
NAMI EAST BAY NEWSLETTER

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

January-February 2022

Our Perspective in January 2022

Wednesday, January 26, 7:30 pm

We are all unwilling participants in this era of the historic pandemic, so let's take stock. As we go into January of the new year, it's time to share our perspective of where we families with individuals with mental illness have been, where we're going, and what lies ahead.

Our roundtable discussion will include **Rebecca Woolis**, family therapist and author of [When Someone You Love Has a Mental Illness](#); **Beverly Bergman**, Family Caregiver Advocacy Specialist; **Patty Espe- seth**, Chief Administrative Officer of the Alameda Health System and support group leader; **Katy Po- lony**, Family Advocate for In-Home Outreach Team and Co-Founder of Families Advocating for the Seriously Mentally Ill (FASMI); **Kate Kosmos**, School Psychologist in the Oakland public schools; and **Liz Rebensdorf**, support group leader and President of NAMI East Bay.

Speaker Meeting starts at 7:30 pm

The presentation will be **Zoom/online**, and at- tendees 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 form in the newsletter, and video-recorded and ac- cessible via the What's New link on our website.

Support Meetings

For the duration of shelter-in-place and social-dis- tancing 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." 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.

Advocacy Protest in Planning Stage

Families Advocating for the Seriously Mentally Ill (FASMI) is in the very first steps of planning for an in-person protest, likely in front of the Alameda Board of Supervisors office, to ask that money from the state's \$2.3 billion Behavioral Health Continuum Infrastructure Program (BHCIP) fund be used for building treatment beds for the seriously mentally ill.

Dates are not finalized but we are aiming for the end of January, possibly sometime from the 23rd to the 25th. We are working on a press release for me- dia, involved organizations, groups, and interested parties.

More information will be info forthcoming as we cement it. Contact fasmi-discssion@googlegroups.com.

Flashlights

We are not in the habit of repeating items found on social media, but here goes:

When a flashlight grows dim or stops working, do you just throw it away? Of course not. You change the batteries. When a person messes up or finds them- selves in a dark place, do you cast them aside? Of course not. You help them change their batteries.

Some need AA—attention and affection; some need AAA—attention, affection, and acceptance; some need C—compassion; some need D—direction.

And if they still don't seem to shine ... simply sit with them quietly and share your light.

(Author Unknown)

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SPEAKER NOTES

Obsessive-Compulsive Disorder

Summarized by Thomas T. Thomas

Obsessive-Compulsive Disorder (OCD) can be said to inform behavior more than other mental illnesses and is co-morbid with many of them. The International OCD 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 the guest speaker at the November meeting, **Timothy Quinn**, since 2014. He states that these groups “are an integral part of mental health maintenance.”

Quinn’s comments and observations were supplemented by group members **Mary Weinstein**, whose daughter has OCD, and **Shelley Holst**, who experiences OCD herself. Weinstein and her husband Peter are also instrumental with [OCD SF Bay Area](#) in Redwood City, one of many local affiliates of the International OCD Foundation.

Timothy Quinn had been experiencing symptoms since he was six years old, but the condition was most triggered when he went off to college, with its stresses and anxieties. He said that the condition must have a genetic base—but no single gene or set of genes has so far been identified, although there are places in the DNA code to look—because his father had anxiety and his sister experiences OCD. The condition affects all types of people in all walks of life at all ages. And OCD may not be a single disorder but a spectrum or a group, like “the schizophrenias.”

Quinn struggled with the condition for years until he joined a group in San Francisco led by a therapist. He now co-facilitates his own peer-led group—which meets without a therapist—in the East Bay under the Bay Area affiliate of the IOCDF, which does have therapists on its board of directors. His group meets every Saturday from 3 to 5 pm, originally at the Kaiser medical facility on Broadway and now by Zoom online. The group is trying to find a different physical meeting place, however, because some members are triggered by thoughts of contamination at a hospital. His group is open to people experiencing OCD as well as spouses, parents, siblings, and partners of those with the condition.

