

## In Our Own Voice

*Summarized by Thomas T. Thomas*

At the January meeting, **Robert Villanueva** showed a video of NAMI's public education program "In Our Own Voice" (IOOV), for which he is both a presenter and a national trainer. Combating the stigma of mental illness, the program offers personal and compelling stories from people who are living with brain disorders and working toward recovery. As an IOOV trainer, he empowers others to share their stories. Villanueva also spoke about his own struggles with bipolar disorder and how he has managed to control the illness.



*ROBERT VILLANUEVA*

Villanueva is active with NAMI, which he described as the largest grassroots organization dedicated to mental illness. In addition to working on the IOOV program, he participates in a program to erase stigma in Southern California and in research at the University of California at Berkeley.

The IOOV video is divided into five sections: Dark Days, Acceptance, Treatment, Coping Skills, and Successes, Hopes, and Dreams. Villanueva appeared onscreen in each segment and also commented on and took audience questions about the content of each segment.

### **Dark Days**

Villanueva grew up in the East Bay, where his mother had been diagnosed with manic-depression. She self-medicated with drugs and alcohol and cycled between depression and fits of rage. He recalled being awakened with his siblings in the middle of the night for tasks as trivial as searching the yard for his mother's lost keys. He left home at 15.

He had always loved physical activity and the outdoors, especially running and hiking. He excelled at wrestling in high school, where he was inspired by a great coach. When he grew up, he became a wrestling coach himself, as well as driver of a garbage truck.

By the age of 28 he was sleeping too much and felt like he was "wading through mud." He would miss work, calling in with the "three-day flu." At other times he was manic and could hold down two or three jobs and still find time to help friends.

The periods of hypomania were seductive, when he would have a lot of energy and feel great. During the periods of depression, or "flat time," he couldn't make decisions and was numb to the world. He also experienced headaches, cramps, and other pains he later learned were psychosomatic. "In the Hispanic community," he said, "a man is not supposed to show sadness or depression, so instead I felt pain."

He described these feelings as “the reality inside my head.” He has since come to recognize leaving the bed unmade, dishes in the sink, and mail piling up as visible evidence of his illness.

In one of his low periods he visited a psychiatrist, was diagnosed as depressed, and was prescribed an antidepressant—which caused him to cycle rapidly.

During the course of his illness, Villanueva eventually walked away from his home, family, and job. He felt that he “didn’t belong in the world,” and he knew “something’s wrong with my brain.” Finally, on his way to throw himself off the Bay Bridge, he stopped at his psychiatrist’s office, demanded help, and was sent to the hospital. His darkest day was sitting in a phone booth telling his wife and stepdaughter he was in a mental hospital.

He remained in the hospital eight days because it took a while for him to settle down. He recalled having “aha” moments in group sessions when others described feelings and actions he’d experienced.

After getting out of the hospital, he spent the next two years self-destructively. He would go on and off medication when he got tired of the side effects or when he was “seduced by the euphoria” and wanted some fun. It helped to have things to do, like attending his stepdaughter’s soccer games and family functions, where he had to “be normal.” It didn’t help if people asked “Why don’t you settle down?” when he was hypomanic and “Why don’t you get out of bed and go to work?” when he was depressed. Villanueva was in his own world, his own reality, and didn’t realize he was sick. He would miss doctor’s appointments, and they never knew when he was off his medication.

### **Acceptance**

“Acceptance was huge for me,” he says, “because I was as stubborn as they come.” He noted that young people sometimes have an easier time accepting illness than older people.

Once he accepted the illness, however, he could get out of bed in the morning and shower, but he still had no place to go. He started going to Barnes & Noble, where he could read books about mental illness, which led to books about psychology and neurochemistry, which led to medical dictionaries to understand the terms. He read for nine hours a day, five or six days a week, and ended up with “a B.A. from the University of Barnes & Noble.”

Villanueva’s psychiatrist recommended a peer support group, and he would attend, listen to their stories, and think, “That’s me!”

He read Kay Redfield Jamison’s *Touched with Fire*, about bipolar disorder and the artistic temperament, and learned that the illness covered generations. He took a look at his own family history and saw that, in four generations, the longest-lived male was 58 years old. “If I didn’t take care of my illness,” he said, “I would be dead in my 40s.”

Villanueva finally quit fighting and accepted his diagnosis. “Some people take a decade to believe their diagnosis,” he said. He found he was most open to suggestion and receiving information when he was stable—neither at a high nor a low point.

## **Treatment**

“The number one thing is being honest,” he said, “with the doctors, with the people around me, and with myself. They can tell when I’m not taking my medications.”

Villanueva gave permission for his psychologist to talk with his psychiatrist and his general practitioner. They worked out an agreement that he had to show up for all appointments for at least three months and stay on any medication they prescribed for at least six months. He kept those appointments—even if he was driving a big rig that day and had to park it in downtown Pleasanton to get to the doctor’s office.

Since one of his problems was isolating himself, he made plans when he was stable and healthy for what he should do when going through an episode: get up, make the bed, take the medications—similar to a Wellness Recovery Action Plan (WRAP). In all, he tried 14 different medications in different dosages to find the ones that worked. “All medications have side effects,” he said, “and you just have to push through.”

Although he had walked away from his family and blood relations, he found support in his peer group and his NAMI connections. Today, he still has episodes, but they are not as many and not as strong as before. He lives on a pension from the Teamsters Union from his days of driving a garbage truck and on SSDI. He considers himself a student and audits classes in psychology at UC Berkeley.

## **Coping Skills**

From a comment that one of his nieces made, about “not having a clock in his head,” Villanueva has learned that he must live by the clock and establish rituals for himself.

He goes to bed at 10 p.m., rather than when he is feeling sleepy, and he has taken the television out of the bedroom so that all he does in there is sleep. He eats by the clock, rather than when he feels hungry. And he goes to the gym and works out because it’s good for him, not just when he feels like it. He takes his medications at the same time every day.

When he travels, he takes care to monitor his sleep, meals, and medications.

His coping skills include maintaining a balance and being okay with his medications—which was hard for him, because he grew up in an drug environment. Also important to his life is being careful not to become isolated. “Sometimes just showing up is a big victory.” He described attending his first New Year’s party in many years, where he “wasn’t the life of the party—but I was *at* the party.”

## **Successes, Hopes, and Dreams**

“When I first did the In Our Own Voice program,” he said, “I was still living at a friend’s house, and my biggest success was making my own bed. I’m reminded every day that I have to make my bed.”

Today, Villanueva trains IOOV volunteers in California and across the nation for NAMI. He takes part in research programs on stigma and mental illness, and he has traveled overseas to speak on approaches in the U.S. to dealing with these issues. He hopes one day to become an enrolled student and earn a PhD in psychology. “I’m helping the people who helped me,” he said.

Now his nephew has begun showing signs of bipolar disorder. Villanueva hopes that we can break down the stigma of mental illness, so that the boy can grow up and talk freely about his condition.