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# NAMI EAST BAY NEWSLETTER

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

March-April 2021

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## Strategies for Coping Through Emotionally Challenging Times

Wednesday, March 24

We are all looking for ways of building resilience and maintaining our wellness. **Sarah Carr, LMFT**, is the Founder and Clinical Director of mindfulSF, a Bay Area-based company that offers science-driven mental health services and wellness workshops. Sarah is a Licensed Marriage and Family Therapist and a Certified Mindfulness-Based Stress Reduction Teacher. She is trained in Cognitive Behavioral Therapy (CBT), Acceptance and Commitment Therapy (ACT), Mindfulness, and Self-Compassion. In her clinical work, Sarah specializes in the treatment of obsessive-compulsive disorder and anxiety. She facilitates workshops focused on mindfulness-based strategies for building resilience, supporting well-being, and effectively managing stress and anxiety. More information about Sarah Carr and her organization can be found at [www.mindfulSF.com](http://www.mindfulSF.com).

### Speaker Meeting starts at 7:30 pm

The November presentation will be **Zoom/online**, and we are asking attendees to preregister. Go to our website <https://namiestbay.org>, click on “What’s New,” and follow the link.

**Note:** The meeting will be recorded both in written form, for the next edition of this newsletter, and as a video recording accessible via the What’s New link on our website.

## 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://namiestbay.org>, click on “What We Offer,” and follow the link to “Online Support Groups.” Or you can register [here](#) via Zoom.

**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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## Discussion Group on Hearing Voices

Wednesday, April 28, 7:30 pm

By the time you read this, we will have held our first 4th Wednesday online discussion group with staff from the Felton Institute’s Prevention and Early Intervention program.

Our next discussion will be with Ed Herzog on April 28 at 7:30 pm. Ed, a NAMI East Bay board member, is one of the founders of the Bay Area Hearing Voices Network (BAHVN), part of the international HVN-USA. His organization offers weekly, on-line hearing voices groups for family members and adult voice hearers, as well as support and education.

A report from the February 24 conversation with the Felton Institute will be in our next newsletter. These specific-topic discussion groups are offered to alternate with the bimonthly speaker meetings and the format will be more casual and interactive and less didactic. Register on our website under [What’s New](#) and you will be sent the zoom link.

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## Note to Our Readers

This edition of our bimonthly newsletter is a little bit different and represents a planned-for upgrade in perspective. We at NAMI East Bay are collaborating with our friends at NAMI Alameda County to share information and resources (see page 4), along with a new regular column on advocacy efforts (page 5). You will benefit from getting a larger perspective. However, the odds are high that many of you are on both our electronic mailing lists; so let us know if you feel bombarded by a doubling up of the newsletter. As always, we welcome contributions, recommendations, comments, etc. from our readers.

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### SPEAKER NOTES

## Independent Living Association

*Summarized by Thomas T. Thomas*

Recently introduced into Alameda County to impact housing stock, the [Independent Living Association](#) (ILA) works to develop and support privately owned or operated homes that provide shared housing for adults with disabilities. Tenants in these homes are able to live independently, are often on a fixed income, and do not need supervision or care from their landlord. Tenants may have external case management or other kinds of outside support.

The guest speakers at our January 27 meeting were ILA Program Manager **Francesca Barua** and Senior Manager **Sarah Swain**. They are both with [Community Health Improvement Partners](#) (CHIP) of San Diego, which started the ILA in that county, introduced it in Alameda County in 2017—with funding from [Alameda County Care Connect](#)—and more recently in Fresno County. There is interest in expanding the ILA program into Santa Clara, Riverside, and San Bernardino counties.

ILA supports home operators, their tenants, service providers, and the community. It works to provide quality, supported, and affordable housing for tenants, and objective and unbiased information for operators and the community. “Stable and safe housing is essential to recovery and the management of mental illness,” Barua said.

The speakers offered a key definition of the kind of housing ILA supports, formerly called “room and board”—and definitely not “board and care.” The difference is in the licensing requirements. Hospitals, long-term care and skilled nursing facilities (SNFs), and rehabilitation centers that provide medical care and support are licensed and regulated by the state. Single-occupancy residencies (SROs), apartment houses, and ILA homes are not licensed because their staffs do not provide such care. Tenants may receive medication support and help from outside suppliers such as In-Home Support Services (IHSS), but not from the housing staff itself. The ILA home may provide one to three meals a day, or offer cooking facilities for tenants to prepare their own meals.

