

Idelio Valdes: A Man Without Limits

By Sue Arrowsmith

While four decades of life merits celebration to most people, for Idelio Valdes, whom doctors did not expect to live this long, it is his greatest achievement.

On the day of his fortieth birthday, Valdes was busy making phone calls. He dialed to confirm the attendance of 80 family and friends to his birthday party at a Tony Romas restaurant, as he paced his Coral Haven apartment. He looked around the living room, his favorite place in the house, where a massive collection of CDs and DVDs frame a flat-screen television. Against one wall a stack of disability manuals and speech notes lay on a long writing desk. A sofa occupies the space on the opposite side.

“In here, I can see the life I’ve created for myself,” says Valdes.

Valdes was born with a congenital heart defect commonly referred to as “Blue-Baby Syndrome.” Infants with this defect display a blue or lavender discoloration of the skin because their hearts cannot pump enough oxygenated blood to their bodies. At 11 months of age, Valdes underwent the first of two open-heart surgeries to correct the problem, but suffered a stroke and developed Dystonic Cerebral Palsy, which affected his right side. Dystonia affects the nervous system. The strain involved in coordinating movement against involuntary muscle reaction can be painful. Then at other times, all tension is suddenly gone and the muscles become limp. Brain surgery is an option, but odds of survival are about fifty-fifty, according to Valdes. His parents, Magaly and Idelio Valdes, finally accepted the hard truth that their only child would never lead a normal life, but he had other plans for himself.

Three years ago Valdes was appointed to the Florida Developmental Disabilities Council (FDDC) by Governor Jeb Bush, whom he often corresponds with through emails. Dubbed “the energizer bunny” by his friends, Valdes has been recognized for his tenacity and fierce drive to prove that people with disabilities can be independent. He juggles multiple jobs, including an usher in a movie theater for the past eight years and a motivational speaker who travels all over the country to share his story with others.

“A disability can happen to anyone,” says Valdes. “I give people hope.”

In spite of his many recent achievements, eight years ago his path was not so clear. Born into a wealthy family, his protective parents were determined to provide for him in every possible way. Like many living in post-revolutionary Cuba, his parents fled to Miami when Valdes was three. His father owned and operated a small supermarket while his mother and grandmother dedicated themselves to his care. But as Valdes reached adolescence, he began to crave independence.

“When I was growing up, my parents would make me stay at home when it was cold or rainy. It didn’t make sense to me. I would argue with my mother that when I grew up and had a job I wouldn’t be able to stop working because of the weather,” Valdes recalls.

In high school, he obtained a drivers license without his parents’ consent in spite of his independent right arm. Valdes taught himself how to cope with the pain. He began perfecting the ability to control his body and conceal discomfort in order to

slip out the front door without a fight. If someone said he couldn't do something, the next day he was already trying.

His parents did their best to shelter him from the world outside, but in 1997 their safety net snapped. Through a series of business ventures, his father lost everything. That same year his grandmother died. The Valdes family had to sell their lush home in Westchester and move into a tiny warehouse without a bathroom. Family and friends suddenly disappeared. Valdes lived there with his parents, practically penniless and alone, for three years. The experience marked him forever as he suddenly saw for the first time how fragile his world really was. If his parents were to die as well, he would be sent to a group home or institutionalized.

"I learned that life is now. My parents are not going to be here forever, says Valdes.

He decided to claim his life. Through a local Family Care Counseling Center, an organization that assists people with disabilities, he applied for assisted living and found an apartment of his own. He learned about being a self-advocate, which means he could earn a living while educating others about his handicap. Valdes found his calling and before long, he was attending conferences in Tallahassee.

On his own, though, Valdes found new obstacles.

"Traveling was boot camp," says Valdes, who once lost his return airline ticket while at a conference. On other occasions, he forgot to pack important items or lost money.

Everything was new, a challenge. With the use of only one hand, dressing, packing or cooking would take hours. But the prospect of losing his independence kept him motivated. He created methods to stay organized and calm.

"I used to panic whenever I lost something. Now I give myself four days to find it before I worry," Valdes says, a set of keys always secured around his neck.

Being functional with a disability requires discipline, self-awareness and extreme organization. Valdes takes 14 medications daily, which make him feel sleepy for the first hour after he takes each batch. That makes it difficult to drive, so he must time the doses according to his schedule. Even with medication, his body needs rest periods throughout the day.

The balancing act can be stressful, but even more so is the thought that everyone is watching your every move in case you fail. Though his parents are now supportive of his choice, they still check on him all the time. A supervisor from the Family Care center also drops in periodically to make sure he is on top of things.

"I'm human too," says Valdes. "I make mistakes like everyone else, but with such great expectations, I can't fail."

At the birthday party, Valdes unveils a half-hour documentary about his life titled "40 or Not, Here I Come," which he produced with a friend. From now on, it will be part of his motivational speeches. For Valdes, who is a movie buff, the film was another of his ambitions realized.

He attributes much of his success to his intense faith. Almost every morning, the first thing on his agenda is to visit a nearby chapel in St. Agatha Catholic Church.

“God gave me the gift of forgiveness. Without it, I would have become a hermit,” Valdes says on tape.

The camera follows his offbeat steps as he waves at neighbors, pays the rent and offers a tour of his apartment. Everything is spotless and in its place.

The lens then follows a wall of yellowed pictures—Valdes as a child with his family—as a doctor’s voice chimes in with a breakdown of his illness.

“All his life people have been telling him he can’t do things,” says Omar Rodriguez, a friend who attended the party. “Now he is trying to teach people to believe in themselves by his example.”

Valdes has his sights set on working at the nation’s capital, but not before lobbying to improve conditions for thousands of disabled persons in Miami. Most recently, his focus is on increasing handicap parking in South Beach and wheelchair ramps on public buses.

As the documentary ends, Valdes looks into the camera. His soft, often child-like expressions make him appear timeless, though now and then the face of a 40-year-old man fades in.

“I wanted to make this party to celebrate my life with my friends because the day of tomorrow, when I die, I don’t want people to mourn my death.”