgery.

Q. Is hearing voices a family generational problem? What about the influence of genetics?

A. Hearing voices is strongly correlated with adverse childhood experiences. Researchers have spent millions of dollars looking for a biomarker linked to the phenomenon and still haven’t found one. However, genetic traits may influence the sensitivity a child exhibits to certain traumatic events. And the age between 16 and 24 is a time of existential crisis when things seem to be falling apart for some people.

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

Musings

This is our last newsletter in the accustomed format. In 2023, we will be sending out monthly or twice monthly bulletins online. Readers who are paid members and who do not use computers will be able to receive monthly paper bulletins; we will be contacting those folks and institutions separately regarding the change. Our bulletins will include announcements about our fourth Wednesday speaker meetings and group discussions, along with alerts about county happenings, events put on by other organizations, and commentary and reader submissions sharing information, tips, and insights.

Accordingly, this is the time to express gratitude to a couple of newsletter helpers. Sally Pugh, our office liaison, dutifully keeps memberships up to date and prints out labels—along with nobly working with some of the technical matters. Carla Wilson, board member, regularly picks up the newsletters and carts them off to the big regional post office to negotiate with their bulk mailing process.

And then we have volunteer deluxe, Tom Thomas. He conscientiously attends each speaker meeting and takes notes, which he skillfully writes up. He then receives the other content sent him and edits and formats that material into the newsletter you receive. If you go to his website, www.thomas-thomas.com, and follow the link to NAMI East Bay, you will find his archive of newsletter presentation notes, starting in 1993. There's a ton of history there.

Thanks to all three of these individuals for their involvement and dedication “to the cause” over the years.

Moving on to other planned 2023 changes, see the notes below regarding how you can help out.

Rather than relying solely on the technical expertise of Michael Godoy (thank you, Michael!), we will be expanding our team of folks who will handle the technical world that surrounds us. We will be exploring a hybrid model for our support groups so that participants will have a choice of in-person and Zoom meetings. We will also be working on getting a peer support group started. We will be collaborating more functionally with other family and community agencies to support trainings, educational presentations, etc. We will develop a leadership team of board and advisory board members and interested

members. We have several tasks on hold for the present, such as reviewing our office space and location, using podcasts and blogs, and holding regular family in-person get togethers.

So, in preparation for 2023, could you:

1. Give us feedback on these plans.
2. Let us know if you would be interested in being trained to be a co-support group leader or Family-to-Family class teacher.
3. Think about recommendations for speakers and discussion group topics—or what you could contribute to a bulletin such as a personal essay, tips for coping and managing behavior, things that worked for you, etc.
4. Consider representing NAMI and the family voice on such committees as the county Mental Health Service Act Committee, the Housing Consortium of the East Bay, or any of the topic-specific groups out there. The family voice absolutely has to be heard and we will bring you up to speed on this process.
5. Think about how you might plug into any of these changes.

We need your help in our working to make NAMI East Bay a more open, collaborative, and community-oriented organization.

—Liz Rebensdorf, President, NAMI East Bay

Solutions for Supportive Homes

Do you have a family member who lives with serious mental health disabilities? Do you worry about what will happen when you are no longer there to care for them? We are families who share these worries and we have a plan. We invite you to join us in creating permanent, supportive homes for our loved ones.

Solutions for Supportive Homes is a non-profit organization of Bay Area families and allies dedicated to creating affordable, permanent, supportive homes for adults who live with serious mental health disabilities. As caregivers, we know our loved ones need the security of a healing home environment, empathic support for daily tasks, and help accessing care and services. As advocates, we know that public options for homes like this are desperately scarce, and private options are, for most families,

completely unaffordable.

Solutions for Supportive Homes proposes a new approach through a model that enables equity ownership to ensure the security and stability of permanent residence; provides live-in resident assistants to support each community; and organizes community activities that foster engagement, connection, and meaning.

Our vision is to create a model that can be successfully replicated at a low threshold of investment. We are building toward that vision in steps, in partnership with families, funders, and service providers.

We have launched a pilot residence: the Vernon Street Project, a nine-unit building in the Adams Point neighborhood in Oakland. This welcoming Beaux Arts building offers private studios and apartments, a tree-filled private garden, a large community space for activities, and a private space for the live-in resident assistant. Solutions for Supportive Homes is partnering with the property owner to rent units to families who are interested in considering participation in equity partnership. We seek families and residents to work with us to co-create the community and to plan for long-term ownership.

The Vernon Street Project has five openings for new residents and their families. Interested in learning more? Email us at VernonProject@s4sh.org.

—Linder Allen

CARE Court (Cont.)

Under this law, family members will be given more of a role in the care of their loved ones. Family members, first responders, health care providers, and others can petition to refer a person to this new civil court, where a judge oversees their mental health treatment. The hearings will be confidential, rather than in open court. The person referred for help (the respondent) will be provided with an attorney to represent her in court as well as an advocate to assist her with setting up a two-year care plan. The plan specifies treatment in the community as well as supportive housing as necessary and may be reviewed periodically before it expires. At the end of the second year, if the treatment plan has failed, the respondent may be referred for conservatorship.

Unlike Laura’s Law, also known as Assisted

Outpatient Treatment (AOT) counties will not be allowed to opt out of the program. CARE Court will begin with seven counties in 2023—Glenn, Orange, Riverside, San Diego, Stanislaus, Tuolumne, and San Francisco—to be followed by the rest of the state in 2024. All programs should be in place by December 1, 2024.

The new program will be expensive, requiring for each client a care team in the community, several supportive services, and a housing plan. Implementation of CARE Court will depend on a solid infrastructure of mental health care in the community, but we have no such continuum of care. Mental health care agencies are under-staffed, and we have a dire shortage of mental health workers. The counties will need strong motivation to make the program work, as little of the required infrastructure exists today.

Governor Newsom is offering \$3 billion through the Behavioral Health Continuum Infrastructure Program (BHCIP) and the Community Care Expansion (CCE) program to expand community care and supportive housing. While these funds exist at the state level, it will be up to each county to apply for grants through BHCIP and CCE.

Like Laura’s Law, CARE Court will be entirely voluntary and will lean heavily on the “black robe effect.” Contrary to the early fears of civil libertarians, CARE Court will not result in people being deprived of their civil liberties.

CARE Court can only order “community” treatment, meaning treatment outside of a hospital. After two years, if the treatment plan has failed, the respondent may be referred for conservatorship. But while a conservator may try to obtain inpatient treatment for her client, psychiatric hospital beds in California are vanishingly scarce. For example, out of every twenty people brought to John George Psychiatric Hospital on a 5150, only three will be admitted—despite the required finding of being a danger to self or others or gravely disabled due to a mental disturbance. The other seventeen will be discharged to the community without meaningful treatment.

As Alison Monroe of FASMI writes, “It is a good incremental approach [toward improving the care of this neglected population] but we have a long way to go.”

—Alice Feller



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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

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