NAMI EAST BAY NEWSLETTER

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

January-February 2019

Outpatient Treatment Available in Alameda County

Wednesday, January 23

Our January speaker will be **Penny Bernhisel,** award-winning Program Manager of the In-Home Outreach Team (IHOT) and the Assisted Outpatient Treatment (AOT) programs for Alameda County Behavioral Health Care Services. IHOT provides intensive outreach and engagement, mental health screening, and in-home engagement for individuals with a history of hospitalizations or law enforcement encounters, and who are not currently engaged in services. AOT, based on a recovery-centered model, is an intensive community support service for the seriously mentally ill who are at great risk for hospitalization.

Both programs are a result of sustained family advocacy and are relative newcomers to Alameda County. Ms. Bernhisel, a social worker with broad experience working with those living with serious mental illness, received the Mental Health Achievement Award in 2017 for outstanding contributions to the field. Come learn about these programs aimed at helping our treatment-resistant loved ones.

Speaker Meeting starts at 7:30 pm
Albany United Methodist Church
980 Stannage Avenue, Albany
Corner of Stannage and Marin
Meeting is free and open to the public.

Support Meetings

NAMI East Bay offers the following monthly support meetings:

- **Support and Share Group for Families of Adults** is held on the 2nd Wednesday of each month. The next meetings January 9, February 13, and March 13.
- **Support and Share Group for Families of Children, Adolescents, and Young Adults** is held on the 3rd Tuesday of the month: January 15, February 19, and March 19.

Support Group Meetings are held at the Albany United Methodist Church, 7-9 pm. Enter through the gates to the right of the door on Stannage Avenue, turn left through the large room, go down the hall, and come up the stairs. Signs will be posted.

All support meetings are free to NAMI members and non-members, offering a chance to talk with others who understand, give emotional support, and share ways they have found to cope.

Opportunities to Help Out

Fred Finch Youth Center has an opening for a full-time Parent Partner in their high-intensity Wrapa-round program. The Parent Partner's role is to provide one-on-one support to other parents by sharing experience and expertise in navigating and assisting families in how to utilize various local agencies. For more information, go to

https://www.fredfinch.org/opportunities/

Click on Current Job Opportunities and then Parent Partner - East Bay Wrap AC. Or contact Naomi Yu, Care Coordinator, at 510-485-5351.

Another opportunity is out there for those of you who can give us a couple of hours every other month to help with newsletter labeling. This happens the last week of the month and involves some simple work, lots of chatter, and refreshments. Let us know if this appeals to you in 2019.

Family to Family Class

As we go to press, there are only a few more spots left in our popular 12-week Family to Family class starting mid-January. Topics covered include diagnoses, medications, the brain, communication, empathy, problem solving, consumer perspective, family issues, advocacy, etc. The class is free but it is not drop-in and participants must register through our office.

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SPEAKER NOTES

Hearing the Consumer Voice

Summarized by Thomas T. Thomas

As family members, we have our own lived experience as we watch the relatives we love struggle with mental illness. Many of our loved ones have difficulty sharing what they're going through, but if we understand their struggles, we may be able to support them better.

Towards that goal, we had an opportunity to hear from some of people who carry a diagnosis of mental illness, hear voices, and are articulate in being able to describe their perspective. One of our NAMI East Bay board members, **Chris Hunter,** and two board members from the Bay Area Hearing Voices Network, **David Hallsted** and **Oscar Herrera,** shared their experiences with hearing voices and extraordinary mental states at the November 28 meeting.

Chris Hunter said he tries to be an "open book" about his experiences. He had earned two degrees in three years and enjoyed a fast-paced, successful life as a marketing and information systems consultant, was newly married, and traveling constantly, but not getting much sleep. Then about five years ago he was diagnosed with a mental illness, schizo-affective disorder, and he views this as an illness. "But," he cautioned, "don't look at your loved ones with a diagnosis in mind."

He started hearing voices. It sounded like people talking to him, ordering him around, and intimidating him. He believed they were also tracking his whereabouts. He became paranoid and believed people—the government—were on the roof and watching him. Because Hunter thought the voices would begin harming his wife, he checked himself into a hospital.

