



Newsletter –August 2009

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## My Special Child

We have all heard that “every child is special”. Some children are however, more special than others.

2 days after my son was born, he had to be treated for seizures. Being an inexperienced mother, all I could do was pray earnestly for his recovery and hope that there will not be too much damage to his brain. The paediatrician told us that it was too early to detect if his brain was affected until he was older. He had 2 more seizures after that, at about 3 and 6 years old.

During his toddler years, we noticed that his gross motor skills were lagging behind kids of his age. He was very clumsy, tripping and hurting himself most of the time. He could not even catch a ball. When he dropped his smaller toys on the floor, he had difficulties finding them. His knees were often bruised and wounded, but he learnt to bear with the pain of his injury over time. Medicines and antiseptic sprays were with us whenever we went out.

He had to go for occupational therapy to improve his motor skills. One specialist diagnosed him as having SID (Sensory Integration Dysfunction). Skills that other children take for granted, he had to learn them through practice. He had difficulties with simple co-ordinating skills such as, sitting on a swing without screaming when it moves, walking on the sand at the beach, throwing a balloon in the air and catching it, looking for marbles on the floor. Some of the more bizarre activities that we were advised to do at home include brushing his limbs 5 times a day using a baby hair brush to desensitise them, massaging his gums with our fingers to desensitise his mouth as he wouldn't clamp a spoon onto his lips while feeding. Watching him feed himself with a spoon and fork at mealtimes can be a nightmare too.

In our desperation to seek a remedy for him, we went to the extent of trying out new methods of treatment recommended to us by therapists or friends who were in similar situations. We put him on a gluten-free and dairy-free diet for 2 years. He had craniosacral therapy sessions, “Samonas” sound therapy, and



even underwent “Biofeedback” therapy. All these “quack” therapies or treatments did not come cheap.

At that time, I was in a dilemma too, trying to balance a career and a special kid. I decided against quitting my job to spend more time with him. The medical coverage provided by my employer was very generous and covered some of the therapy sessions that he was undergoing. I justified my decision on the belief that he would be much better under the care of these professionals than under me. And we definitely needed the extra income to pay for his therapies including some quack ones which were not covered under medical insurance.

He had problems with reading and writing in kindergarten. We sent him for an IQ test to evaluate if his intelligence was at par with the Ministry of Education’s mainstream education system. We were prepared to send him to a school for the educationally challenged. However, the tests found him good enough for mainstream education. But, we were cautioned that he would probably be struggling most of the time because our mainstream education is designed for the above average children.

His primary school years were not plain sailing either. Since the start of Primary 1, he had difficulties finishing his homework and learning his weekly spelling word list for both English and Mandarin. My effort to coach him often ended up with both of us in tears. My father-in-law, a retired teacher, was roped in to help him with his schoolwork. Under his patient supervision, he improved a fair bit but still lagged behind his peers.

When he was in Primary 2, his form teacher was a very understanding and supportive woman. Convinced that self-esteem was worth much more than grades, she and I teamed up to work out a special scheme for my son. While the rest of the class would have to learn 10 spelling words every week, my son would just have to learn half of them. He would be marked on the 5 words that he learnt. The teacher left us to help him catch up with the rest of the words in his own time. Instead of failing spelling test week after week which can be very demoralising for a child, he was getting a star for the 5 words that he had learnt. He began to enjoy learning spelling from then on.

Our Government has always promoted the cultural and commercial usefulness of Singaporeans having a command of a second language to furthering one’s career, especially so when many Singaporeans are now working as expatriates in these foreign lands. Learning Mandarin as a second language was a burden to him. Seeing how much he struggled with English alone, we decided that he should just concentrate in getting his survival skill first (ie learning English). We also felt that if he needed to learn Chinese later on in life during his course of work, he would still be able to pick it up by himself. We applied for exemption for Mandarin on medical grounds. It was granted. We have never regretted this decision. He picked up spoken Mandarin later on in his secondary school because his peers were conversing in Mandarin.

