

## **A Parent's View on the Equality in Education in the Philippines for a Child with Multiple-disabilities and Visual Impairment**

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My husband Fritz and I were living in New Hampshire in the United States when we had our first child, Enrique. Although I delivered by Lamaze, my delivery was quick and everything went very smoothly throughout the 38 weeks of my pregnancy. I had never gotten sick, I was quite energetic and was very excited about the birth of our first baby.

Enrique was born on June 1, 1994. I recall how his APGAR score within the 1st minute of birth was a "9" and his 2<sup>nd</sup> score taken on the 5<sup>th</sup> minute was a "10". His fingers and toes were complete, his reflexes were good, breathing was normal, complexion was good, eyes were barely open, but they were normal. Everything was perfect! We could not have asked for anything more.

It was not until the second week when I had taken him for his routine check-up and I was asked of any concerns or issues, did anything remotely amiss surface. Although his eyes looked quite normal, I mentioned to the Nurse Practitioner that I had noticed them moving rapidly from side to side. She told me "Do not worry, at this age, children are still trying to focus." There was no reason for me not to believe her. Why shouldn't I? She was the expert!

Four weeks later, the same Nurse Practitioner saw him for his routine check-up and immunizations. I brought up again the matter of his eyes and the reply I got was, "You

first time mothers are all alike!” Of course I felt quite foolish and paranoid, so I dismissed my fear.

On Enrique’s third month, we had decided to move to a new pediatrician, not because we did not believe the first doctor, but needed to find a more convenient location from our house. As usual, I was asked of any concerns or issues I might have. I had mentioned that not only did his eyes move rapidly, but he still could not focus on a raisin and did not have eye contact with me (as mentioned in parenting books that I had been reading). After having checked his eyes, right away, the pediatrician mentioned that my son’s eyes did not look normal, but he could not tell us exactly what it was, so would just refer us to a specialist. We finally saw a *strabismus* specialist and after doing so many tests on our baby, he finally was diagnosed with **optic-nerve hypoplasia** (under-developed optic nerves). It just sounded so scientific; all we needed was a simple layman’s term. My husband and I thought that perhaps a simple pair of glasses would correct any problems, but throughout our conversation, it had started to sound more serious, so we thought to ask about the special care, schooling and facilities that our son may need in the future. We had not known until that day about early intervention, but we were lucky to be living in a society wherein the services we needed were all readily available to us. Not only did they have home visits, but they were all for FREE! The services were being offered by the local State Department of New Hampshire, for their residents.

At that point, we were not fully aware of Enrique’s “real” condition. We were still unsure about how much he was able to see, how useful his vision would be, and what life would be like for him – basically we had to wait and see, and take everything day by day, as we were still given the hope that his vision MAY improve in time. Although chances were slim, we were told that children’s eyes continue to develop until they are about 9 years old, so that gave us hope.

We were asked to go through tests – series of tests. One of the tests we were asked to do was an MRI, since it was common to optic-nerve hypoplasia cases to have additional disabilities and problems. From there, we found out that Enrique’s optic nerves were not only under-developed, but a few months after the scan was done, we found out that he also had a cyst in the brain that was about the size of a dime, but very large in proportion to the brain size of an infant his age. His physicians told us that it was necessary for him to go through an operation for the removal of his cyst, as it may cause hydrocephalus. It was a lot for us parents to take, but more so, we were afraid for our son. He was only 7 months then, and our only concern was to give him the best possible treatment available. We went through his pre-operation procedures, having to take new MRI’s, physical tests, and the like, until a week prior to the operation, the doctors decided Enrique was developing quite well and noticed that the cyst had managed to stop growing; and his operation was cancelled. We as parents were

actually quite confused, as we had prepared ourselves emotionally and mentally for this procedure, only to find out it was being called off. Of course we were happy about the cancellation since we knew that complications could occur in any operation; but we had to digest the apparent contradiction with the original recommendation of his doctors who had stressed the urgency. We wanted to make sure that the decision to cancel was the right one.

We pursued Enrique's home therapy sessions in New Hampshire until our family relocated back to the Philippines when Enrique was one-and-a-half. In Manila, we were able to get assistance from the Resources for the Blind, (RBI) Inc. and were guided on how to train him for his independence-both for his self-help skills and for orientation and mobility. It is so important to find the right support for our children. I was lucky enough to have realized this while my son was still at a very young age, but it did not mean it was easy. Knowing what my child needs and what is best for him does not mean it is readily available to him. In fact, it has been quite a struggle since.

As Enrique got older, we noticed that his developmental delays were becoming more apparent. We were receiving services from the Resource for the Blind, Inc., his regular Pediatrician, Developmental Pediatrician, Ophthalmologist, Neuro-ophthalmologist, Occupational Therapist and Speech Therapist, having him assessed regularly, yet things did not seem to be falling into place.

In the span of twelve years, I have searched for the best possible schools and facilities in Metro Manila for Enrique. He started at age 2 ½ on a one-on-one program with a sped teacher who met with him an hour each day, about 3 days a week for about 8 months, but for the next school year was passed on to an inexperienced teacher because the first teacher could no longer find the time to attend to him as she had other commitments, and agreed to only monitor his program. Unfortunately his new teacher was given the responsibility to handle my son only because her own mother had just recently lost her vision and they felt she was the best alternative. She was a preschool teacher, but did not have any special education training. I decided to continue the program since Enrique was now in a pre-school and was able to mingle with other children his age. I saw how much he enjoyed their company and most importantly, because he was actually learning from his peers. He was in that program for a year, until I moved him to the newly opened Early Intervention Pre-school Program of RBI. This was a blessing. A program was finally offered for children with visual impairments. Even I as a mother, learned so much, since this was where I had met parents of other visually impaired children and where we actually started the Parent Advocates for Visually Impaired Children, known as PAVIC. At RBI, they offered early intervention, a pre-school program that introduced pre-Braille and Braille skills, and even the use of the abacus. This was heaven at this point. My son was getting the proper training from the right group of teachers and he was among other children who required the same