There he was given a cocktail of medications, with varying results and side effects that he didn't want to live with. "Taking medication is a fifty-fifty proposition," he said. Instead, he tried to treat himself through "reality testing, logic, and thinking." And after seven months the voices began to subside and only came to him at night.

Hunter had been fully off his medications when the voices came back more strongly, along with bouts of delusion and euphoria. For example, he believed that the store clerks at Barnes & Noble were arranging the books on the shelves just for him and his interests in cosmology and science.

In 2015, Hunter had himself hospitalized again and began taking medication, primarily to keep his relationship with his wife in shape. He has worked with a therapist for the past two and a half years to deal with the traumas of his childhood and his bouts of post-traumatic stress disorder (PTSD).

Hunter said he is living with the voices and that there is no set way to recover, no magic formula. "Everyone has their own place to end up," he said. He has also become a caregiver to his sister, who has borderline personality disorder, has trouble holding a job, and experiences emotional explosions that are both hot and cold. He also a counsels his mother as she deals with this situation.

Chris Hunter said he tries to be an advocate and represent the consumer voice. He has presented his story in NAMI's Family to Family class for the last three years. He sees the world and tries to think with the "wise mind."

What can families do to help a loved one who hears voices? "There's nothing you can do but work on yourself," he said. "The expectations you may have for your loved one—the dreams you had when he or she was a child—can be hard to deal with when they're living with extraordinary states of mind.

"So you have to find balance in your own life. I wish for everyone to find that center for themselves."

Oscar Herrera said he began hearing voices 33 months ago, after a successful thirty-year career as a jeweler, and from the first they began speaking to him 24/7. After six months, they became clearer and more informative. "They began asking do I want to make a deal with them," Herrera said, "and would I be submissive? That is not what I wanted to know.

" 'Where do you come from?' I asked. 'Who are you?' 'I'm a ghost,' they said. 'Show me your energy,' I said. 'Why are you a ghost? Are you sad or happy?' And they replied, 'We are all energy.' "

Herrera said he never believed the experience was a mental illness but a spiritual awakening. Then he began reading about UFOs and thought the voices were extraterrestrials.

When an "obnoxious, insulting" voice came to Herrera, he was puzzled. He asked where the voice got its power, and it answered, "I am energy."

To test this, Herrera held out his car keys and

said, "If you have power, I want you to catch my keys." But when he dropped them, they hit the ground. "You have no power," he concluded. He decided the voices were from a different dimension and that he, Herrera, was solid while they were not. One time he felt a push but did not see anyone. He kept asking, "Where are you? In my body? In my brain?"

Because they followed him every second, telling him when he did something right and criticizing when he did something wrong, Herrera determined that they had to be sick, critical, parasitic voices. When they told him to commit suicide, he replied, "That is not on my agenda."

He kept challenging the voices, counterattacking the entity. He asked if they were positive or "dark" energy. "If positive," he said, "you should tell me positive things."

He visited a spiritualist church, with psychics and mediums, but they could not tell him what the voices were. He went to Southern California and Arizona, to a UFO group, who believed the voices were extraterrestrial energy that had come to our planet to get into our bodies. The voices once told him to park along the road and walk out into the desert, but Herrera refused, saying he might get lost.

"People who hear voices may be receiving energies at a different frequency," Herrera said, "but they are put there for a purpose." He said he had no interest in medication, because he wanted to know where the voices come from.

"You are in a circle with a wild horse," he said. "You have to tame it."

David Hallsted that voice hearing is a common experience, and he blogs about it, in addition to being a certified business coach.

When he was very young, he could hear music in his head. He would be alone, talking to himself, and he would just know things. The voices have helped him be more intuitive about things. "Hearing voices is the best thing that ever happened to me," he said. He "just rolled with it." When he had to take an examination or make a report, the voices helped him.

The first time he heard multiple voices, he was in the house and one said, "I'm here." And then another said, "Shh!"

When he hears the voice, Hallsted said, it has a definite location but the body attached to the voice is optional. "When you talk, you can feel the resonance inside your own head. But these voices have no resonance; so they are outside your head." (Chris Hunter noted that functional MRI scans have shown voice hearing is associated with auditory processes in the brain.) Hallsted noted the voices are spontaneous, speak in third person, and change voice forms and mannerisms depending on who's speaking.

