

ALUMNI SPOTLIGHT

A Dream Deferred: Schizophrenia and the Search for Home in Ecuador

by PHIL AVILA

I HAVE VISITED Ecuador over a dozen times since 1976. First as a student, then as a journalist, and later as the father of two growing children. But my visit last year was decidedly different: my wife, Yolanda, and I were hoping to overcome the latest and most formidable obstacle in our longtime dream of moving there permanently—the outlook for our thirty-one-year-old son, who has struggled for nearly the past decade with schizophrenia.

Timothy currently lives with us in New Jersey, having moved back home after spending time in psychiatric hospitals, a group home, and a supervised apartment. We feel blessed in many ways for the services he has received in our state, one of the best places in the country to live if you have a severe mental illness. He goes to a local hospital's outpatient clinic to see his psychiatrist, who monitors his progress on his regimen of drugs, which includes clozapine. That drug has proved to be invaluable to him as he moves forward in his recovery. He also spends most days at a local occupational center, where he receives counseling and does assembly work. He has tried to get back into the traditional workforce, but has difficulty focusing.

I fell in love with Ecuador the very first time I explored its majestic landscapes and came to know its kind people. I was a foreign exchange student during the 1976–1977 school year at the Centro Andino, a study center operated in Quito by the University of New Mexico and Northern Illinois University. I traveled to nearly every corner of the country on a shoestring budget, and when my fellow students held a Halloween party that Yolanda was invited to, met my future wife. I went as a Colorado Indian, she as a gypsy.

It was my year at the Centro Andino that inspired me to seek a master's degree in Latin American studies at the University of Texas

in 1978, with the help of a fellowship. Yolanda and I were newlyweds when we arrived in Austin that first summer. Undoubtedly, it was one of the best years of my life. I can still smell the early-twentieth-century Buenos Aires newspapers I thumbed through at the library as I prepared a paper on immigration for Professor Richard Graham. I'm sure that I learned more there than in any other class I ever took. I also had the privilege of hearing Professor Nettie Lee Benson tell her anecdotes that brought Mexican history to life. Yolanda found a job at a daycare center to help us make ends meet while I worked part time writing briefs for NPR's *Latin American Review* and doing on-the-street interviews for the *Austin American-Statesman*.

Most important of all, our first child, Michelle, was born in Austin in July 1979, a fitting end to a whirlwind year. After graduating, I took a job as editor for a weekly paper in Central Illinois, but it wouldn't be long before Latin America began to call again. In 1981, I was named an Inter American Press Association (IAPA) scholar, and spent the year with Yolanda and Michelle in Quito, freelancing in-depth articles on the country I would grow to love even more. Yolanda's brother encouraged me to make a down payment on a house in a new neighborhood in northern Quito called Carcelén. I was sure that someday we would live there, but at the end of the year, it came time to make a difficult decision. I had been offered a job teaching Spanish at an international high school, which would have allowed us to remain in Ecuador. But simultaneously I was invited to present the research I had done on the licensing of journalists in Ecuador at the IAPA's annual conference in Brazil, and thus continue to pursue journalism. We chose the latter.

This, in turn, led to a job at the *Caracas Daily Journal*, Venezuela's English-language newspaper, where I worked as a reporter and an editor, and freelanced for several U.S. business publications. Timothy

was born in Caracas, and had trouble from the start. He was premature and spent two days in an incubator with jaundice. Later that year, he began having the febrile convulsions that would mark his infancy. We decided that the best thing to do would be to return to the United States, and I was fortunate to be chosen to attend the Minority Editing Program in Tucson, which led to a job as a copy editor at the *Wall Street Journal*. I truly loved working there for the next twenty years, moving from editing on paper with pencil into the computer age, from what was mostly a white male desk to a diverse staff, from the heyday of newspaper prosperity into the days of austerity and eventually layoffs.

Timothy outgrew the febrile convulsions, but needed speech therapy to begin speaking and we enrolled him in a special preschool program. Yolanda and I devoted countless hours to him, and he was able to go to mainstream kindergarten.

The skills Yolanda learned with Timothy quickly translated into a career in special education for her, leading to a focus on working with autistic children. She found a job in the Elizabeth, New Jersey, school district, which had a large Spanish-speaking population. Michelle, who from an early age took an interest in art, would become an art teacher.

We spent several weeks every summer visiting Yolanda's family in Quito. One summer, Michelle worked with the Ecuadorian sculptor Sara Palacios. We took the children to the Galapagos Islands and the Amazon basin, to Cuenca and Guayaquil. Yolanda took up photography as a hobby, and spent a week one year in her grandmother's village of La Paz in northern Ecuador documenting daily life. Her mother always surprised us with the beauty of the garden she cultivated in the house we still hoped to someday call home.

But Timothy began to stumble in high school. He struggled academically and became more withdrawn. With a lot of help, he made it through to graduation. He tried community college, but that didn't work out. Then, he moved from one job to another before things finally fell apart. At age 22, he was hospitalized for the first time. It turned out to be a lengthy stay.

Just as we had thrown ourselves into Timothy's care as a child, we now began educating ourselves about mental health. We attended a support group for parents, joined the local chapter of the National Alliance on Mental Illness, and took its Family-to-Family class. I started producing the group's monthly newsletter. It was only the beginning of our journey with Timothy.

In 2008, I was laid off from my job at Dow Jones after Rupert Murdoch purchased the company. I had another choice to make: pursue journalism in a changing landscape or follow my newfound passion. I chose the latter.