ILA’s intentions and goals are modeled after those

of the Better Business Bureau. That is, they certify the home operator’s business practices and provide a professional association for operators. They check out the operators and the home facilities, to make sure they have the right intentions and provide a quality living situation. And they partner with county and local government, law enforcement, consumer groups, and treatment providers to make these homes known in the community. But ILA is not a regulatory or licensing agency, cannot mandate that operators join, and cannot enforce its policies on non-ILA members.

For tenants, ILA offers a complaint process that includes documenting the grievance, exploring the situation, following up with suggested corrections as necessary, and suspending the home’s membership if corrections are not made.

For owners and operators, ILA membership is free and voluntary. Operators attend a one-day course on ILA standards, submit an application form, supply copies of their rental agreement and house rules, and pass a home visit based on eight ILA quality standards. The standards cover a safe, well-maintained environment; clear resident policies; a grievance procedure; assurance of privacy; prevention of abuse and discrimination; a competent, owner-trained staff; clean amenities; and a focus on the tenants. Although most rooms are shared, the standards require a certain amount of personal space and no bunk beds. Bathrooms must meet the board-and-care standard of no more than six people to a single facility.

The value of membership for the operators includes business development opportunities, marketing, and support. The value for tenants is a resident screening process and maintenance of their legal rights.

The ILA organization is based on four pillars:

- **Education and training**—for operators, on business development and mental illness; for tenants, on their rights, how to thrive, and how to become part of the Peer Review and Accountability Team (PRAT) that evaluates such homes; for the community, on the importance of ILA standards and other community tools.
- **Peer Review**—through the PRAT team ensures operators meet quality standards. The review has an inside and outside checklist, and visits are made with 24-hour notice. ILA members get individual coaching, mentorship, and resources.

- **ILA Directory**—lists housing availability on the [ILA website](#) (which is mobile friendly). Each entry describes the house, amenities, rental amount, and has pictures.
- **Advocacy**—supports members, tenants, and the community. ILA explains what such housing is and is not. The organization monitors legislation and keeps members apprised of state and local laws.

ILA's current membership in Alameda County includes 35 homes, run by 14 operators, and offers 222 beds. (In San Diego County the organization includes about 100 homes.) Rentals in Alameda County range from \$755 to \$1,000 per month for a shared room (comparably higher for a single) and average \$880. This amount pays for utilities, any meals provided, and on-site laundry. ILA homes have no requirements for a security deposit, criminal background check, credit check, or lengthy rental history. The directory is geared for immediate placement. Tenants may include adults with disabilities other than mental illness.

“Poor quality homes,” Barua said, “are usually in poor condition, have repeated calls for code violations, and are known as problem neighbors and subject to NIMBYism. High-quality homes have relatively stable tenant populations, trained owners, and provide an environment where occupants can volunteer, work part-time, and go to school.”

ILA in Alameda County trained 585 people in fiscal year 2019-20 and 68 more from July to December 2020. This included training in mental health issues, tenant screening, tenant rights, becoming an LGBT+ ally, and COVID-19 rules and cleaning procedures. Attendees gave these courses a 96% satisfaction rating. The organization held 25 PRAT inspections in 2019-20, and 16 more in the last half of 2020.

You can email the speakers directly:

- Francesca Barua at [fbarua@sdchip.org](mailto:fbarua@sdchip.org);
  - Sarah Swain at [sswain@sdchip.org](mailto:sswain@sdchip.org);
  - CHIP Outreach Coordinator Crystal Warren at [cwarren@sdchip.org](mailto:cwarren@sdchip.org);
- or contact [Alameda@ilacalifornia.org](mailto:Alameda@ilacalifornia.org) to reach the local organization.

### **Q. What kind of buy-in is ILA getting?**

The buy-in in Alameda County has been good. The community and the neighborhoods are getting better resources. The local service providers are getting an increase in the housing stock available to place their clients. And operators get education and tie-in to

service providers. Some communities only refer clients to ILA-member homes.

### **Q. Does ILA help provide properties to operators, such as under the California Land Trust?**

That has not been set up yet. ILA is looking for organizations and realtors that can support operators.

### **Q. What are the drug and alcohol policies in ILA-member homes.**

It is addressed in the operator's house rules. Many don't allow drugs or alcohol inside the home. ILA suggests that the operator manage the behavior resulting from drug and alcohol abuse, rather than the substance itself. As to smoking, many require tenants to smoke outside or use smokeless substitutes inside.

