
NAMI EAST BAY NEWSLETTER

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

January-February 2016

Panel Discussion: Community Collaborators and Resources Wednesday, January 27

In our large, vibrant urban community, there are many agencies and services that don't have the words "mental illness" in their names but provide relevant and significant services to both families and consumers. Sometimes we learn about them from others or through sharing spaces at health fairs or the Solano Stroll. With that in mind, we've invited representatives from different community resources to join us for an informational evening. We will have short presentations by each group, along with written materials and the opportunity to engage in dialog. So far—and we're still recruiting—we will have representatives from Bay Area Community Services (BACS), In Home Support Services (IHSS), Center for Independent Living (CIL), Al'Anon, and Mental Health Association of Alameda County. Invitations are out to other agencies as well, but they haven't confirmed; check our website for updates.

Please join us for an informative evening.

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 are January 13, February 10, March 9.
- **Support and Share Group for Families of Children, Adolescents, and Young Adults** is held on

the 3rd Tuesday of the month: January 19, February 16, March 15.

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.

Family to Family Class

Our annual 12-week (30-hour) Family to Family class will be on Thursday nights starting January 21. The class is filling up fast but, as of this writing, a few spots are left. Teachers are Tommie Mayfield, Lindsay Schachinger, and Liz Rebensdorf. The class covers diagnoses, brain function, medications, communication, problem solving, empathy, advocacy, etc., along with support and interaction. Participants must pre-register and need to be family members or otherwise involved with an individual with a mental illness. Please leave your name and contact information via our email (www.namieastbay.org) or phone (510-524-1250).

Family Social Night

We invite you and your loved one to a family social night on Monday, January 25, 5-7 pm, at the office. This is an opportunity for our relatives with mental illness to casually meet each other over pizza and board games—and for family members to connect. It is crucial that you notify the office by Friday, January 22, if you plan on coming so we can order enough pizza.

SPEAKER NOTES

What is the Hearing Voices Network?

Summarized by Thomas T. Thomas

Hearing voices, seeing visions, experiencing extreme states, and holding unusual beliefs are all part of the “lived experience” for many of our family members and friends who have severe mental illness. At our November 18 meeting, we heard NAMI East Bay Board Member **Ed Herzog** speak about his experiences with his son’s voice hearing, which led him to help set up a local workshop in April 2014 with Ron Coleman of the Europe-based hearing voices movement, which drew 120 paying participants. Recently, Herzog became a founding member and vice president of the Bay Area Hearing Voices Network.¹ BAHVN Board Members **Sederia Lewis**, **Dina Tyler**, and **Manton Hurd** also appeared on the program with him and shared their perspectives.

“My journey began with my son,” Herzog said. “Five years ago he said he was hearing voices. I didn’t know what to do about it. I was confused and scared. I only knew it was a symptom of a dangerous mental illness.” What followed was extremely painful, with hospitalizations, 5150s (confinement of a person deemed dangerous to self or others), and “hard times.” At the center were the voices and the beliefs stemming from them. Herzog tried at first to be reassuring about the voices, then attempted to talk his son out of them, and finally resorted to medication—but nothing helped.

Through the internet, Herzog heard about Ron Coleman and the European hearing voices movement. What he learned at the 2014 Berkeley workshop changed the way he saw his son’s voice hearing. He learned that the voices were an important aspect of his son’s experience and acknowledged the anxiety and fear they produced. He looked at his own reaction and what he could do to change it in order to help his son. He learned to respect the voices as real entities, because they were real for his son. And finally, he learned to be open-minded, become curious, and offer good listening.

“We all have strongly held beliefs,” Herzog said. “And when someone tells you they’re wrong, you

get angry and upset. I stopped telling him the voices were not there. I stopped contradicting his experience and tried to have mindful engagement with the voices, finding out who these people were and what was going on with them.”

And with that, Herzog said, the emotional temperature in the household lowered. The voices became a normal experience and less a focus of tension and anxiety.

Sederia Lewis became involved with BAHVN because she and other members of her family had experienced extreme states, held beliefs not in synch with others, and heard voices that were leading her and guiding her. “I never shared the voice experience with a therapist,” she said. “I always kept them to myself.”

