

The Child Development Centre at Matilda, LEGCO submission for 3 April 2008.

Since we are also and EETC and Watchdog has already covered early intervention and the needs of the English speaking community, I would like to share the perspective of a parent who has already left Hong Kong due to the lack of appropriate services for her son.

SEN & Hong Kong – A Parent's Perspective

Let me begin by stating that although we were considered expatriates in Hong Kong, our family were not short-term residents. Having met my husband there, marrying there and giving birth to two children over the almost 17 years I resided there, (my husband spent almost 20 years there), we thought of Hong Kong as our home. It was a wonderful place to live full of opportunities that rarely present themselves in our home countries - for work, travel and leisure activities it was unparalleled. The only fly in the ointment was something that we could never have foreseen. Our second son is autistic and even though Hong Kong is many great things, as parents of a special needs child, it became an ongoing nightmare. From the moment we realised we would be in need of specialised care we faced obstacles and expenses that had us wondering how what we thought of as fortunate lives seemed to have gone so wrong so quickly. Our earliest encounters were positive enough with people directing us to possible services, but our frustration was borne of the waiting lists that presented themselves for every level of service from speech therapists to group classes.

In Matthew's early years, we found people who worked with him but he made little or very slow progress. His behaviour was deteriorating and we couldn't figure out what would be the best course of action. At this time a kindly meaning person at one of the centres took me aside and told me that Matthew was more than likely destined to fall between the cracks in this system. His special needs weren't profound, but his needs were too special for inclusion in a mainstream class. Her assessment was blunt – get out of Hong Kong now. We weren't willing to abandon hope yet. Our lives were here and our other son was doing so well. Our decision was to ride it out and learn more about what was available. Just before his 4th birthday, we placed Matthew on a wait list for a formal diagnosis with a Psychologist at the Child Development Centre. The news was devastating; he was diagnosed as atypical autistic. For the last two years, we had been told Matthew didn't present as autistic and now we were trying to grasp how this would affect our subsequent decisions for Matthew's care. Luckily we received some caring and thoughtful guidance from the CDC and quickly moved to get Matthew into some intensive behaviour therapy training back in my home country of Canada over the summer months. We had success and for the first time, we felt there was hope for our son. Upon our return to Hong Kong we continued with ABA through Autism Partnership. This was without a doubt the best course of action at the time although it was incredible to learn that it was our only option. Luckily they could take Matthew on otherwise; we would have had no recourse but to leave. We continued with this intensive therapy for five months at an exorbitant cost. The reason for the high cost is evident when you realise the child needs one-on-one attention for as many as 30 hours per week in order to achieve any results. This presented another quandary, I felt torn between spending more time working with my son and helping him at such a crucial stage in his development and maintaining the full-time job that was necessary in order to fund this training.

Neither my husband nor I could afford to take time out of our work schedules to attend meetings or reporting sessions and much of the work and follow up care fell upon our helper. Helpers are a magical thing but they are never a parent and we agonised over the fact that we just couldn't be there full time for our son. One of the acknowledged truisms about autism is that early intervention is essential for any level of response and future development. Hence the despair over the lack of time we could spend working with our child. Only a parent who has gone through

such an experience can understand the heartbreak you face on a daily basis when you question whether you are doing all you can for your child. Each day was like another admission of defeat and as time marched on we grew more and more concerned that Matthew's progress just wasn't fast enough and we weren't giving him all of the care he needed.

In January 2006, we found a less costly, but still by no means cheap, alternative for care when a space opened at the Children's Institute, a small school specialising in treatment for autistic children. Our relief was palpable as Matthew was now approaching 5 years of age and he needed a school. He enjoyed the company of other children immensely and was so happy to be at a school all day. We found he responded more positively to therapy in a group environment and he was prone to copying language and actions from more advanced children. Chiefly for this reason, we hoped to get Matthew into a learning support centre in an ESF school. We know he would flourish in a setting where he had both the support he needed and the opportunity to integrate into mainstream classes. Unfortunately, Matthew's application was unsuccessful and once again, we were faced with a lack of options. When a place opened up at Springboard we were thrilled and enrolled Matthew there in September 2006. But the Springboard programme, in a school setting, is only up until middle school years. Then what?

It's incredible to imagine that there are families who face this reality – no schooling options for their child. This is a basic human right for all children. How can it be that there exists a so-called "world class" city that abandons a huge sector of its society? Any parent reading this need only imagine what it would feel like to hear there is no school for your child – soul destroying stuff.

At last it became too much and the ultimate price we were paying was the wellbeing of our child. We could no longer hope for the best and continue on in an openly hostile city. You try riding a train or tram with a special needs child and you'll quickly learn that Hong Kong is not kind to those who are different. That this prejudice permeates the society right to its core is beyond question. One of the last advocacy meetings I attended had a gentleman from the Education Department as guest speaker. After a lengthy slide show that was woefully short on facts and statistics, the floor was opened for questions. One parent asked the obvious – "Why don't our children have the basic right of schooling?" His answer was a revelation – go to the international schools and if they won't help you, then send them to a local school. When you are given such a glib, disrespectful answer from someone who is meant to be in the business of education, it truly sheds light on how hopeless this system is. Imagine being told your child who is struggling to master the basics of their native tongue should learn Cantonese if they want to stay in Hong Kong, these were this gentleman's exact words – that's when you know it's time to pack your bags. Pack our bags we did and it was beyond a doubt the wisest thing we have ever done. Both of our children are thriving in the open spaces and fresh air of Australia and Matthew is progressing in leaps and bounds. We finally have our dream of a mixed approach of integration and support in a local primary school attended by his brother as well and we have been welcome as true members of a learning community. Further to this, we have assistance from other governmental organisations and Matthew's enrolled in swimming, gymnastics and horseback riding, all geared for special learners. Now the only issue I struggle with is why didn't we do this earlier? It's a futile argument, but I can't help but wonder if I had moved to a more humane, giving city years ago, how much further ahead would Matthew be now?

Kerry Valentine

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