



National Center for Cultural Competence

Georgetown University Center for Child & Human Development
University Centers for Excellence in Developmental Disabilities

From Father to Father

By Salvador Hernandez

I don't consider being the father of children with special needs as a problem, but more as a challenge that God "the all powerful", puts before us, since we do not choose it.

This is my personal story. My three children were born with special needs. Ronald, my first born, who is six years old, is the one who has required and has continued to require a lot of assistance for his development. Even now, we still have not received a complete diagnosis of his medical condition. The closest information that we have received is that he has Hajdu-Cheney Syndrome, a genetic condition that affects the growth and development of his bones as well as other aspects of his life.

As immigrants to this country it has not been easy to address the challenge of my son's special needs. Language barriers have not been the only issues that we've confronted, but also I have experienced discrimination from the different institutions and organizations that I have visited. In terms of language, simply because I have been unable to express myself or have the adequate English vocabulary to explain my son's condition, this was a problem when we needed to request any services. I was not always offered an interpreter and I was not aware that I have the legal right to be provided an interpreter at no cost to me.

If you add cultural factors to the language issue, the situation becomes more complex, when as a newcomer parent you have to understand the ways that professionals act in a given situation. For example, in my son's situation it seemed to me that the professionals reacted in a more detached and impersonal way. Here the professionals seem used to treating every case or family situation the same way, and give news that can be very upsetting to a family, as if it were nothing of importance. They also seem to expect that children will obtain milestones and independence quickly. In my culture, the contrary is true. The norm is to treat families with more warmth and understanding and allow children to develop at a slower pace.

We have tried to rise above the issues of language and culture, because we understand that to dwell on them is not the way to get our children's needs met. This perspective has helped us to depend less on interpreters and manage our own language needs as much as possible. Additionally, from a cultural

perspective, we have learned to assist our family members and ourselves (as parents) to be less overprotective of our son, preferring to support his development and present him with challenges so that he can be the best that he can be.

Having overcome these barriers and accepting our children's conditions has allowed us to participate in a support group for parents of children with special needs. We have also been able to obtain federal and state benefits for our children. Being able to navigate the system, respond to emergency situations or simply answering questions like: Why is your child like that? Or Papi, why don't I have fingernails, have been the links in the chain of strength, knowledge and courage to fight for our children.

I have learned to advocate for my children the same way that I support other family members that are going through the same situation. The birth of a child with special needs can make parents feel that the world is caving in, but the support of other families, helps you to learn that you are able to face adversities. This has enabled me to support my other two children, three year old Frank and two-year old Karina, both of which have language delays.

With all of the experience that we have gained, we have been able to identify sources of evaluation and support to assist our children in their development. My son Frank is already obtained age appropriate language skills and my daughter is receiving speech therapy. In order to move forward, we have experienced, sad, painful, anguished, fearful moments. As a result, you realize that you can not do everything on your own.

My wife had to quit her job and I had to miss work many times to take my son to the doctors or to the hospital for emergencies. Thank God, I have been able to keep my job. I have learned that help is available, but you have to look for it. Some of the services and supports that I have received include the following:

- Moral support- through a support group
- Economic support through SSI
- Educational support through programs such as early intervention, Head Start, etc.
- Technical assistance through supports such as medical, rehabilitative, therapeutic and psychological services
- Health services through health insurance
- Housing through housing programs, and
- Training through programs for parents.

All of these services and information helped us to not only find support and help at very difficult times, but also opened new roads so that we could continue to grow and be strengthened to face our challenge.