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NAMI EAST BAY NEWSLETTER A local affiliate of the
National Alliance on Mental Illness (NAMI)
July - August 2021

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NAMI EAST BAY NEWSLETTER

A local affiliate of the National Alliance on Mental Illness (NAMI)
November-December 2021

Obsessive-Compulsive Disorder

Wednesday, November 17, 7:30 pm

The International Obsessive-Compulsive Foundation (www.iocdf.org) is a huge organization, with interest groups across the world. One such group is the Oakland/East Bay OCD Support Group, run by our guest speaker at the November meeting, **Timothy Quinn**, since 2014. We are delighted to hear from Tim about this disorder, which oftentimes informs behavior more than other mental illnesses and is co-morbid with many. He states that the groups “are an integral part of mental health maintenance.”

Speaker Meeting starts at 7:30 pm

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

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

Family to Family Class

We will be offering our annual eight-week class online, Thursday evenings 6 to 8:30 pm, January 20 to March 10. The class presents a comprehensive overview of mental illness, diagnoses, medication, communication, problem solving, and coping. The class fills up quickly; so let us know ASAP if you’re interested. Since it is online, we need to get written materials to you, and we’ll need some lead time. Contact our office.

Communicating with a Person with Mental Illness

Bob Krulish, a certified trainer, offers a free seminar on how you can improve communication using LEAP principles developed by Dr. Xavier Amador, author of *I’m Not Sick, I Don’t Need Help*. You can register for the November 13 workshop by going to www.bobkrulish.com.

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://namieastbay.org>, click on

Psychosis REACH

Psychotic Recovery by Enabling Adult Carers at Home (REACH) is a free training offered by the SPIRIT Lab at the University of Washington. It offers “concrete, evidence-based skills for relatives and

“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.

Fourth Wednesday Discussion in December

Our online discussion group is not scheduled for December, but see the results from August on page 4.

friends of individuals with psychotic disorders,” using a modified form of Cognitive Behavioral Therapy (CBT). Information and registration for upcoming trainings is through <https://uwspiritlab.org/psychosis-reach-overview>.

African American Wellness Project

This group was formed to respond to inequities in the healthcare delivery system. Its newsletter contains comprehensive information about both physical and mental health issues (www.aawellnessproject.org).

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Telephone: 510-524-1250 - Email: namieastbay@gmail.com - Website <https://namieastbay.org>

Editor: Liz Rebensdorf

Mailing: Carla Wilson

Format: Tom Thomas

Technical Logistics: Michael Godoy

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SPEAKER NOTES

Panel Discussion on Advocacy in Alameda County

Summarized by Thomas T. Thomas

The September 22 Speaker Meeting presented an overview of mental health advocacy in Alameda County. Panel members included **Tanya McCullom**, Program Specialist with the county’s Office of Family Empowerment, and **Alison Monroe**, **Katy Polony**, and **Dianne Lam** representing Families Advocating for the Seriously Mentally Ill (FASMI). Topics included an overview of current state and federal legislation, an explanation of how the [Alameda County Behavioral Health Care Services](#) (ACBHCS) operates regarding funding and decision points, and an update on FASMI activities with advocacy actions we all can take.

To start the discussion, NAMI East Bay President **Liz Rebensdorf** described how the California legislative process works, from concept to analysis, discussion, and public input in the Assembly and Senate, to a bill to be signed on the governor’s desk. Current bills of interest to mental health advocates now in the process, while the legislature is on recess from Sep-

Alameda County Behavioral Health Care Services, to which their office is attached, has a fiscal year 2021 budget of \$563 million, employs more than 700 full-time-equivalent mental health professionals and serves approximately 79,000 individuals for mental health issues and 7,000 for substance abuse. Of these, 55% are male and 45% female.

The ACBHCS priorities have changed with the pandemic and with new legislation. Their current focus includes Covid-19, mobile crises and emergencies, health and cultural equity, community stakeholder engagement, and budgeting and fiscal changes. These priorities involve many position changes—and hiring is a long process. Among them is a new position, the Health Equity Officer. And the Covid-19 impacts have required employee redeployment, increased coordination among departments and agencies, community outreach and engagement, and changes to clinical services, such as telemedicine.