attention he did. Enrique was in this wonderful program for 3 years, but had to move on to big school, since he was already turning 7. RBI managed to help us find a new school, but I did not find that the attention and training he was getting in this new school was catering to his needs. The teacher was good, well trained, and I could see how much she adored my son, but there were simply too many students and unfortunately another boy with visual impairments was also autistic, and my son would start imitating his sounds and screeches, and I noticed a regression in him. By this time, he was eight and I was forced to find him his 5th school (Hen. Pio del Pilar Elementary School)), where he stayed on for two years. Since our family moved into a new home, the drive would have been much further, and I also found the number of children multiplying in the classroom faster than the teacher could find an assistant, and once again had to search for a new school for him. I found a private institution that offered SPED and still, had to move him out a year after, because months after the school year began, I realized they were not equipped for accepting children with visual impairment and multiple disabilities. This past year, despite the distance, I brought him back to Pio del Pilar, but managed to get a one-on-one teacher to work more closely with him while in the classroom.

Although I know it has been unhealthy for him to be moved from school to school in an effort to find a program that best suits his needs, this was necessary as he tends to not only outgrow the curriculum, but I have found a great lack of consistency and have observed the inadequacy in the system.

**First** of all, I have established that a good relationship between SPED teachers and the school administrators is crucial. School administrators sometimes change and it takes a while for the SPED teachers to try and explain their program and the needs of each individual child. It will then depend on the administrator to support the program or not. Because of this lack of consistency, I have seen many children suffer. My own son for example had been mainstreaming in a grade 1 class when he was 8 years old, and was pulled out the year after by the new school administrator since she did not believe in mainstreaming. She did not see the importance for my SPED son to be with children his age, but instead, she isolated him in a classroom with only SPED children. Our children need a more functional inclusive program, especially for the multi-handicap visually impaired (MHVI) child. We need to make sure that not only do they get the proper social skills integration, but it is crucial for the teacher to come up with a *functional curriculum* that the administrators will support.

**Second**, we need a good teacher-student ratio. Although we have some wonderful teachers, we are not able to maximize their skills, knowledge and potential due to the number of children they have to attend to. My son's class for example has about 10 children to 1 teacher. It probably would not be so difficult if they were all normal blind children, but the teacher has to handle 2 normal blind, 3 low vision and 5 MHVI children

all at the same time. This obviously makes it a little more complicated, as she is not able to distribute her time equally. Not for each disability, nor for each child.

**Third**, we need the facilities. Our MHVI children need the space. They need room to explore and have enough space to be able to put all their things and equipment away, where it is easily accessible for them to reach when they need them. Most especially for children with multiple disabilities, a place is needed for them to practice their daily living skills. They should have a small kitchenette to learn to prepare their own food, a full toilet and bath to learn their bathing and dressing skills, a bed they can practice tidying on, a closet where they can learn to fold and hang their clothes in and put their personal belonging into drawers.

**Fourth**, all children need exercise and the space to be able to run around and play – this is no different for our children. In fact, it is even more important for us parents and teachers to make sure our children get sufficient and the right exercise. Not only to release their energy and to learn, but also to acquire the confidence to roll, crawl, walk, jump, skip, and run. Difficulty in coordination can sometimes be a setback. It takes a lot of effort for our children to learn these “basics” as it doesn’t always come naturally to them. Independence can be a problem for many of our children, but for as long as we give them the liberty and freedom to go about and explore, they will gain the confidence and be able to do all this on their own.

**Fifth**, many of our children need therapy, whether it be speech, occupational or physical. Unfortunately, these services are offered outside the school system, and it is still necessary for us to find a separate institution to avail of these programs.

Although I am aware of the services my son needs, it is quite difficult having to take him from one center to the other, and to try and make sure all his teachers, doctors and therapists are coordinated and consistent in their methods, approach, and goals.

What we need is a system making available all these services under one roof, addressing the needs of children with multiple-disabilities and visual impairment, based on each child’s capacity. It would entail having all the child’s teachers to come up with a functional curriculum unique to each individual MHVI child and meet on a regular basis to monitor the child’s progress and to discuss the different methods and approaches the child responds to. This would ideally be an institution physically located within a school with a strong education/teacher training/developmental psychology program, which would allow gradual integration of the child into the larger system.

This is where we are at for now. He will be a teen-ager (an adolescent) in less than a year, and we parents, teachers and other specialists, will again have to face new challenges. Puberty? What are we to do? We have made conscious efforts to

integrate him socially and to mingle with his peers, but once his sexual drive starts to kick-in, I think you will soon find me screaming!

We have tried to prepare him for his future of independence, yet have so much more to attain. Before long, we will have to consider his being able to support himself and to be a productive individual in society. We will have to find a livelihood program for training and later on a paying job that will give him the sense of importance, belonging and pride. I am glad to know that RBI and PAVIC in the Philippines offers workshops on handling adolescent VI, child protection policies, etc. However, it would still be a great dream to have our government support such programs and mandate laws, so that our children can fend for themselves, secure jobs, and become productive members of society.

We as parents have to fight for our children's rights. It is our right to fight for their needs and to be sure they get proper education and are given equal opportunity. We must all collaborate and find ways to approach our local government to mandate and pass laws on the acceptance of our children in the school system, that our children be given proper training and the right to work.

Good luck to us all! Thank you.