Through the Bay Area group, Lewis has learned more about her experience, gotten a better understanding, and been able to socialize with people who have similar experiences. She now leads a peer group of voice hearers that meets biweekly in Berkeley and is able to be a support to her family in their own experiences.

Dina Tyler started hearing voices when she was five or six years old and would retreat to her room to avoid her family’s near-constant fighting. Over her lifetime, the voices have changed, from single speakers to masses of people chattering, and they later became associated with visions. “I slipped into another world,” she said, “a spirit world where I could see and talk to these people. One would yell at me, but others were friendly and comforting.”

Distracted by the voices, Tyler was diagnosed with Attention Deficit Disorder in high school and given Ritalin and Adderall. In college, her voices became stronger and louder, and she would lapse into a catatonic state, staring at the wall for hours at a time and forgetting to eat or bathe regularly. There she was diagnosed with depression and psychosis “not otherwise specified.” Her therapists all wanted the voices to stop, and later she was also diagnosed with bipolar disorder, schizophrenia, and schizoaffective disorder. “People were afraid of the voices, so I stopped telling about them.”

Three to four years ago, Tyler attended an event with Ron Coleman. There, she found a community with whom she could talk about her experience, get different perspectives, and learn ways of dealing

¹ <http://www.bayareahearingvoices.org/>

with the voices. She now leads a biweekly peer group in San Francisco.

“With the group, I’ve been able to make meaning out of the experience and regain power,” Tyler said. “I look at the voices, and some are jerks and tricksters, and I can choose not to listen to them. Some voices are helpful and guiding—but they can yell at me, too. I’m the one who discerns. I can bargain with them and make them treat me with respect. I can also sort the voices out and relate them to things I’ve experienced in my life.”

In response to questions from the audience, the speakers variously noted that the voices are different from the random thoughts that might go through a person’s head, including internal criticism. “Sometimes this is not me,” Tyler said. “I have picked up a knife and held it to my arm. The voices are sometimes so mean. And I’m a good person.”

Fortunately, Tyler was able to finish college with accommodations like books on tape, which helped her overcome the voices. But, while she is in recovery, Tyler still worries about revealing her condition, and sometimes in conversations she struggles to get out a response.

Lewis said that the voices were loud and external—but still guiding. They were not “self-talk.”

Manton Hurd noted that the voices one hears adapt to the strategy the hearer uses. “We are incredibly diverse,” he said.

Hurd talked about the books available on the subject, including [*Living with Voices: 50 Stories of Recovery*](#) by Marius Romme, one of the first psychiatrists to treat his patients’ voice-hearing experiences seriously, and [*The Origins of Consciousness in the Breakdown of the Bicameral Mind*](#) by Julian Jaynes, whose controversial theory treats human consciousness as a learned process that is still developing.

Marius Romme established the Hearing Voices Movement in the Netherlands in 1987 when his patient Patsy Hage challenged him by saying: “You believe in a God we never see or hear, so why shouldn’t you believe in the voices I really do hear?”

Romme tried a different approach with Hage. Later he organized a television program in Europe where people could call in and describe their experiences. The response was so great that it inspired the movement, which is now active in more than 30 countries and 17 U.S. states.

The values of the Bay Area Hearing Voices Network include:

1. Voices are understood as a state of mind.
2. Diverse explanations are accepted for the origins of voice hearing.
3. Voice hearers take ownership of their experience and define it for themselves.
4. Voice hearing can be interpreted and understood in the context of lived events and interpersonal narratives.
5. Understanding and acceptance provide more help for recovery than continued suppression and avoidance.
6. Peer support and collaboration are empowering and beneficial for recovery.

“When I’m in the peer group,” Tyler said, “I feel safe and the voices take a back seat. I know they’re not going to put me in the hospital.”

The East Bay group meets 1st and 3rd Mondays, 6-7:30 pm, at the Berkeley Drop-in Center, 3234 Adeline Avenue. The San Francisco group meets 2nd and 4th Wednesdays, 6-7:30 pm, at 160 Ninth Street (between Mission and Howard—ring the doorbell or knock). Attendance is open, and people hearing voices, having visions, or experiencing extreme states are all welcome.