“Across the board,” McCullom said, “people seeking services have dropped off due to the pandemic. So our revenue has dropped, requiring new financial planning.”

Advances in this time have included opening [Amber House](#) crisis residential treatment in Oakland and the [Safe Landing Project](#) at Santa Rita Jail; redesign-

tember 10 to January 3, include housing and crisis intervention. Bills on the governor's desk awaiting signature include:

- **SB224** to bring mental health education into the K-12 public schools.
- **AB118**, the Community Response Initiative to Strengthen Emergency Systems (CRISES) Act, to change mobile crisis response teams from primarily law enforcement to mental health professionals.
- **AB988** to implement national legislation already passed that would institute in California the 988 number for mental health services, like 211 for traffic information.

After laws are passed, they are sent down to the California counties, which are the funding source.

Tanya McCullom described the Office of Family Empowerment, which currently includes herself and two others, all family members themselves. She focuses on mental health issues with children. A second team member manages the office and focuses on adults and older persons. And a third deals with workforce development issues.

ing forensic services regarding mental health and the criminal justice system; redesigning services to meet health equity strategies; implementing the [Community Assessment and Transport Team](#) (CATT) at Bonita House; and expanding the designation of LPS 5150 (danger to self or others or gravely disabled) and 5585 (gravely disabled minor) involuntary holds.

"We stand on the shoulders of giants," FASMI's **Dianne Lam** said. Her organization was born in 2017 out of frustration when Voices of Mothers and Others (VOMO) was disbanded, and their membership is still mostly mothers. They originally had a focus on getting more hospital beds, with the dream of creating another Villa Fairmont.

In its first iteration, FASMI collected data from attending meetings of the Mental Health Advisory Board and Mental Health Services Act stakeholders. They also reached out to local and state politicians.

In the second iteration, starting in 2020, the group focused on key issues: more psychiatric beds, more permanent housing, better continuous care, decarceration in Alameda County, advocacy to politicians, and protests at John George Pavilion. They are also ir

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touch with allies throughout the state.

"Our goal is to become a family force to be reckoned with," Lam said. "The system is so wrong, it needs everything."

Katy Polony is not only the mother of a son with schizophrenia but a service provider herself, working with an [In-Home Outreach Team](#) (IHOT). "We work hard," she said, "but the job is enormous. And we know that people are falling through the cracks. There are more people in the caseload than the team can provide for." She also noted that most of the people in her program work for nonprofit organizations contracted with and paid for by the county. And the workers are not paid well—not enough to live on in the Bay Area.

She reduced FASMI's many goals to three: more hospital beds, more housing, and an adequate continuum of care.

"People are not getting treated," she said. "If they live at home, they don't always get their medication. But they're less likely to be 5150'd if they live with

Some of the things people can do by themselves is to write books, like DJ Jaffe's [Insane Consequences](#). She noted that Jaffe had served on NAMI National's board, and one of his conclusions is that denial, no stigma, is the problem.

On a more local and personal scale, individuals can write letters to the editor and op-eds for the local paper. "They should write their own story," Monroe said, "because policy proposals are too abstract."

They can also write to their county supervisor and get involved with local initiatives like supportive housing. "Families with experience are known to have credibility with Alameda County," Rebensdorf said.

Crisis services without places to take people for treatment won't fix the problem, Monroe said. Peer services alone won't fix the problem. Voluntary services by themselves won't fix it. "We want to poke a magic wand at a pumpkin and make it a coach," she said, "but it keeps turning back into a pumpkin."

Monroe cited the [National Shattering Silence Co](#)

But they're less likely to be stabilized if they live with their family instead of on the streets. People die if they are not hospitalized." As to housing, people without families have no place to live but at unlicensed board-and-cares. "Dismal as some of them are, they still cost money," she said. And finally, Alameda County does not provide enough case management teams. Case managers are required to make the case to refer a person to Level One or full-service treatment—and then they must maintain the connection while the person is homeless.

"We need fundamental change in the system," Polony said. "The system is backward: people have to convince the system that they need attention. Family members with serious mental illness cannot advocate for themselves.