### **Q. How are vacancies in member homes listed?**

ILA sends operators weekly emails or phone calls, and posts their vacancies on the website. An SMS text project is being set up and will roll out soon.

### **Q. What is the ILA policy on pest infestations, such as from recently homeless tenants?**

Operators are expected to have policies and practices to prevent pests. For example, they are expected to treat bedding between tenant occupancies for bedbugs. They can inspect the belongings of incoming tenants, and should be active in treating breakouts.

### **Q. What mental health training do the home operators get?**

Currently, in Alameda County, the training is provided by the Mental Health Association of San Francisco. For example, they teach the signs and signals of an impending breakdown and the best ways to communicate and de-escalate a situation. Other training includes aspects of community service housing.

### **Q. Are pets allowed in ILA homes?**

Some allow pets, not all. Of course, emotional support and other service animals are allowed.

### **Q. Are we losing or gaining quality homes?**

Alameda County has gained 30 ILA-member homes in the past year. So the housing stock is growing. The organization has a partnership with service providers to facilitate this. ILA wants to work with home operators and help them become a member of the Independent Living Association.

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](http://www.thomasthomas.com/NAMI.htm).

### Musings

If you've ever taken a psychology course, you quickly became familiar with the normal curve. This is the bell-shaped curve that graphically shows the distribution of measurements like income, IQ, personality traits, etc., with most things that are more common in the middle ranges and those with fewer occurrences at the extremes. The distance from the middle is the standard deviation measure. One can think about this also as a continuum. In the context of psychiatric diagnoses—our focus here—I'm thinking the normal curve may not apply.

We all have up and down moments in a day. Perhaps someone said an unkind word or you broke your favorite cup and you're grumpy. Or perhaps you're having a bad or good week. We can see the cause-and-effect. These are common moods that fall into that large middle-ground cluster on the curve.

Let's think about thinking. Magical thinking is the foundation of much literature, art, and drama, and we all indulge in less-than-realistic wishing and hoping for impossibilities. How logical are we when we anthropomorphize inanimate objects and talk to our computer? Or how about when we are just falling into or waking up from sleep and our thoughts slip and slide? These are also characteristics which fall into that large bulge of the normal curve.

Yet it's simplistic—and wrong—to include mood and thought disorders on the normal curve continua, because they involve a qualitative difference in how the brain develops, works, and processes neurotransmitters. In talking with our ill relatives, we sometimes strive for common ground and think the techniques we use to snap ourselves out of an irrational thought or temporary mood will work for them. At best, our experiences may enable us to empathize with what others are going through, but what works for us doesn't necessarily work for everybody.

Added to all this is that our relatives are impacted at different points on the continuum. Two people with identical diagnoses may be functioning at different levels since the impact varies. There seems to be an internal tug between stability and instability. And one individual can pull it all together and present as rational and fine at one point in the illness but not be so able another time when the illness becomes overwhelming. Family members witness

this often at the point of crisis and call for help, only to see their relative pull it all together and present as quite functional and not needing intervention.

Another factor is the addition of drugs or alcohol, where excessive use may push a person's functioning into the extremes, and addiction provokes other behaviors. Conversely, psychotropic medications can work to subdue and harness some of the dysfunctional behaviors, yet medications may work differently in the people who take them.

In the middle of all this, family members are trying to juggle the many variables and be supportive of growth and recovery. It's an extremely complex task.

—Liz Rebensdorf, *President, NAMI East Bay*

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### NAMI East Bay Welcomes Input from NAMI Alameda County

NAMI Alameda County (NAMI AC) is overjoyed to be welcomed to submit articles to NAMI East Bay's (NAMI EB) newsletter. This will help us increase our footprint along with that of NAMI EB.

NAMIs EB and AC have always had a strong collaborative relationship. NAMI EB started in 1965 as a chapter of the American Schizophrenic Association. NAMI AC began as one of many loosely connected chapters of FAMI (Family Alliance for the Mentally Ill). At the same time the Mental Health Association of Alameda County (MHAAC) was formed and FAMI merged with them. In the early 1980s, FAMIs became NAMIs, local organizations became affiliates of NAMI California, and state organizations became affiliates of national NAMI.

