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 <u>Bay Area Hearing Voices Network</u>, **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



CHRIS HUNTER

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.



OSCAR HERRERA

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 DAVID HALLSTED 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."