

Parents as main facilitators of their children's early intervention process

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This essay shows the methodology applied in the early attention of a child with low vision since his birth up to these days.

The original part in this particular case is that a special school has not given the early attention process, but the own parents of a low vision child, who are totally blind persons, have given it. They reviewed a large group of articles and books from different web sites to design a strategy that can be used as a model for other parents of children with visual impairment and education professionals as well.

My name is Rosario Galarza, I am a communications graduate. When I was 2 years old I became totally blind because of a bilateral RETINOBLASTOMA.

In august 10, 2002, I got married to John, who is also a blind person, graduated in linguistics. He lost the vision when he was 9 years old because of a medical negligence. After our marriage we had a lot of talks about having babies because we knew there was a risk factor of 45% that our child could inherit the disease from me. By that time, besides the risk factor, the only one thing that we knew about retinoblastoma was that it could cause blindness.

My son, Erick, was born in October 7, 2003. Since then, our lives changed completely because we had to learn new things like changing diapers, and singing lullabies.

I remember my first hard task as a mother, which was to get Erick used to sleeping alone in his cradle since he was born. He used to wake every two hours crying with hunger, and my husband carried him and brought him to me to suckle; then Erick fell

asleep again and I had to take him to his cradle once more. Sometimes, he suddenly woke up crying and I used to take him in my arms softly singing sweet lullabies or winding a little bear up that played a sweet melody. This little bear was his first favorite toy and he used to spend much time listening and watching it.

After 16 days of birth, even though nobody noticed something strange in Erick's eyes, I decided to have his eyes examined. The ophthalmologist took the time needed to examine his eyes and as he detected no red reflection in both of them, he diagnosed Erick with bilateral retinoblastoma and recommended to do pupil dilation for observing the quantity and magnitude of the tumors. After the pupil dilation the doctor discovered 3 small tumors in the right eye and 2 tumors in the left eye and decided to use a laser treatment to destroy them. After the laser treatment the doctor prescribed a new appointment for the next month.

Within this month, I was collecting a lot of information about retinoblastoma and I realized that most of the doctors do not provide complete information of the disease for the parents and familiars, so that I was encouraged to share information with all those parents who are terrified and devastated because of this diagnosis.

A month later, when Erick was nearly 2 months, during the routine checkups, the doctor noticed that one of the tumors in the left eye was growing dangerously close to the optic nerve and immediately recommended us to remove Erick's left eye before the cancer could spread to other parts of the body.

Two weeks later Erick's left eye was enucleated and with it the deadly cancer. The pathology report revealed that the cancer was gone and there were no tumor cells in the optic nerve. No other treatment was prescribed. However, my son continues to receive eye examinations every 4 months for preventing the presence of new tumors in the right eye.

After the surgery, my husband and I started to investigate more about the early intervention process with low vision children in different web sites about it. We could download many articles and read them carefully to learn the best way to stimulate our son.

We first put over his cradle animals mobile that turned round playing melodies. When Erik was 2 months old, he liked watching the mobile spinning and he tried to reach it raising his small hands, then I gave it to him so that he could touch it.

Erik also had a small piano with animal voices and different kind of melodies. He enjoyed listen the animal voices and sometimes he liked to sleep over my shoulder while I was rocking him softly at the same time as the melodies played. It was around

Christmas and we put garlands and lights in the house and Erick was dazzled with them, so we decided put lighted garlands over his cradle because we had read that those objects are good for stimulating his available vision. Little by little I was introducing in his games some musical and colourful-lighted toys for stimulation his vision and encouraging musical creativity.

Erick was always listening everything carefully and I used to give him different kinds of rattles with various colours, sizes, textures and sounds. I usually put the rattles on the left, on the right, up and down with the purpose that Erick could follow the sound and he always turned his head in the right direction of the sounds.

When Erick was 4 months I bought for him a game with many rings to fit into a kind of tube, first, I taught him how to put the rings out and he learned to do it by himself quickly. At this age, he liked listen the sounds of the claps and I decided to join his hands to show him how to do it. At the beginning he was not able to make strong sounds with his hands, but as the days went by and nearly his 5 months he made his first claps.

When Erick was 6 months he was very lazy for crawling so I bought a kind of inflatable cylinder for him, on which he could be laid and rolling softly. Although in the beginnings he was scared and did not want to do it, little by little with patience he could do it by himself. At this age he could catch a biscuit from a plate and then he cracked it into pieces to eat it up.

At 7 months of age, a friend of mine and I started to encourage him to do different kind of exercises using a mirror in front of him. Our main target was that Erick could recognize each part of his body, and when he turned 9 months, he could identify correctly his mouth, nose, eyes, head and his feet.

At this age he started to use the harness and he enjoyed running up and down around the house, opening and closing doors, emptying drawers, feeling independent and secure at once.

