

Chapter 2 - A Long Journey of Diagnosis

It may not be easy to diagnose that a kid is with Asperger's, even if the parents have extensively consulted professionals. It took my family 2.5 years.

Ag is not our first child. Sue and I are experienced parents. Furthermore, after Ag was born, Sue quitted her job and became a full time housewife. We had a domestic helper at home. Therefore, Sue could spend long hours with our children. Gi started to speak before eleven months old, but Ag did not speak, except "Mum" even at age 2. Sue and I knew something was not right. We paid more attention to Ag. We had consulted lots of professionals, nurses, family doctors, therapists and trainers but nobody had ever mentioned Asperger's Syndrome. Eventually, when Ag was 4.5 years old, we took him for a very comprehensive assessment. Then we were informed of the diagnosis. This did not make sense. Sue and I did not neglect Ag and we indeed started consulting professionals quite early yet it took 2.5 years to get diagnosed. How could this have happened?

In Hong Kong, there are Maternal and Child Health Centers run by Department of Health. Parents can take new born there for health check, free of charge. This is normally done by a registered nurse. If the nurse finds any problem, the baby will be further examined by a physician. When Ag was 1.5 years old, we raised for the first time that Ag was late in speech learning. The nurse advised: "Don't worry. Ag was just behind a little bit. Please continue to observe." From then on, we got the same piece of advice in every follow up visit. When Ag was 2, we consulted a family doctor. We still got the same piece of advice. I would not say all those clinical and medical staff were ignorant and unreliable, but they could have been more serious when examining Ag.

Down's Syndrome was never a concern for us because we did proper examination when Sue was pregnant. From the day to day observation, we knew that Ag did not have hearing impairment. We tested this several times by speaking to him from behind and he had reaction. Ag could not be deaf. He could understand instruction, but he was just speechless.

Slowly, Ag exhibited some unusual behavior. He liked jigsaw puzzles a lot. He could easily put together jigsaw puzzles of 70-80 pieces. This was very demanding for a toddler of just 2 years old. Ag seemed to enjoy it and assembled the same set of jigsaw repeatedly, day after day.

Ag liked to arrange his toys in a straight line, 0.5 meter long, then 1 meter 2 meters and so on. He kept lining up his toys daily. He also liked watching little train circling on the track on and on. He seemed to be obsessed, ignoring everyone and every matter. He did everything in silence.

We also tested him by touching his arms, his shoulders but he did not respond, not even raised his head or eye ball. There was no eye contact in any circumstances.

When taking his bath, he was very afraid of being sprayed head-on. He would attempt to avoid, occasionally even pushed away our domestic helper. He did all this in silence. We knew from his face that he was in fear. One day, I was at home when he took his bath. He stayed in the bath tub considerably longer than normal. Since it was time for dinner, I urged him out. Ag refused. Against his will, I and our helper pulled him out, dried him with a towel and dressed him. Ag struggled fiercely. Even we had completely dressed him up, taken him out to our living room, he still struggled hard, trying to undress himself and making way to the bath room. I and my helper tried to stop him. He struggled with all of his strength, violently and ruthlessly. After around ten minutes, I gave in. I knew either Ag or I would get hurt. Ag rushed back into the bath room and resumed his bath. In no second, he was as calm as a little sheep. In his tub, he kept head down, focusing on his little toys as if nothing had happened. He did not even raise his eye ball for a single moment. How could a young toddler, 2 years old, fight fiercely against two adults like a small tiger, but in absolute silence for more than 10 minutes? His face was red and twisted. He stared just towards the bathroom and never turned his eyesight to us. This scared me.

When Ag was 2.5 years old, we brought him to meet a speech therapist. I would never forget that assessment. In forty-five minutes, we heard just the assessor's instruction. No matter how hard she tried, using as many different methods or toys as she could get, Ag was absolutely speechless. The assessment result was obvious. Immediately, we arranged speech therapy for Ag.

We lived in Sai Kung district. Every Wednesday, Sue took Ag for therapy. My office was in Wanchai. Normally, I took half day leave and joined Sue in the clinic in every other session. To me, these training sessions were very important. Sue and I wanted to be there, to get involved, to assist, to understand the progress, to share with the therapist so that we could follow up at home appropriately.