My first job in the mental health field was as a telephone counselor on a warmline. While working there, I began earning a graduate certificate from the University of Medicine and Dentistry of New Jersey (UMDNJ) in psychiatric rehabilitation. I wanted to learn all

I could to help Timothy. Later, I worked with an agency that helped people move from psychiatric hospitals to apartments in my community, providing supports as they transitioned to independent living. Then, I worked as a family support partner for Spanish-speaking families in my community who had children with behavioral and emotional challenges. Tim had the same ups and downs that the people I worked with experienced, but from our initial despair hope was growing every day.

Before long, I realized that I missed writing and editing. An opportunity came up to do this for a cancer patient organization, The Life Raft Group, so I made the move. I also began contributing to *SZ Magazine*, a publication for people with schizophrenia and their families.

Around the same time, two developments in Ecuador caught our attention. We learned of an organization that had emerged for families of people with schizophrenia called SQZ Feilades. I began corresponding with its director, Martha Monge G., about services available in Ecuador. Meanwhile, we were becoming intrigued by a growing population of foreign-born residents in Cotacachi, a small town in

Imbabura Province led by an indigenous mayor. Once again, we began wondering if it would be possible to live in Ecuador with Timothy. This was the impetus for our trip in August 2013.

The Pan American Health Organization estimates that in Latin America more than one-third of people with nonaffective psychoses and more than one-half of those with anxiety disorders do not receive specialized mental health care. There are only two psychiatrists per 100,000 people in the region. Ecuador's capital, Quito, is home to more than 1.5 million people, yet there are only three private psychiatric clinics and two public psychiatric hospitals in the city, according to the British Embassy.

Since emerging as a community-based approach to treating severe mental illness during the past two decades, psychiatric rehabilitation services have spread rapidly to many parts of the world. However, according to the Pan American Health Organization, they have been slow to take root in Latin America, despite the Caracas Declaration of 1990. The declaration, which resulted from a regional summit, was meant to be a springboard for modernizing mental health services in Latin America, with particular emphasis on legislative frameworks. Like other Latin American countries, Ecuador's services are divided into two systems, public and private, with access to private services limited to the small percentage of the population with private health insurance. The public services, in turn, receive meager funding, while priority is given to transmissible diseases, maternal and child care, and nutritional problems.

Ecuador's Ministry of Public Health is limited by its small budget, totaling just \$561 million in 2006. Per capita health spending is only \$177 in Ecuador, compared with about \$3,500 in the United States. Public services are limited to psychiatric hospitals, with no community-based programs in place. A positive development in recent years is the establishment of a crisis telephone line that helps



Phil Avila with his wife, Yolanda, and son, Timothy



Town of Cotacachi, with Imbabura Mountain in background

increase access to those services that are available. This is all we knew before our trip.

The first item on our agenda was to find out more about SQZ Feilades. Martha Monge G. was recovering from cancer treatment, but was kind enough to meet with us one morning in Quito. A former journalist who had worked in the United States, Martha started her nonprofit in 2007 and has been working since then to support people with schizophrenia and their families in Ecuador, while lobbying the government for a legal framework and improved services. Her son, Iván, has schizophrenia.

She was in the process of organizing the First Iberoamerican Convention on Mental Health, which was held in Quito in November 2013. This seemed to be a natural development as mental health patient organizations like SQZ Feilades emerged in Latin America. She told us her other main focus has been to persuade the government to categorize schizophrenia as a disability. This would allow people with schizophrenia in Ecuador to receive benefits such as financial help with medications.

Despite the lack of mental health services in her country, Martha remained enthusiastic about the outlook. After our meeting, we accompanied her to drop off information on the convention to some potential attendees and to visit what she said was the first community mental health center in Ecuador—a pilot project in Calderón, just north of Quito. The center offers psychiatric and psychological services, including group counseling and educational sessions. A definite movement in the right direction, we thought. But when we spoke with the director, he said the center doesn't really serve people with schizophrenia.

We also found a glimmer of hope on a separate visit to the Sagrado Corazón psychiatric hospital just outside of Quito. We spoke with Elizabeth Hoguera, a social worker at the hospital, who said that Timothy could qualify for the Seguro Social health system, which would pay for brief stays at the hospital in case of a relapse. They worked with Timothy's regimen of medications. However, when asked about discharge planning, she said they offer very little. In fact, when we told her about the center in Calderón, her face lit up and she said this might be something the hospital could link patients with.

Our next stop was Cotacachi, where we rented an apartment for a week and fell in love with the town. Located between Otavalo and Ibarra, Cotacachi is known for its leather goods and sits in the shadows of the mountain of the same name. After several futile stops at pharmacies, we came upon one that could obtain Timothy's medications. We also explored several possibilities that might lead to jobs that Timothy could handle. But we didn't have time to locate a psychiatrist in nearby Ibarra who worked with people with schizophrenia. Or even Quito for that matter. Martha told us that very few psychiatrists in Ecuador work with people with schizophrenia.

This is a challenge that remains for our next visit to Yolanda's homeland. Settling in Ecuador won't be easy, but we aren't giving up hope. As for Timothy, he had a great time on our trip reconnecting with cousins and friends from the past. He is as hopeful as we are. ☀

Phil Avila currently works as a freelance journalist writing on mental health topics. He has also published a collection of poems, On the Equator. He received his master's in Latin American studies from LILAS in 1979.