“We help each other understand and cope, and we ask questions,” Lewis said. “Like what do the voices say? What is their tone? Is it one voice or many different voices. Are they male or female? Have they changed over time? Are you likely to experience them in certain situations? How do you feel about the voices? What purpose do they serve?”

The Bay Area Hearing Voices Network also offers training for clinicians and for group facilitators. They will coordinate workshops with external trainers like Ron Coleman.

Family members can play a role in voice hearing by empathizing with the hearer, said Ed Herzog, who leads a once-a-month group for families. “You can ask the voices why they are so angry with your family member, and be understanding and curious about the sources of anger, rather than shutting down because of your fear.”

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

Musings from the President

Well, the Christmas tree has been taken down, but the string of outdoor lights will stay up for a while longer to get us through the dark winter ahead. This is always a time of reflection—looking back and forward at the same time.

It's been a busy year at NAMI East Bay. The outreach infrastructure is a bit more sparkling with our new brochure and website. Both ventures took a group effort with professionals giving us good working rates and we feeding back our creativity and information priorities. The programs we've offered have tried to address various aspects of the immense arena of mental illness. As usual, we recommend that you take a look at the presentation summaries by Tom Thomas, who has voluntarily written up the content of our six yearly general meetings—for the last 22 years! Check out www.thomasthomas.com and follow the NAMI East Bay link on the lower left side of the page.

We've witnessed the birth of the Hearing Voices Network. Under the energetic leadership of Board Member Ed Herzog, the Bay Area group has grown to the point where it has become its own nonprofit organization and is offering sessions through Berkeley Mental Health. Traditional treatments are not always successful for our families, and we value the exploration of alternative perspectives. See the Speaker Notes on page 2.

We've also been intimately involved in the birth of the Housing Network of families, providers, county staff, and developers. See the article on page 5.

We welcome University of California student Michael Godoy to our board and welcome his [NAMI on Campus at Berkeley](#) group to our ranks. It's great to be in the company of enthusiastic young folks who are willing to bring the topic of mental illness to the vibrant university community. We will also be working with the other UC group, You Mean More, and its focus on Suicide Prevention.

Most recently, some of us actively participated in the advocacy efforts to get a pilot program of Laura's Law (aka Assisted Outpatient Treatment/AB 1421) started in Alameda County. Following the lead of our neighboring counties of Contra Costa and San Francisco, there will be a process in place to get treatment to some of our most ill family members—

those who are frequently incarcerated or hospitalized, who are decompensating, and who will not admit they need help, thus refusing treatment. The pilot program is unfortunately small, reflective of the turmoil surrounding the Board of Supervisors' decision on November 17 and re-confirmed on December 15 (see the legislation article on page 5). This has been an advocacy effort riddled with political and emotional layers, along with what we judge to be resistance from county leaders. Looking forward, the task in 2016 is to keep this going and bird-dog the crucial decision-making along the way. If you have any interest in this project, we ask for your help; specifically, we need grounding in the actual law.

Back on the home front, this will be the year to get organized. We will be looking into a group mail service and be thoroughly cleaning and organizing our humble office space. The procedures and the space need to be more manageable and efficient. One goal is to convert our large amount of VHS tapes into discs—for you to borrow and for us to present. Here again, we ask our readers to come forth with ideas and suggestions—and perhaps some elbow grease as we tackle this project.

As I write this in the beginning of December (hah, fooled you about the tree being taken down; I haven't even put it up yet—a literary indulgence), we are in the process of sending out our annual fundraising appeals. (Note: There seems to have been a problem with some of the mail deliveries, so let us know if you didn't receive a hard-copy appeal and we'll be sure to get it to you.) Our readers have been generous in the past, and we thank you for your current generosity and thoughtfulness. Funds raised will go towards the VHS-DVD conversion and library additions.

In the heartfelt spirit of the season, I wish you all a Happy New Year. For our families, this doesn't always translate into riches, travel, or good health and fortune. It may mean your son comes in off the streets, your daughter can carry on a rational conversation, your spouse makes eye contact—or all can laugh at a joke, contribute to future planning, emerge from the solitary back bedroom, and look happy or interested or engaged in life. May this happen to you in 2016.