I joined these training many times. I concluded that there was nothing wrong in the way which Sue and I taught Ag. However the speech therapist was even better. She had more and better training aids than we had. She was knowledgeable and professional. She explained to us the theories behind. She used a great variety of toys which are training aids. Each of these was for a particular training purpose. I noticed that in every session, she tried something new i.e. new method or new approach. In a few instances, she even made toys or tools for her own usage or goal. Clearly, she had an agenda.

Speech therapy was in term of three months each. In the first term, Ag started to speak, word by word. In the second term, Ag's speech ability continued to improve. Sue and I were happy and relieved a bit. We kept going for the third term. However, in the middle of the term, a senior therapist suddenly told us: "It is no longer necessary to bring Ag to clinic for further training. Ag has already developed ability to learn from the day to day dialogue." This remark was much unexpected. Could Ag really do this?

Indeed Ag could, but slowly. Other issues came up which drew my attention. He was three years old then. He behaved as below.

- He played in solitude all of the time and in silence.
- He hardly responded to people. Even he did, there was no eye contact. Actually, he never raised his head.
- His tone was flat, no variation. He uttered word by word at a constant interval. There was no affection.
- If he answered our questions, it was not up to the point. He was jumping around instead.
- He had no sense of danger. When we went shopping, we had to hold his hand all the time because once we released, Ag would keep going, going and going. Even if we yelled, he would not stop. Once we lost him in a shopping mall. We found him quickly. However,

no matter what Sue said, softly or angrily, he showed no sign of understanding. He was already 3.5 years old.

- He never had any facial expression. He often played alone, occasionally with Gi, but even then, I noticed that the two boys were together physically but there was hardly any communication. He never showed joy. He never laughed or gurgled.
- He showed no social etiquette. At kindergarten, he would never say good morning to other children or teachers even when Sue was next to him, encouraging. He never grinned to anyone.
- He scribbled a lot of drawings but nobody could tell what he sketched. It was messy. I asked but his description made no sense. He seemed to have no idea of the real world.
- He was afraid of height. If I held him up to my shoulder level, he screamed and kicked fiercely. When we brought Ag to a playground, he was afraid of going up a slide or a swing. If we pushed him, he yelled and struggle in despair.
- He could not spit. When washing hands, he simply stretched out his hands under running water. He could not rub his palms interactively.
- He could not hop with both legs. Body balancing on one foot was very difficult. He was unable to ride on a tricycle, because he could not control the pedals.
- Ag did not show any affection to people. My elder son, Gi, wanted Sue every moment when he was an infant. He wanted Sue to accompany him every night, otherwise he could never fall asleep. This lasted until Gi was four. To the contrary, Ag never requested for company, not even once. Initially, I was happy because Sue and I did not need to bother. We were free. Today, however, I would say that if an infant never pleads for company of parents when going to bed, this is not a good sign, might even a symptom of Asperger's.

When Ag was 2 two years old, Maternal and Child Health Center referred his file to Social Welfare Department Early Education and Training Center (EETC) for assessment. There was a long waiting list. The estimated waiting time was around one year. Seeing Ag's abnormalities, Sue and I checked with nurses, speech therapists whether Ag was autistic. Everyone replied "Does not seem like". I could not leave it so I started to read. I found more than 60 symptoms on the list. If an infant exhibited 30 or more, then it was considered autistic. In my opinion, Ag was showing 10 or a bit more.

In August 2006, Ag finally undertook an assessment in an Early Education and Training Center, EETC. Sue and I brought him there. I observed and recorded down as much as I could. Today I still have it in my file. The outcome was bad, very bad. Everything was behind. Gross motor, fine motor, language ability, self-care capability were behind normal by 1 to 3 years. Self-esteem was behind by two years. Cognitive ability was behind by 6 months. In no area Ag reached the norm. But the report did not mention Asperger's Syndrome or Autism or any comment close! EETC started to schedule training. We did not wait long this time. At age 3.5, Ag started special education. There were two training sessions per week, including speech therapy, occupation therapy and physiotherapy. In addition, there was a monthly training session. A group of kids came together to learn basic social skill.

