## 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. 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 dangerous mental illness." What followed extremely painful, was 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



From Left: Dina Taylor, Manton Hurd, Sederia Lewis, and Ed Herzog

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

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http://www.bayareahearingvoices.org/

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 schizo-affective 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 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 <u>Living with Voices</u>: 50 Stories of Recovery by Marius Romme, one of the first psychiatrists to treat his patients' voice-hearing experiences seriously, and <u>The Origins of Consciousness in the Breakdown of the Bicameral Mind</u> 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."