"We need a group of families who will not be ignored, to get the public to pay attention—if only through direct action," she said. "We need to call attention to a tragic situation involving thousands of people in the county."

Polony said voluntary programs like CATT and Amber House are good things, as is the effort not to incarcerate the mentally ill. "But without someplace to go, people end up on the streets."

FASMI's **Alison Monroe** spoke about undertaking advocacy as an individual. "I wish I could share a strategy that would work," she said. "But it takes advocacy groups to lobby public officials and the county bureaucracy."

Monroe cited the [National Shattering Silence Coalition](#)'s list of solutions. Among them are recognizing mental illness as a medical disorder; focusing on abuse and neglect; repealing the [Institutions for Mental Disease \(IMD\) exclusion](#), which prefers small treatment facilities and limits Medi-Cal coverage for hospital stays to those with less than 16 beds; and ending incarceration for the mentally ill.

FASMI doesn't have a website yet, but you can reach them at acfasmi@gmail.com.

In discussions that followed the speakers' presentations, the attendees touched on several issues:

- An effort in San Francisco to sue programs that are not fulfilling their mandate in treating the mentally ill. Audience members noted such suits can be effective in changing the law.
- A new building program at Santa Rita Jail that will provide hospital beds and psychiatric services. But audience members feared that it would be under the control of law enforcement rather than county mental health services.

In wrapping up the program, Liz Rebensdorf noted that taking up advocacy as a family member is sometimes hard, "when all your energy is drained by the person sitting across the room."

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.

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Musings

Families are so visibly relieved when they share that their relative is "finally in therapy." In today's reality, this generally means a 20- to 45-minute individual talk on a varied schedule from once a week to once a month with a trained therapist—oftentimes at substantial cost. Details depend on specificity of target issues or problems, specialties of the professional therapist and—bottom line—insurance coverage.

Our August speaker, Dr. Kim Norman, has a provocative take on therapy which is worth delving into further here. (Notes on his presentation are shared in

therapy, and that would be such behaviors as retreating, clarifying thoughts and emotions, rewording, prioritizing, etc.

Of primary importance is your modeling of self-care, whether it be yoga, massage, deep breathing, hiking, or sitting under a redwood tree. This is not only modeling self-care but is also accomplishing your own necessary self-therapy.

Family members are not trained therapists, but we can certainly provide help.

—Liz Rebensdorf, President, NAMI East Bay

this newsletter and the August 28 meeting is video recorded and accessible on our website under “What’s New”). Essentially, his message was that a bit of arrogance underlies the concept of therapy and that, indeed, all sorts of experiences can lead to growth or “aha” experiences.

We in the Bay Area enjoy a plethora of trained therapists to choose from, although in this pandemic age those resources are becoming scarcer as anxiety and depression and need for therapy increase. Nevertheless, the amount of choices open to us urban folk contrasts with the lack of services available in areas away from the cities. That is why Dr. Norman has been exploring alternatives to face-to-face therapy and why he recommends David Burns’s *Feeling Good Handbook* and the website www.gritX.org, which are described more fully in the Speaker Notes and recording.

For those of us with relatives with mental illness, the notion that everything is a growth experience is both a blessing and a challenge. Families are already burdened with the practical logistics of caretaking and providing for housing, food, clothing, etc. Now, here we are being told that we’re also the therapists ... but really, you already know that. Look around.

Consider how you choose certain words when you communicate, how you stifle your irritation and impatience at times, how you strive to be supportive and empathic, how you help your relative express him- or herself more clearly, how you intuit when to just sit silently. These are all acts of therapy.

Other acts of helping, which is the definition of therapy, include just engaging over any topic or taking a walk or singing a song together. These are all socializing actions. The modeling of coping skills is

An Advocacy First Step

A family member asked me recently how he can actually change the world. Now it’s hard to tell. We family members have been trying to change the world for years. In some ways it’s been getting worse—fewer and fewer beds and board-and-cares or other suitable housing. And in some ways it’s getting better—some journalists and elected officials do understand now that serious mental illness is a medical issue; it causes terrible suffering and disruption; it needs treatment; and many people affected by it are too ill to know they need help. And there’s hope that the latter insight will grow and reverse the trend of trying to wish away serious mental illness and facilities to deal with it.