To this day, I still believe that although our Singapore education is somewhat rigid and does not cater to each child according to his/her own abilities, we, as parents, can go that extra mile to make learning a more enjoyable experience in school. We must have the courage to

let our children travel on that “slow lane” if they cannot catch up. We must be prepared to work with the teachers, the principals and even higher authorities if our children’s needs cannot be met. So far, I am very thankful that most of his teachers have been quite accommodating to my son’s special needs.

We had him examined by 2 educational psychologists in his primary school years. The first diagnosis was that he displayed signs of a child having dyspraxia and possibly high spectrum of autism. The second diagnosis was that he was dyslexic. We were utterly confused by then.

It appeared that the more professionals we took him to see the more special his needs surfaced. Very often, the symptoms are quite similar and it is extremely difficult to pinpoint with absolute accuracy what the child’s problem is. To me, the diagnosis was a mean to finding out the ways to helping him overcome his needs. It is not to be used to label him or to provide an excuse for his behaviour.

When he was 12, he was diagnosed as having tunnel vision. He is considered visually handicapped. After this diagnosis, it dawned on us that his limited eyesight was the reason for his poor gross motor skills. For example, he could not catch a ball not because he had poor eye-hand coordination. It was simply because by the time the ball was within his field of vision, it was too late for him to catch it. I learnt that a mis-diagnosis by professional is possible, though rarely.

Very often, in our desperate attempts to make our child better, we are prepared to go to the extreme ends of treatment, as in my case. Looking back, I realise that I will never know for sure how significantly effective the various therapy sessions, or the diets, were. There was no control test carried out to allow me to make an objective comparison of what he will be like with or without the treatment.

I learnt that it is important to set a budget when trying out a new therapy program. This form of control prevents us from possibly paying through our noses for the additional therapy sessions especially so when the therapists determine that our child has not reached the desired results. As parents, we know our children more intimately than the professionals. If we do not agree with the diagnosis, it is right for us to point it out to them. After all, they based their conclusion on only a few hours’ of observation and assessment. They too, are capable of making mistakes.

In the search for a “cure” for my child, I discovered that deep within me, I was the one who wanted him to be “cured” so that he could be normal like everyone else. Then, I can have an easier time raising him, just like any other mother. I worry about his future and what life will be like for him when we passed on. During moments when I felt guilty for his condition (did I eat something wrong during pregnancy?), I questioned God why He gave me such a child? Why me?

During one of the “Life in the Spirit” sessions, God revealed to me that I was the one who needed healing. I was not able to accept His gift with its special package. It is like trying to bargain with God for a better gift; and better, only by my own human standards. God assured

me that with His special package, I will also be given me the extra graces and strength I would need. And I, in turn, now, take much consolation and carry a certain level of pride, that of all the mothers out there in this world, God deems me SPECIAL enough to be selected to look after His special child. What an honour and privilege! And how can I reject His Gift because of my own selfishness?

Life is still not a bed of roses for him or for me either. But I know that there is someone to share my burden whenever I am tested as a mother. My greatest pleasure and satisfaction is watching him grow up to become the God-centred teen he is today.

by Joanna

#### Familiaris Consortio (Christian Family in the Modern World)

36. The task of giving education is rooted in the primary vocation of married couples to participate in God's creative activity: By begetting in love and for love a new person who has within himself or herself the vocation for growth and development, parents by that very fact take the task of helping that person effectively to live a fully human life. As the Second Vatican Council recalled, **"Since parents have conferred life on their children, they have a most solemn obligation to educate their offspring. Hence, parents must be acknowledged as the first and foremost educators of their children.** Their role as educators is so decisive that scarcely anything can compensate for their failure in it. For it devolves on parents to create a family atmosphere so animated with love and reverence for God and others that a well rounded personal and social development will be fostered among the children. Hence, **the family is the first school of those social virtues which every society needs.**"