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.

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 "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.

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.

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 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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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 III (FASMI). Topics included an overview of current state and federal legislation, an explanation of how the <u>Alameda County Behavioral Health Care Services</u> (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 September 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.

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; redesigning 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 in

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'ed 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."

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, not 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 <u>National Shattering Silence Coalition</u>'s list of solutions. Among them are recognizing mental illness as a medical disorder; focusing on abuse and neglect; repealing the <u>Institutions for Mental Disease (IMD) exclusion</u>, 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.thomastthomas.com/NAMI.htm.

Musings

I love the concept of associating research with an IKEA manual. Nevan Krogan, a program director at the UCSF School of Pharmacy (*SF Chronicle* 10/4/21) describes his gene research as imilar to the first page of an IKEA manual, where all the parts of a piece of furniture are laid out and identified, with the following pages showing the sequence of how to actually put them together. That is where some important research is at this point in time and what I want to share here.

The Stanford Mood Disorders Day is held annually, the last two years via an online platform. For me, as a brain psychology wonk, spending four hours hearing Stanford academic psychiatrists discuss their research is time well spent. Topics were special populations, novel mechanisms and new drug treatments, and new bio markers and technologies. Here are some interesting takeaways, among many, I got from the August 28 event:

Pediatrics - Bipolar disorder (BP) is often associated with attention deficit disorder with hyperactivity (ADHD), sometimes wrongly. Youngsters with BP are distracted internally whereas those with ADHD are more susceptible to external distractions. ADHD informs a child's behavior continually, while BP is more episodic. An early onset diagnosis of BP is more problematic. Family focused therapy is a good intervention.

Psychedelics - Researchers are looking into the effects of micro doses of psychedelic hallucinogenic substances. This investigation is occurring generally outside the USA. Psilocybin (mushrooms), LSD, and MDMA (Ecstasy) are seen as less harmful than heroin and alcohol in terms of limited abuse potential and addictive properties. The thinking is that the medically managed use of these substances allows the brain to form new network connections.

Focal Electrically Administered Therapy (FEAST) - is a new form of directed and more specific electro-convulsive therapy (ECT). It is like the cardioversion process that folks with atrial fibrillation undergo, but the difference is that the focus is the brain and not the heart.

COVID - the coronavirus can lead to deficits in the cognitive domain with problems in processing, memory, and attention. There is mixed evidence

regarding how the virus enters the brain.

Precision psychiatry - All neuropsychiatric diseases are disorders with the brain's networks. Treatments are increasingly being studied which will address specific components of the mood disorders. Such treatments include both medications and non-medication approaches.

To see the video recording of the 3-1/2-hour event, go to www.med.Stanford.edu.

—Liz Rebensdorf, President, NAMI East Bay

Fourth Wednesday: Peer Support Services

At our August Fourth Wednesday online discussion group, we had a robust conversation with Jeff Caiola, who leads the Depression and Bipolar Support Alliance (DBSA) support group; see below for information. In response to issues raised, here is a list of current support group opportunities for individuals with mental illness. They are open to any adult (18+) with a mental health condition; no formal diagnosis is required.

NAMI Alameda County: Connection Peer Support Group, every Tuesday 7 to 8:30 pm. Call 510-560-6498 (select the Peer Specialist option) or email kathrynlum@comcast.net.

NAMI Chinese: Asian and Pacific Islander Support Group, 2nd Saturday 11:00 am to 12:30 pm, given in English, email api@namichinese.org. Go to https://zoom.us/j/7413232578, Meeting ID: 7413232578.

- Cantonese Peer Support Group: 2nd Saturday 1:30 to 3:00 pm, given in Cantonese, email info@namichinese.org. Go to https://zoom.us/j/7413232578, Meeting ID: 7413232578
- Mandarin Peer Support Group: 3rd Saturday, 1:30 to 3 pm, given in Mandarin, email info@namichinese.org. Go to https://zoom.us/j/7413232578, Meeting ID: 7413232578.

NAMI Tri-Valley: For information on Peer Support Groups, go to www.nami-trivalley.org.

Depression and Bipolar Support Alliance (DBSA): every Thursday 7 to 9 pm (log in as early as 6:30 pm to get situated); every Saturday from 11 am to 1 pm (log in as early as 10:30 am). For

information and to receive links, email Jeff Caiola at berkbipolar@yahoo.com.

Bay Area Hearing Voices Network (BAHVN): Berkeley Support Group are Mondays 6 pm to 8 pm. Go to www.bayareahearingvoices.org for group link.

Peers Envisioning and Engaging in Recovery Services (https://peersnet.org): This Alameda County organization is run by and for peers. They offer Wellness Recovery Action Plan (WRAP) groups, along with other resources.

Wellness centers are offered by Bay Area Community Services (www.bayareacs.org) and Bonita House (www.bonitahouse.org), where there are opportunities for socialization and group discussions. Because of COVID-19, formats and services have been modified so check the websites.

There are also quite a few national and international groups organized around diagnoses of schizophrenia, bipolar, depression, borderline personality disorder, and obsessive-compulsive disorder. Some offer support groups or chat rooms for those carrying the diagnosis. For example, the International OCD Foundation (www.iocdf.org) has a list of support groups by state media location. Do a Google search.

NAMI East Bay Update

This has been a period of confusion, coping, and transition for all of us.

Support groups - The Zoom platform has enabled us to offer weekly support groups and, as of this writing, this will remain in place with a probable gradual addition of a monthly in-person format next year.

Family to Family Class - We will be offering our annual eight-week class online starting in January. (See the announcement on page 1.)

Mailing list - For financial reasons we need to do some cuts on our large mailing list, particularly with the print edition portion. If you want to continue being on the list, now is the time to let us know that, or join our affiliate by completing the form on the last page or joining/renewing online. We also welcome donations.

Board membership - We are actively inviting interested readers to talk with us about joining our board. In the past we've always done this on a more personal basis, but times have changed. If you'd like to join our monthly meetings of friendly folks where we discuss affiliate business and plans for speaker presentations, trainings, conferences, etc., do let us know so we can arrange a visit. We are particularly open to new board members who have some tech know-how regarding the website and newsletter layout or some comfort with treasurer duties.

Listening Group on Mental Health Concerns

Alameda County Behavioral Health (ACBH) invites you to attend an upcoming Mental Health Services Act (MHSA) listening session on December 8, 3 to 4:30 pm, to better understand the mental health needs of our communities here in Alameda County. We have scheduled this listening session specifically for the members of NAMI East Bay.

As part of ACBH's planning process for the next MHSA Plan Update for FY 22/23, ACBH is cohosting this listening session to provide education on the MHSA and receive community input on the mental health issues in our county. MHSA is the result of 2004's Proposition 63, where a one-percent tax is levied on incomes over \$1 million, with resultant funds directed towards mental illness issues.

To join this discussion, go to https://global.gotomeeting.com/join/990615501. You can also dial in using your phone: United States +1 (571) 317-3122, Access Code 990615501.

The listening sessions will be facilitated virtually by Tracy Hazelton, MHSA Division Director for ACBH, and co-hosted with NAMI East Bay Affiliate President Liz Rebensdorf.

Thank you for considering attending. Should you have any questions or if you'd like to provide additional feedback, please feel free to email the MHSA mailbox at MHSA@ACgov.org.



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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.

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Contact me for Family to Family Education Class Name: Address:	Phone No.:
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