October is OCD Awareness Month, and this past

month was marked by the One Million Steps for OCD at Lake Merritt in Oakland on October 21. The event hosted tables from various local groups, including those for related conditions like hoarding. Quinn and Weinstein are quick to point out that, although some people with OCD hoard, perhaps because they fear throwing away something important, and some hoarders have OCD, hoarding is not a regular feature of the OCD experience. The same goes for conditions like Tourette syndrome.

So what is OCD? It is a mental disorder in which a person gets caught up in a cycle of obsessions—or unwanted, intrusive thoughts, images, or urges—and compulsions—or behaviors that the person engages in, attempting to rid themselves of the obsessions or to ease their distress. It is a downward spiraling or feedback cycle. Some common triggering thoughts or images are those of contamination, as noted above, sexual orientation, or harm to self or others. These are thoughts that occur to everyone at some point but trigger the compulsion in those with OCD. “The thought comes in and sticks,” Quinn said, “and that creates a loop. The more you do the behavior, the more you need to do it—until you reach the breaking point and decide you need to do something about this.”

Quinn himself suffered with the condition for years and thought he was going crazy, until he saw a therapist in Santa Cruz who identified his condition as OCD. But he still wasn’t dealing with it until he finally started treatments with another therapist in 2000.

There are several therapies that can be applied to OCD. The gold standard, and the one that works for most people, is Exposure Response Prevention (ERP). Working with a therapist, the person lists their triggers and anxieties, assigning the relevance to each on a scale of one to ten. Then starting with the lower end, say three to four, the person considers the triggering thought, sits quietly with the uncomfortable feelings without engaging in the compulsive behavior, and so learns eventually that the feeling will go away without the behavior. This also helps a person recognize when the underlying process acquires a new behavior.

ERP is sometimes used in conjunction with [Dialectical Behavior Therapy](#) (DBT) and [Acceptance and Commitment Therapy](#) (ACT). “These therapies can help you find out what you value and help you keep these things in mind while you do the hard work,” Holst said.

Alternatively, a person with OCD may benefit from [Cognitive Behavioral Therapy](#) (CBT). This therapy is based on rational approaches to unhelpful ways of thinking and learned patterns of unhelpful behavior. Quinn and Weinstein are quick to point out that not all CBT therapists are trained to work with OCD patients, and since most specialists are in single practice, they can't afford to do the paperwork required for insurance coverage. The [NOCD website](#) (short for "No OCD) lists therapists with the necessary training and handles insurance for them.

There are also medications that can help. A selective serotonin reuptake inhibitor (SSRI) like Celexa, which Quinn takes, is normally prescribed for depression but in high doses can treat OCD. Some antipsychotic medications at low doses and some anti-anxiety medications are also helpful. There have also been studies with ketamine at Stanford University for people who are otherwise drug resistant. And the FDA has recently approved at least one machine that uses [Transcranial Magnetic Stimulation](#) (TMS) to treat OCD.

Quinn described how his support group functions. A meeting begins with a check-in, where the members briefly share their history with newcomers, talk about challenges and what's working well, and set goals for the week. They then share stories about OCD in the news and discuss the disorder in open forum, which can run the gamut. One of the group's norms is not to seek or give "reassurance."

This is a common pitfall for friends and family members of those with OCD: they respond to the content of the obsession or compulsion instead of the process. Then the person with the condition might not hear clearly what the other has said, might ask for a repeat, and then still not be sure, ask yet again. So begins the downward cycle. "It's okay to answer once, or to say 'I see you're having a hard time,' but then stop," Holst said.

Family members are encouraged to learn about the disorder but should not help the person with his or her obsessive thoughts or rituals. For more information on what family members can do, see [When a Family Member Has OCD](#) by John Hershfield.

The good news is that today there are many more therapies, trained practitioners, and medications to treat OCD than were available thirty years ago, when Quinn, Weinstein's daughter, and Holst first encountered the disorder.

Q. Have you seen trends in OCD since the pandemic started? Has the whole world become a little "OCDish"?

Definitely. More people are focusing their obsessions on thoughts of disease and contamination right now. The pandemic has also affected people with an underlying vulnerability. But the content of obsessive thoughts is different for each person and could attach to anything. It's based on what you care about most. You can also have several obsessions going at once..

