

Report from the Board¹

Summarized by Thomas T. Thomas

At our January 25 speaker meeting we heard from three of our NAMI East Bay members who described their recent activities. Board member **Ed Herzog** told of his experiences with the Hearing Voices Network. President **Liz Rebensdorf** talked about two initiatives in Alameda County designed to address the problem of housing for the mentally ill. And one of the founders of the NAMI affiliate on the UC Berkeley campus, **Michael Godoy**, discussed his new position as a program manager at the University of California San Francisco, working on scalable mental health therapeutics.

Hearing Voices Network

Ed Herzog said he became interested in the voice-hearing experience five or six years ago when his son began hearing them, and Herzog didn't know what to tell him. His son was 30 years old at the time, under stress with a new baby, working the night shift, and not getting much sleep. Herzog has since learned that the experience can occur at any age, and children often hear voices and have imaginary friends.

Mental health professionals told him the experience was “very dangerous” and was a symptom of schizophrenia. They told him to fear the voices and to monitor the experience closely. The only treatments available were medication—which didn't stop the voices—or hospitalization if things got rough.

The voices came to dominate his son's life, because he didn't know how to cope with them. For him they were real. Even when Herzog took his son out into the empty street and demanded he show who was speaking, the experience remained real.

In frustration, Herzog looked on the internet and discovered the Hearing Voices Movement. He found it was popular in Europe—England has more than 200 such groups—but virtually unknown in this country. The founder of the movement was Dr. Marius Romme, a Dutch psychiatrist. The chief proponent and developer of the network in England is Ron Coleman of [Working to Recovery](#). Coleman has lived experience of the phenomenon and still hears voices, even while he is lecturing and conducting training sessions.

Learning about all this, Herzog got together with other family members and people who have the lived experience of hearing voices, having visions, receiving



ED HERZOG REPORTS ON THE HEARING VOICES NETWORK.

¹ The speaker originally scheduled for January 25, Dr. Rebecca Carrillo of Berkeley Mental Health, had to cancel because of a family emergency.

special messages, and holding strange beliefs. They created the Bay Area Hearing Voices Network (www.bayareahearingvoices.org). The group organized a training session under the NAMI East Bay auspices and brought in Coleman. They were surprised when 120 people showed up and paid \$40 for the session.

“Millions of people hear voices and never come in contact with a mental health professional,” Herzog said. He cited the common experience of hearing someone call your name in the middle of the night, or hearing the voice of a loved one who has passed away. When Coleman asked people at the training session about such experiences, soon every hand was raised.

The goal of the network is to reframe the voice-hearing experience, to use the voices and the content of what they say as a way to understand the person. Herzog learned to approach his son with an attitude of curiosity, rather than with fear and anxiety, and rather than trying to reassure him. “Reason and logic don’t work,” he said. Herzog learned that his son usually heard a woman’s voice, which was mean, and a man’s voice, which was kinder, and both voices told him what to do. Talks with his son have become “a window into his subconscious.”

“The troubles are not over,” Herzog said. “But this has given us a language. It has allowed me to be with my son—not pushing him away and labeling him. I also learned that I had to change. I have no control over him, but I can change my own attitude.”

The Bay Area Hearing Voices Network has two meeting sites:

- **East Bay** at North Berkeley Senior Center, 1901 Hearst Avenue, every Monday, 6 to 8 pm.
- **San Francisco** at Conard Café, 160 Ninth Street, second and fourth Wednesdays, 6 to 7:30 pm.

The meetings are free and conducted on a drop-in basis. Family members are welcome to come with their loved one to a first meeting, but the program is moderated by peers and meant for people with lived experience. It is a place where they can meet with others, learn coping strategies, and hope at some point to manage the experience. To contact the Hearing Voices group, you can email them at bayareahearingvoices@gmail.com.

Housing in Alameda County

Liz Rebensdorf has been part of two committees in Alameda County to address the dreadful shortage of housing for people with mental illness.

The Shared Housing Collaborative is an informal group that meets monthly and is hoping to become allied with the East Bay Housing Consortium to develop funding and a model for housing in the Bay Area. Two of their members have visited the Cesar Chavez residence in Davis, which provides supported housing for people both with and without a mental illness and provides a social worker on site.

The collaborative is also looking at senior housing as a possible model for people with mental illness. In the senior sector, people start with relative independence and little need for assistance and support but gradually require more and more help as they age. The mental health model would be the reverse of this, with people starting out needing lots of help and then gradually requiring less and less as they gain more skills and confidence.

But, Rebensdorf warned, nothing this group develops is likely to be an immediate benefit for NAMI East Bay family members. “Once you take federal money in these projects,” she said, “your program is open to all and positions are filled on a lottery basis.”

The other group she’s involved with is working with the county housing director in looking at board-and-care facilities. These owners are both aging out and terminating the provision of housing for people with mental illness—who can sometimes be challenging—sometimes in favor of those with developmental disabilities. Also, she noted, licensing of board-and-cares usually has less to do with treatment of mental illness and more with adhering to building codes. Consequently, the county is now looking at unlicensed room-and-board facilities, exploring a supportive referral model, called the Independent Living Association, which has been found successful in several California counties.

Rebensdorf also recognized NAMI East Bay Vice President Margot Dashiell for her work in getting an Innovations grant to fund an 18-month pilot program to increase social activities at the Lakehurst Project, a single-room-occupancy hotel in Oakland.

Scalable Mental Health Therapeutics

Michael Godoy is a program manager in Kim Norman’s Young Adult and Family Center at UC San Francisco. He is working on a number of software applications and websites that will be offered for free to help people around the world deal with mental health issues. These include:

- **Help Chat**, an iOS application for mobile devices like iPhones and iPads that will provide an anonymous peer support group for the user. On demand, the app will offer someone with whom the user can talk to and express feelings and ideas. This is helpful when a person feels unwell and needs to talk.
- **You.org** is a website in development for release this summer. It provides an online portal to support programs and services. The user begins with a Self-Interview Section, where he or she discusses concerns and notes symptoms. For example, if the person shows indications of anxiety, the site refers the user to the page called “Breathing Room,” which helps people monitor breathing as a way to regain control. Or it might direct the person to a Journalism application, which helps them to express their thoughts through writing.
- **Online Courses** are in development to help people deal with specific issues. These are videos of simulated therapy, developed with a clinician, that include an assignment, discussion, and a group session. The first course is called “Women Warriors” and deals with women who come back from combat situations with post-traumatic stress syndrome. The training helps them reframe and take control of the narrative of war. The second course is “Next Mission,” a coed video on post-traumatic growth. Finally, there is “The Fourth R,” which follows up reading, writing, and arithmetic with “resiliency,” which many young adults have said they need, because success is being able to persevere through adversity.

“Technology is going to solve all of humankind’s problems,” Godoy said. “Applied to mental health, the new technologies have great power.”