1. Tell your story. There are several things you could do with your story:

- Share it with your county supervisor and other elected officials and tell them what helped and what hasn’t helped.
- Make it into a letter-to-the-editor after some news event.
- Make it into an op-ed.
- Include it in a book like [*Tomorrow Was Yesterday*](#) by Dede Ranahan.
- Make it into a video.

2. Help Families Advocating for the Seriously Mentally Ill (FASMI) organize into a diverse group with a simple message and take our message to elected officials. Learn who your state, federal, and county representatives are—especially county, because the county is responsible for keeping your loved one alive and well, if anyone is. Come with us when we get meetings with these elected officials.

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3. Every once in a while, you can show up at meetings of bureaucrats, like the Mental Health Advisory Board, and use the opportunity to tell them what isn’t working. There are innumerable state bodies also, like the Mental Health Services Act Oversight Committee, that rarely hear from us, though

The book [*Hidden Valley Road*](#) by Robert Kolker, about a family with six children diagnosed with schizophrenia, devotes a large amount of space to the search for answers, with generally inconclusive results. In some cases, the provocation leading to specific research was the exploration of a coincidence, a

sight committee, that rarely hear from us, though they often hear from disability rights groups. We can use Zoom to drop in and remind them of something they have forgotten.

4. Take advantage of occasions—state and federal legislation being proposed, or budget discussions going on—to practice telling your story. Say what *has* helped and what *hasn't* helped.

5. If you want, take advantage of county budget discussions and tell your story to the supervisors in writing or in person. Tell them what the county needs to spend money on. Particulars matter. Your story matters.

—Alison Monroe, FASMI

NAMI California Conference

The annual NAMI California Conference will be held virtually on October 14-15, 2021. To see the comprehensive list of speakers, topics, and event details, go to <https://namica.org> and follow the links to conference registration.

COVID and Serious Mental Illness

Research (per the Treatment Advocacy Center report 8/4/21) is showing that persons with serious mental illness (SMI) are a high-risk group in the fight against the COVID-19 virus. Based on an international review of 19,000 patients with both a SMI diagnosis and the virus infection, it was found that there was an increase in the likelihood of dying at a rate 1.67 times that of people without the psychiatric diagnosis. Several factors have been implicated in this finding such as healthcare access and social factors, along with comorbidities such as smoking, obesity, and substance abuse.

But another significant question is raised related to these findings and that is regarding immunological differences and the medical impact they create. We plead with researchers to further explore this area.

One research was the exploration of a coincidence, a synchronicity. Why are our ill relatives becoming sicker with this?

There was some recent fuss made and, fortunately, individuals with SMI were moved up in the line to receive vaccines. Around the same time, a new relevant book came out, [*The Angel and the Assassin*](#) by Donna Jackson Nakazawa. It examines the impact that microglia, immune cells in the brain, have on everything from depression to Alzheimer's Disease to psychosis, described as a "paradigm-shifting reading for all of us." We can only hope that the scientific world can turn its attention to this area of inquiry regarding the immunity factor.

Providers for Diverse Communities

We live in a wonderfully diverse community with neighbors and friends from around the world. Here is a list of resources available for client-specific communities and their county service area (N-north county, S-south, C-central). Google them and check their websites for more information.

- Afghan: International Rescue Committee (N), Afghan Coalition (S).
- African: Partnership for Trauma Recovery (N).
- Asian - East: Asian Health Services (N), Korean Community Center of the East Bay (N), Tri-City Health Center (S).
- Middle Eastern and Arabic: Diversity Health in Training Institute (N,C).
- Native American: Native American Health Center (N,C).
- Native Hawaiian and Pacific Islander: Richmond Area Multi-Service (N,S).
- Filipino: Filipino Advocates for Justice (C,S).
- South Asian: Hume Center (countywide).
- Southeast Asian: Center for Empowering Refugees and Immigrants (countywide).



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Please check your mailing label. If the code "21" is over your name on the right side of the label, your dues are current through 2021. If your mailing label indicates a previous year, or nothing at all, your dues are not current.

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.

☐ 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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