Q. What other serious mental illnesses might be co-morbid with OCD?

OCD can be found with bipolar disorder in particular and is prevalent with attention deficit disorder (ADD), as well as with schizophrenia and schizoaffective disorder. "Sometimes there are a variety of things going on," Quinn said, "but in the current mental health industry, you can only get help for one."

Q. Does [Eye Movement Desensitization and Reprocessing](#) (EMDR), originally designed to relieve the stress associated with traumatic memories, help with OCD?

Not really. Trauma is an event that needs to be re-integrated, while OCD is a process that needs to be replaced. People with OCD can switch the content of their obsessions without controlling the underlying process. The person must work with the feeling rather than respond to it. But the OCD itself can sometimes cause trauma.

For more on the treatment of trauma, see [The Body Keeps the Score](#) by Bess van der Kolk, MD.

Q. Is substance abuse associated with OCD?

Sometimes, because people with OCD can use drugs or alcohol to self-medicate.

Q. Is there a link between long-term use of Clozapine (generic for Clozaril), which is one of the gold standards for schizophrenia, and incidence of OCD?

We have not experienced that, although [some studies](#) suggest there may be a link.

In closing, Timothy Quinn and the others said it is nice to have a toolbox, which wasn't available thirty years ago, to treat people using different therapies and medications for the different forms of the disorder.

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

At our weekly support groups, a standard recommendation is the book [*I am Not Sick—I Don't Need Help!*](#) by Dr. Xavier Amador. Folks comment that the LEAP principles outlined in the book help with communication with their ill relative. So when an online webinar training on the LEAP method was announced for Saturday, November 13, several of us took the opportunity to learn more. I want to share an overview and an interesting takeaway.

All too often, we hear stories of crisis, not recovery. An important aspect of recovery is self-awareness, yet we ascribe denial of illness to too many individuals when the predominant issue is lack of self-insight or anosognosia (“without knowledge of my illness”). Research studies have demonstrated that there are differences in brain structure of persons with mental illness and these differences are not attributable to effects of medication. Poor insight is a manifestation of the illness and not a coping strategy, and this is witnessed also with individuals with a stroke, dementia, and traumatic brain damage.

Unfortunately, this symptom predisposes an individual to noncompliance with treatment. Being self-aware is a top predictor of medication adherence, along with the presence of a relationship with someone who listens, respects and encourages therapy, hence the importance of LEAP (Listen, Empathize, Agree, Partner), which underlies the communication of a supportive relationship.

To Listen is to reflect back the content of what is said, perhaps with such words as “You’re saying ... right?” or “If I heard you correctly ...” or “What I’m hearing ...” Don’t omit some things, over-react, or rush to empathy. Delay giving your opinion by asking for more details and expressing your desire to learn more. The goal is to establish a relationship before giving an opinion or response. When giving your reality-based opinion, you may want to apologize for how this may make the individual feel, acknowledge that you might be wrong, or agree to disagree.

To Empathize is to normalize the emotions, such as “I’d be scared—or angry—or worried, too.” Feelings need to be recognized and validated.

To Agree is to set goals that might mitigate a path towards recovery—or stabilization. “What

would make your life better?” Discuss advantages and disadvantages of elicited suggestions and goals.

To Partner is to find a goal you both can agree upon and find ways to help achieve the next steps.

The LEAP plan is not complicated but a useful tool in establishing a productive relationship with your relative with a mental illness. The most poignant takeaway I got from this seminar came out in the role-play section, where the volunteer described her family and work setting but, in this set-up example, the presenting speaker worked from the premise that this was actually only a delusion as he exemplified the LEAP-oriented conversation. Can you imagine being told that all that you think about yourself and your life is not real? Yet, many of our relatives are in that state, holding such beliefs, and we need to help them in the recovery process. The use of LEAP principles can be part of that process.

—Liz Rebensdorf, President, NAMI East Bay

Discussion Group on Patients’ Rights

Notes from the October 27, 2021, online discussion group with Francesca Tenenbaum, director of Patients’ Rights Advocates (PRA).