—Liz Rebensdorf, President, NAMI East Bay

Innovations for Isolated and Older Adults

One of the primary components of the Mental Health Services Act (Proposition 63) is that of Innovations. There have been three rounds so far, and each round involves addressing the needs of a target population with an 18-month project. So far, the first round was not specific to a certain population, and the second addressed improving outcomes for the African-American community. A year or so ago, we suggested that the needs of isolated adults with mental illness should be addressed—and so they were, by funding ten grantees, each of whom wrote a relevant proposal and proceeded to implement it. Margot Dashiell, our vice-president, was one of the grantees. She developed a program titled, “An SRO (Single Room Occupancy) Culture of Inclusion to Decrease Isolation Among Residents with Serious Mental Illness.” (At the same time, needs of the LGBTQI2S community are being addressed via a separate, parallel process.)

We have the opportunity to hear about Margot’s project and the nine other programs at the Innovations Round 3 Learning Conference on Friday, January 22, at the Clark Kerr Conference Center in Berkeley. This all-day conference will feature an exhibit hall, lived experiences panel, workshops, performance by Stagebridge, and videos, as well as continental breakfast, lunch, and a raffle. The event is free but participants need to register at acinnovations.herokuapp.com/thirdRound_2014. This will also be an opportunity to meet some of the staff from the county’s Behavioral Health Care Services and find out how you can participate in and support their efforts as a family member.

Legislative Progress on Mental Illness

Advocacy battles go on and on. The comprehensive federal bill HR 2646, Helping Families in Mental Health Crisis Act (Murphy), is making its way through the congressional legislative process now and, of course, has its mobilized loyal opposition. There is bipartisan support, and our local advocates did meet with Representative Barbara Lee and secured her endorsement. In the Senate another bill, S 1945, is proceeding along a parallel course. We are hopeful that something good and productive will

come out of this after all the modifications have been achieved. In the meantime, take a look at our website for a review.

At the local level, as noted above, AB 1421 (AOT, or Laura’s Law) has now twice been approved by the Alameda County Board of Supervisors for a small pilot program. See our website for a full description of the bill with FAQs (scroll down under Public Policy).

The latest confirming vote was again countered by those who oppose all aspects of this law, who say it requires forced medication (which it doesn’t) and the loss of civil rights (legal representation is available at each step, including the ample accountability reports).

The emotional chasm between supporters and opponents is sadly exemplified by one consumer’s angry question to a family member: “... and what did you do to cause your son’s illness?” We have a long ways to go to heal the hurt and calm the perspectives. Let us know if you’re interested in joining the necessary healing process.

Update on Our Housing Network

A year or so ago, three NAMI East Bay members met over coffee at Cafe Leila and learned about a wonderful housing development in Davis. Several small exploratory meetings followed, where people came to discuss housing concerns. Last May, we invited Dr. Robert Ratner, director of Housing for Alameda County’s Behavioral Health Care Services to speak at our general meeting, and he gave a sobering presentation about housing issues in the Bay Area and describing the heroic efforts his department has undertaken to address the issue. Attendees were invited to join an email network to plan further discussions. Under the robust and spirited leadership of Laverda Allen, a focused group has been meeting, and small groups have been doing visits and research into development, fiscal, and service management issues and then reporting back to the larger group. In January, under the guidance of a facilitator, we will determine priorities and needs as well as the overall direction of the group. If interested, please contact our office for more information.



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NAMI EAST BAY 2016 MEMBERSHIP

Please check your mailing label. If the code "16" is over your name on the right side of the label, your dues are current through 2016. If your mailing label indicates a previous year, or nothing at all, your dues are not current.

We urge you to mail your 2016 dues now. And if you can afford to add a bit more, please do so. Your \$35 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, \$35 per year Open Door Membership, \$3 per year

Make checks payable to "NAMI EAST BAY" and mail to NAMI East Bay, 980 Stannage Avenue, Albany, California 94706

Contact me for Family to Family Education Class

Name: _____ Phone No.: _____

Address: _____

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I'd like to volunteer: In the Office Grant Writing Membership Committee
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