Besides this new experience, I started to introduce small objects like marbles and buttons into recipients with sand and rice with the target of encouraging Erick to find the objects using his available vision. I also used to provide my son with different kinds of elements like cinnamon, vanilla, chocolate, orange, aromatic candles and different kinds of perfumes and deodorants with the target of developing sensory stimulation.

When Erik was 10 months he babbled a lot of sounds like “bababa”, “dadada”, “cucucu” and as he could not utter “father” or “mother” he used to utter “ba” when he tried to name us. I put his hands on my throat and I pronounced the words near his face so he could see and feel me at the same time.

When it was his first birthday, I bought a game of small drawing pins to insert in a perforated board for him. First, I started teaching him how to put out the drawing pins from the board and he learned so fast and when he was 17 months he could insert the drawing pins into the board by himself.

When Erick was 14 months he could be standing by himself and it was time to give the harness up and starting a new stage walking holding my hand. Little by little he was feeling more confident and at his 18 months of age he could walk without any help.

At 19 months of age, I got different wooden puzzles of fruits and vegetables for him. First I used to show the figures to him saying their names time after time, and, when he had already familiarized with the objects (5 different fruit) I mixed them and I asked him about a specific name of fruit or vegetable; then he took his time to find it and after finding it he put the figure on my hand.

Also, I got other game with wooden blocks which had different patterns and as my husband and I could not see them, we labeled them in Braille and we made Erick identify the figures following the same strategy as in the previous exercise with the target of stimulating Erick's vision for discriminating the patterns.

At the age of 20 months and with the help of different inserting games, Erick could identify and recognize simple shapes like circles, triangles and squares and when he turned 2 years he could identify a bit more complicated shapes like lozenges, trapezes and ovals.

At his age Erick began to be interested in the colors and with the help of my sister in law, who takes care of him when I was working, he could identify the red, yellow, green, blue, black and white, and as days went by, and he continued to ask about colors he could recognize the pink, purple and grey. Suddenly over his 28 months he started to be interested in numbers and letters because somebody gave him a magnetic board as a present.

Currently, Erick is 30 months and he is a strong and healthy boy. He has also a comprehensive language, which enables him to voice most of his feelings, and needs. He enjoys listening children songs, singing aloud, imitating the animal's voices and listening fairy tales before going bed.

Since last year, thanks to a skilled ophthalmologist, Erick has a beautiful prosthetic eye that looks real and many times people cannot identify which is the fake eye at first sight. Erick has peripheral vision in his right eye and some central vision too. Even with his limited vision in his right eye, he can see and identify colors and shapes, he has a good

mobility in spaces, which are not so big, and frequently he enjoys picking up the things he drops on the floor

On March of this year he started to go to a regular kindergarten. This was a new experience for all of us because in case of Erick, it was the first time he was going to be alone without any familiar in a new place, and in our special case, as blind parents of a low vision child, we knew that we had the mission of introducing the topic of the visual disability to the teachers. In fact, we did our best effort and we were happily surprised for the good willingness and open-minded tendency of the headmistress.

As any child, Erik enjoys playing soccer, playing with cars and trains, building towers with blocks and discovering new things every day. My husband and I are proud of because he is very witty and smart and we learn something new about him every day him, and we continue to collect information and material about low vision children with the purpose of helping him study in a regular school and guiding his teachers when is necessary.

At the end of this personnel experience I want to say something:

“I know each person has his own opinion about my decision of having a son as Erick, and perhaps most of them have a disapproval attitude toward my decision, but even though I respect each one’s opinion, I do not regret about the decision I made because having Erick is the greatest thing that I ever experienced in my life and I will do the best of me for not to disappoint him.”

Some photographs about my child:

Erick is listening some canaries



Erick playing the guitar



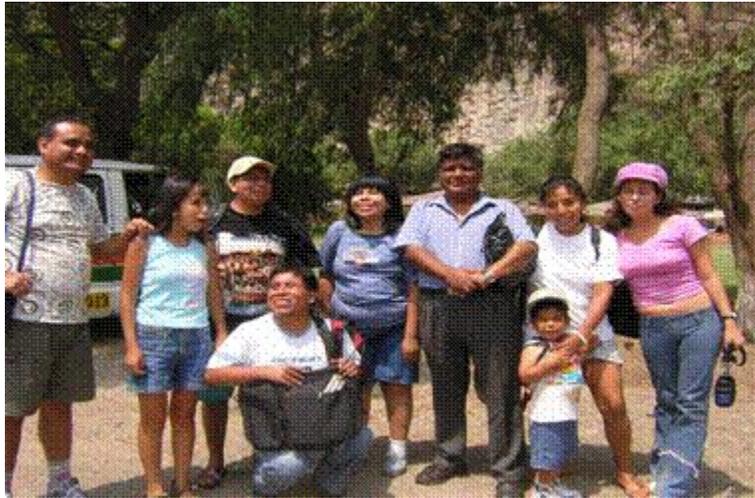
Erick with a horse



Erick is swimming with us



Erick with all our friends in a camping day



Erick with my husband and me