Like NAMI EB, we hold monthly education meetings, community events, Family to Family classes, and participate on the county's Behavioral Health Care Services many committees, representing the family voice. Much of this is done in partnership with NAMI EB. NAMI Tri-Valley, formed to meet the specialized needs of the eastern part of the county, has collaborated with us on many projects. A fourth affiliate, NAMI Alameda County South, was formed in 2012. As of 2014, NAMIs could no longer be folded into other organizations (sharing non-profit status, etc.). NAMI Alameda County split from MHAAC in 2012.

After the split we continued with our Families Support Group, community education, and Family to

Family classes.

**Our consumers group** grew under the direction of our Peers Coordinator, Kathryn Lum. Before COVID we had four Connections support groups, serving the homeless community in Oakland, the BACS program in Hayward, and Southern Alameda Community. Three have been put on hold because of COVID. The remaining group meets weekly through Zoom. We sponsor between two and three Peer to Peer classes each year.

**NAMI Chinese** 美國華裔精神健康聯盟 joined us as the NAMI Alameda County Chinese Committee. Elaine Peng, a member of our board, is a leader of this group.

**The Dinobi Project** is a collaboration between local non-profits, government, and Silicon Valley technology, NAMI AC, Alameda County Behavioral Health Care Services, and Sage Surfer working together to create an app in the mental health space.

Dinobi means “forever in our hearts” in Eastern Nigeria. The name Adadinobi was given to the daughter of active volunteers for NAMI AC. She died of suicide after bravely living with schizo-affective disorder for many years. It is our hope that our project can empower those dealing with mental health and provide assistance for their struggles. Our team created this project to give the support we wish our loved ones had received. To learn more visit our website [www.dinobi.org](http://www.dinobi.org).

Looking forward to working together.

—Peggy Rahman, President, NAMI AC

—Jeffrey Fudenna, Executive Director, NAMI AC

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### Advocacy/Activist Updates

Welcome to the launch of a new column in the newsletter: Advocacy/Activist Updates. In this, our first, we will briefly summarize the key advocacy fights currently going on. We will devote columns to the following. Please contact us with what we may be missing.

**Hospital Beds.** Families Advocating for the Seriously Mentally Ill (FASMI, [acfasmi@gmail.com](mailto:acfasmi@gmail.com)) focuses on increasing the number of hospital beds as well as increasing the amount of supportive housing with an emphasis on licensed board-and-cares. We participate in these activities and are expanding our advocacy and connections with elected officials. We

supported and participated in the February 12 protest spearheaded by Amy Fisher on behalf of her cousin who died in the streets with serious mental illness (SMI), and demanding more housing and treatment beds. We are investigating how to pursue mandated medication while living in the community.

**Reform of conservatorship hearings.** Behavioral Health’s Office of Family Empowerment holds a monthly meeting for family members called Family Dialogue, run by Rosa Warder of the county’s Office of Family Empowerment. For a year and a half we have been advocating for a reform of the Writ Hearing process, through Family Dialogue, that would establish training in SMI for the judges and public defenders involved in these hearings.

**Incarceration of the mentally ill.** Incarceration of those with SMI and the disproportionate incarceration of our black loved ones and people of color is an issue being addressed by the JIMH (Justice Involved Mental Health) Task Force. Several of us have been involved with this task force as well as the Decarcerate Alameda County (DAC) coalition. Dr. Karyn Tribble, the director of Behavioral Health, has developed a proposal to address this issue of incarceration and we are determining what we can support of this proposal and how.

**Housing.** East Bay Supportive Housing Collaborative advocates for the expansion of Licensed Board and Cares which we are losing at a rapid clip.

—Katy Polony, Alison Monroe, FASMI

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### Call for Focus Group Participants

The Supportive Housing Community Land Alliance (CLA) is a new organization spearheaded by Alameda County Behavioral Health Care Services (AC-BHCS) that will use the community land trust model to create affordable housing opportunities for extremely low income people living with serious mental illness (SMI).

The CLA will be holding paid focus groups for consumers and their family members. If you would like to inform someone about this paid opportunity, please direct them to [bit.ly/CLA-focusgroup](https://bit.ly/CLA-focusgroup) to fill out a survey. If you are a family member and would like to participate in a separate focus group with other NAMI East Bay members, please contact [nami-eastbay@gmail.com](mailto:nami-eastbay@gmail.com).



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We urge you to mail your 2021 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.

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