

## Face to Face with Autism

***It is important that Latino parents get informed and ask for the help that a child with this condition needs.***

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*Valerie Valencia, age 13, plays in the pool with her mother, Luz Valencia. (Aurelia Ventura/La Opinion)*

Hope is the last thing that one loses, the saying goes, and although 12 years have passed since her daughter was diagnosed with autism, Luz Valencia continues to hope for a miracle.

"Even though I knew it and they told me that she would never be cured, I had and still have the hope that one day my daughter will talk, that she will be cured," affirms Luz with surprising serenity.

Nevertheless, it was not always like this. "When Valerie was born, everything seemed to be going well with her, she grew healthy, started to walk and to talk. At the age of 15 months she used about 15 or 20 words, but all of a sudden one day she grew quiet... since then she has not returned to saying even one word" says Luz Valencia.

"This story is common among parents of children with autism; it is as if a barrier rises up that impedes them from relating," says Antonio Buono, clinical psychologist specializing in the treatment of autism.

"Very little is known about the causes of this disability, but the good thing is that during the research that is done to answer one question, ten more appear and that is positive, because each time we know more about this developmental disorder," points out the psychotherapist.

"She slept very little; at 2:00 in the morning she would wake up to watch her Disney videos, to look for food, acting as if it were the daytime. She did not want to be touched, and she isolated herself more and more. She had attacks of crying and I could not do anything nor understand what was happening. When we brought her to the doctor he said that it wasn't anything, that it would pass, but that wasn't the case," recalls Luz.

This is a serious problem, explains Buono. Not all pediatricians are capable of recognizing, much less diagnosing, autism because it is not a disability that one can detect in the course of clinical exams, but requires specialized methods of observation because it is a behavioral problem.

According to the Center for Disease Control (CDC), autism affects one in 150 children.

Between 15 and 18 months of age, Valerie was subjected to many exams and she went to Children's Hospital of Los Angeles, where they diagnosed autism. At that time, Luz was working as an administrative assistant in a medical center, with the very positive result that she could stay informed.

Ever since then, and still today now that Valerie is 12 years old, Luz has dedicated her life to looking for help for her daughter.

"I have heard that children have gotten better with special diets, exercise and certain types of therapy; I have tried everything, but without results," she says without losing her calm, because she does not have time to sit and lament. As a member of the board of directors of the Foothill Autism Alliance, Inc., she has become a spokesperson for the Hispanic community in this organization that was founded nine years ago for the purpose of offering support and information to parents.

"Seven years ago, when I joined the group, we were about 10 to 15 parents who met to consol each other, because nobody knew exactly what to do. Now we are 170 people, equivalent to saying that we are the voice of 170 autistic children. We meet the second Wednesday of each month in Pasadena to inform ourselves about the latest advances in research and treatments. We invite doctors, nurses, and therapists so that they can educate us," affirms Luz Valencia.

Patricia Herrera, member of the board of directors of the Alliance, recalls that the nonprofit organization was founded nine years ago by Bob Schneider and Yudi Bennett, parents of a child who also has autism.

"As director of family support programs for the Regional Center, we got involved in Bob and Yudi's creation because we understood the need of parents to get reliable information on existing services," says Herrera, who serves as a member of the board of the Alliance, in the role of voluntary adviser and former member of the regional center.

"We feel very satisfied with our Power Pac, a free directory in which families of autistic children can find – in the area in which they live – medical services and therapies which children require, because not all doctors, dentists, or other specialists can understand our children," affirms Luz Valencia.

When Luz is not busy with Valerie, she dedicates herself to Leslie, her older daughter, a responsible 15-year-old who is a high school student in the tenth grade. Inspired perhaps by the perseverance of her mother, she plans to study law at Harvard to defend the rights of children such as her sister.

Because of her problems with autism, epilepsy, and visual impairment, Valerie is considered to be a child with multiple types of disabilities. As a result of this, four years ago she was admitted to a residential children's program of the Junior Blind of America, a nonprofit organization that serves eight thousand families every year and which offers – in addition to the program already mentioned – programs aimed at successful attainment of an independent and safe life for children and youth with special needs.

"Our programs encourage family unity; for this reason we offer facilities where the parents spend all the time they can and when it is possible we bring the children to their homes to live with the family" points out Camille Wheatley, spokesperson for the Junior Blind of America.

Finally, Luz recommends to parents of children with any disability that they educate themselves and get the help that they need.

"Hispanics are ashamed to say that they have a family member with any disability. It pains them to go out in public, but they should know that this does not help anyone," she concluded.