PRA is a mandated state program with primary goals to oversee locked psychiatric facilities and ensure that patients are treated well. The Alameda County program, headed by Francesca Tenenbaum under the county contract with the Mental Health Association of Alameda County, described five duties of her staff of seven advocates:

1. Investigate complaints from consumers, families, and providers.
2. Monitor facilities for compliance with state regulations.
3. Represent patients in hearings. The certification hearings are done automatically when a person is to be held past the 72-hour involuntary hold following a Welfare and Institutions Code (WIC) Section 5150 hold. Advocates are mandated to reflect each patient’s wishes and argue their position. This duty takes the majority of advocates’ time, averaging a caseload of 500 to 600 such hearings a month, along with 90 monthly medication hearings.
4. Provide education to consumers and providers regarding such issues as how to present in hearings

and how to do holds correctly. If the facility does not follow proper procedure, the patient is released to the community.

5. Provide consultation to facilities regarding compliance. Since availability of services varies during a 24-hour span, Tenenbaum gives out her personal cell phone number.

Tenenbaum raised the issue of why there is such a high rate of involuntary treatment in Alameda County. The county is the subject of a current lawsuit about the overuse of this most restrictive and most expensive treatment. She feels a large part of this is due to lack of provider engagement with consumers, particularly in the case of medication use. The issue of outpatient services being “fractured” is another cause. In the sometimes short window of time when a client asks for help, it needs to be available then, not in six weeks. Also, the family is most often not seen as part of the treatment team, and they have a wealth of relevant history information generally not communicated to providers by the patient.

Early discharges: Advocates walk a fine line when a patient says there is nothing wrong (aka anosognosia) but maintain a perspective embracing civil rights. Facilities can present hard evidence of observable behaviors seen on the ward. Sometimes an early discharge is informed by an insurance company’s involvement. And there are simply not enough hospital beds. More outpatient opportunities and an increase in number of beds are crucial.

Regulations around family involvement and confidentiality: California laws are considered most restrictive. Consent is needed from the patient before the family can be given information; however, this can be tempered if the patient will give limited consent around matters of whereabouts, health, etc. Verbal consent is valid, but it is advised to have a witness. Hearings should not cause friction in family relationships, but it does since parents are often the ones who initiated the 5150 call and who do not want the patient to return home without clinical intervention. When a patient is in crisis, the family is in crisis. Tenenbaum was impressed by “how parents stick it out” and feels her staff often become family rights advocates. The WIC Section 5328 deals with Legal and Civil Rights of Patients Involuntarily Detained.

Regarding AB 1424 form: This [downloadable](#) family history form is specific for 5150s. Parents are advised to write up a clinical history as well.

Life at Psychiatric Emergency Services (PES): Life is hard on the PES ward since all decisions are taken out of the patient’s hands. Each individual is assigned a nurse, and clinical interviews are held in multiple places. A big concern is boredom, although multiple group sessions, occupational therapy, and outside time are scheduled throughout the day. Advocates have noticed that many patients are concerned about the welfare of a pet left at home, and the suggestion was made that if there is In Home Support Services (IHSS) involvement, pet welfare could possibly be a responsibility of that worker. Use of physical restraints has lessened because of health risks and the code requirement that a staff person sit face-to-face with the restrained individual, meaning less staff on the floor. This has led to reliance on chemical restraints in the guise of sedatives. Overuse of sedation is a cause of noncompliance charges.

WIC 5150: There is a systemic backing away from having police be the only initiators of a 5150: it was not intended that police be the first responders. Now a variety of clinicians are being empowered to write up these forms.

Contact information: Patients’ Rights Advocates, 1-800-734-2504. The PRA program also includes a Grievances representative who follows up on complaints from consumers and families if there is agreement from the consumer, 1-800-779-0787. Another member of the program is Family Advocate Bev Bergman, who has a presence at the facilities and deals with the families with a relative who is on a hold, 1-510-393-9275. These services are all offered under the umbrella of the contracted agency, Mental Health Association of Alameda County.

Movie Recommendation

If you like musical theater and are interested in how films can effectively present a story, we recommend you take a look at [Dear Evan Hansen](#), available through streaming services. This is a tear-jerker, but it takes a sympathetic look at mental illness, adolescent psychology and family coping.



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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.

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