In one year, there was considerable improvement in gross and fine motor, just slight improvement in language ability and cognitive capability but almost no improvement in social skill. He still ignored the outside world and had no interaction with people around.

Other than EETC, I also enrolled for Ag training courses run by another non-profit making organization. I showed the report of EETC. This organization took Ag in without further question. Once a week, Ag attended one hour training together with a group of children who were also behind in development. The course focused on mainly social etiquette, body balancing, gross and fine motor. The trainers were experienced therapists. Ag was there for approximately one year, yet no trainer had ever mentioned Asperger's Syndrome to Sue or me.

The first person mentioning Asperger's Syndrome to me was my sister. One of her friend's son was suffering from dyslexia. This lady mentioned the syndrome to my sister. She urged me to bring Ag to private clinic for further assessment. In her opinion, governmental clinic did not have enough resources and the assessment was not in-depth. Initially, I resisted. Ag had undergone assessment by specialist several times. He was undertaking training conducted by specialist and was improving. Why bother to do another assessment? Furthermore, my sister did not know the exact term 'Asperger's Syndrome'. She just knew that there was such a syndrome but was not able to explain further. I was not persuaded.

My wife Sue worried about this more than me. She urged me several times. Seeing that Ag was indeed behind the peer and the big disparity between Gi and Ag, I changed my mind. In July 2007, we brought Ag to a private specialist. Initially, the assessment was scheduled for 3 hours but we realized that it was not enough. So we did a further assessment of additional 3 hours.

One month later, when receiving a report, we were told, for the first time, that Ag was with Asperger's. I was very angry, upset and disappointed. I brought the report to Early Education and Training Center. The Center arranged a clinical psychologist to assess Ag quickly. The result was mild degree of autism. Immediately, EETC arranged additional training sessions.

Even today, I still find it regretful. Irrespective of the fact that Ag had been assessed many times, from age 2.5 to 4.5, by qualified specialists, yet no therapist had ever mentioned Asperger's Syndrome or Autism to Sue or I! I had no doubt that all these specialists cherished our son. However, how could this have happened? I could think of two possibilities. First, Ag was quiet and calm at centers. He hardly created any trouble and appeared to follow instruction, but was very slow and speechless. In general, therapists and trainers did not have any chance to see his behavior at home, those icy behavior which made Sue and I shiver. So they did not consider Ag very poor, just behind in learning and development but not autistic. Second, Ag was trained by multiple therapists in each respective discipline; speech therapy, occupational and physiotherapy etc. There lacked a comprehensive cross domain assessment. In such circumstances, it was very difficult to identify the real issue. Behind in a few areas such as speech ability, gross motor and fine motor, would not necessarily mean autism, hence invoke clinical psychologist. I believed that this was the root cause.

When I became anxious, I arranged assessment by a private clinic. There were two specialists throughout the entire assessment. In between, additional specialist joined. All together it was a 6 hours assessment. How about the assessment committed by governmental agency? It was led by one specialist, normally 45 to 60 minutes. There was a big difference.

I had no intention to blame anyone. I understood the limitation of resources and the complication of ASD diagnosis. It was not an easy job. On the other hand, I was grateful to EETC which provided training to Ag since he was 3 years old. These services were of high quality and

great value-for-money. It costed me virtually zero, while the service fee of private clinic was much higher.

In Hong Kong, people know about Autism, but Asperger's Syndrome is not a term that people generally know. All my friends are university degree holders or experienced parents. When I mentioned this, none of them knew, not even had heard this before.

I write a lot of details of this long journey of diagnosis because I want other parents to be aware of Asperger's Syndrome. In my case, because of lack of knowledge, I lined up for years until a point I turned to private clinic, until then I found out.

How about myself? I never knew that I was also with Asperger's until I reached my middle age. If I had got some kind of guidance or training, I could have had a more pleasant childhood or youth, a happier social life and less difficult experience. I shall describe it in a separate chapter.

Not long ago, I was listening to a radio program about ASD. There were ASD children diagnosed at the age of 6 or 9. I wondered how hard it would be.