"But my experience is that the voices are reaching out," he said. "And I'm good with it."

Hallsted had achieved a level of mutual respect with the voices. "If they touch you, you can go back and touch them. Or you can tell them to stop." He noted that you can also block the voices by smoking or listening to music with headphones.

NAMI Board Member Ed Herzog, who is also on the Board of the Bay Area Hearing Voices Network, said that the group meets in the Berkeley Senior Center on Monday nights. Participation is free and family members are welcome. Next year, they will start a Hearing Voices group for young people age 11 to 25 in Berkeley.

Q. How do professionals deal with the voices and other extraordinary experiences?

A. Ron Coleman, who helped found the Hearing Voices Movement in the UK, engages with the voices as a third person. And "regression hypnotherapy" is sometimes used to treat them. But most practitioners are reluctant to engage with voices, because that would lend credence to their reality. Kaiser, for example, has a "no collusion" policy. But most voice hearers feel relief when they enter a Hearing Voices group, because they are having an experience that others don't perceive as normal.

Q. It appears that you are not at the mercy of the voices. Or are you fighting with them, trying to control them?

Herzog noted that, when you approach the voices as real, it does away with the fear and anxiety.

"Sometimes," Hallsted said, "the voices have problems of their own. Then we try to help them."

"You can gain some control," Hunter said, "by telling them to stop—by physically and audibly telling them to go away."

Past articles in the Speaker Notes series are available online at www.thomastthomas.com under "NAMI East Bay." Also available is a copy of the brochure "Medications for Mental Illness."

Musings

The concept of a continuum pervades our life experiences. We generally can place most concepts, traits, behaviors, etc. on a range of strength or impact; so that a person can be, for example, very, sort of, or not so social, and very, sort of, or not so intense, for example. So it is in living with a loved one with a mental illness.

At one end of the continuum is the active crisis state, when an individual is psychotic and of danger to himself or others. This is where we need the help of the system, and a call to 911 mobilizes police and crisis managers, and incarceration or hospitalization, rightly or wrongly, may result. (Wouldn't it be wonderful if that process worked and problems were resolved rather than just stabilization achieved.)

At the other end of the continuum is the individual who has a diagnosable mental illness but works, has a family life, and is considered stable because either the illness assumes a very mild form or the interventions are a perfect match.

In the middle of this continuum is the situation we discuss most often at support groups and classes. Our relative is in our life, sometimes at ease and stable but sometimes not, sometimes articulate and sociable but sometimes reclusive and non-responsive … we all know this scenario and it seems that in every support group the phrase "walking on eggshells" is used. Many if not most of us live in this tenuous state of caring and loving and grieving and being anxious and fearful—we're in the state of Worry that pervades our daily life and wakes us up at 3:00 am to ponder and ruminate. We may look calm but underneath we have special antennae out for minor behavioral changes and words that may forewarn of another crisis situation.

So our problem-solving does not culminate in a 911 call so that the system can intervene. Rather, our problem-solving is an everyday practical yet tedious process of dealing with situations where we're not quite sure how to proceed … and where there are no easy answers. How does one talk with a person who is hearing voices? How does one handle the holiday events when you've been told that relatives feel uncomfortable with your son and wish he would not participate? What can you do when your loved one says s/he's not ill and doesn't need help? How can you intervene when you see warning behaviors such as staying awake all night or not taking meds? How can you get your loved one out into the community if his obsessive-compulsive disorder won't let him touch the cell phone or wear a watch … and what do you do when you lose him in a crowded venue? How do you handle siblings' relationships with their ill brother or sister? How can you help your relative get out of his head turmoil and relate? How does one console a son or daughter who is intact enough to know that his/her life is not what was expected—and is grieving about that? What will happen when we're not there to run interference?

These are only some of the issues that consume our time and energy. At the same time, we're trying to live our lives and attend to other family members … sometimes not sharing what we're going through with others who don't understand the nuances of mental illness and who think that if someone just got a job, it will all work out.

Sometimes we share and get involved and become advocates for changes we think might make this better. This takes up energy, and systemic changes move slowly … but at least we're taking some action … yet we are still coming home and dealing with the practical issues of someone living with mental illness. So many of us share this difficult position—we need each other since we truly understand. You are not alone.

—Liz Rebensdorf, President, NAMI East Bay

Shout Out!

For 25 years, our bimonthly meetings have featured a speaker or panel presentation about some aspect of mental illness. For pretty much all of those meetings (210 to be exact!) Tom Thomas has been sitting in the back row, taking notes, writing up a summary for publication—and then in recent years doing the layout of the newsletter once all the other content is complete. Tom has been doing this rain or shine and even throughout the recent sad loss of his wife, Irene Moran. He is an invaluable asset to our group and to the community, and we deeply appreciate his willingness, consistency, and competency.

Tom is a professional writer and all of his writeups since 1993 are posted on his website

www.thomastthomas.com under "NAMI East Bay" on the home page. It's interesting to look through the topics that he wrote about—sort of a time-based microcosm of areas of interest to NAMI families. Thank you so much, Tom, for being there.

Year-End Research Summaries

- With "Bipolar Disorder: The Year Ahead" in the December 6 issue of *Psychiatric Times,* James Phelps, MD, looks back and ahead at two major trends regarding bipolar disorder.

  A. Causes and treatment corollaries: Six mechanisms and treatments are suggested, and the writer speculates about their interaction: the pathways seem to be sleep dysregulation, inflammation/immune-based, hormonal/steroid and thyroid, mood bias/reward sensitivity, stress/glucocorticoid, and mitochondrial/energy. The treatments, the author notes include Cognitive Behavioral Therapy and medications.

  B. Phelps notes that personal self-management is a central element in most of the therapies he mentions. Some have looked into passive self-monitoring via phone data (such as usage, speed, and time) since the more common activity of keeping a written log is not easily maintained. The value lies in enabling patients to better manage their own mood stability. With the goal to integrate treatments with bipolar mechanisms, the author notes the goals of creating and maintaining regular sufficient sleep, avoiding mood- or bias-driven decisions, receiving automatic reminders to use mindfulness-based relaxation techniques, and facilitating medication adherence.
- In a December 3 *New York Times* letter to the editor, Jeffrey Borenstein, psychiatrist and president of the Brain and Behavior Research Foundation, comments on a recent article which questioned the amount of money spent on new treatments for mental illness: "Recent advances in treatment include transcranial magnetic stimulation for depression … early diagnosis and intervention for schizophrenia, … potential effectiveness of rapid-acting antidepressants … looking at use of nutritional supplements during pregnancy to reduce the risk of the child's developing schizophrenia … the brain is our most complicated organ but we spend much less on brain research than on cancer."
- In a December 13 *New York Times* article, "Mapping the Brain's Genetic Landscape," Benedict Carey reported: "For the past two decades, scientists have been exploring the genetics of schizophrenia, autism, and other brain disorders, looking for a path toward causation. If the biological roots of such ailments could be identified, treatments might follow, or at least tests that could reveal a person's risk level.

  "In the 1990s, researchers focused on genes that might possibly be responsible for mental distress, but then hit a wall. Choosing so-called candidate genes up front proved to be fruitless. In the 2000s, using new techniques to sample the entire genome, scientists hit many walls: Hundreds of common gene variants seemed to contribute some risk, but no subset stood out.

  "Even considered together, all of those potential contributing genes—some 360 have been identified for schizophrenia—offered nothing close to a test for added risk. The inherited predisposition was real; but the intricate mechanisms by which all those genes somehow led to symptoms … were a complete mystery.

  "Now, using more advanced tools, brain scientists have begun to fill out the picture. In a series of 11 papers, published in *Science* and related journals, a consortium of researchers has produced the most richly detailed model of the brain's genetic landscape to date, one that incorporates not only genes but also gene regulators, cellular data, and developmental information across the human life span."
- In "Self-Other Recognition Impairments in Individuals with Schizophrenia," *Nature,* November 28, Gaelle Keromnes *et al.* reported that "Clinical observations suggest early self-consciousness disturbances in schizophrenia. A double mirror combining the images of two individuals sitting on each side of the mirror was used to study self-other differentiation in 12 individuals with early onset schizophrenia and 15 … with adult onset. The results showed [schizophrenic] individuals, independently of age and … severity, were centered on their own image compared to [controls]."

NAMI East Bay
National Alliance on Mental Illness

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We urge you to mail your 2019 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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