RAISING A CHILD WITH AUTISM

A Journey With No Flight Plan

By Koh Soek Ying

> "Autism is a journey with no flight plan. Some days you simply have to go with the flow and land wherever the winds take you!"
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> – Walk Down Autism Lane (Facebook)

That quote above truly describes our experience, from the point of discovery till now. Nothing could have prepared us for this extraordinary ride where every day presents new discoveries and learning points. What I am about to share are my heartfelt thoughts, from a caregiver's perspective. I sincerely hope that this will be the start of many more conversations within the different communities, bringing greater understanding and help for children with autism.

From security to uncertainty

Our second son Ryan, 22, met all the necessary milestones on his developmental charts, with some exceeding the mean scores and those of his brother, who is two years older.

Hence, you can imagine how shocked we were when his preschool teacher called to share her suspicion that Ryan might have some learning difficulties. He was just over two years old then. She also presented us with several articles on autism. We had never heard of this condition and were clueless about it. It was a turning point for us, and we will always be grateful that the teacher was intuitive enough to have caught it at such an early stage.

Ryan's regression was very subtle. There were symptoms which we initially thought were the typical antics of the "terrible twos". He was a very happy child, but little by little his smiles faded and were replaced with stony, blank stares. His responses grew less spontaneous and he needed a lot of prompting. He used to be able to call "Daddy", "Mummy" and "*Kor Kor*". These first words were soon replaced with a lot of crying, with each episode lasting longer and longer. Initially, we thought that these outbursts were merely the tantrums of an attention-seeking child. In-between these bouts of crying, he would be silent and expressionless. He also started to obsess over objects, especially marker pens. He would hold one marker pen in each hand and refuse to let them go. If we took them away, he would retaliate with incessant crying that sometimes lasted for hours. Nothing seemed to soothe him.

It was exasperating to say the least. Other typical symptoms of autism gradually crept in – the body rocking, flapping of hands, and covering of ears whenever the vacuum cleaner was turned on or when a plane flew past. Certain sounds seemed to debilitate him. Before we knew it, our son was entrapped by the dreaded clutches of autism.

More questions than answers

20 years ago, much of the expertise was from the US, with limited information available locally. Needless to say, we had lots of debates with our paediatrician. We discussed the various possible causal factors – the obvious one being the MMR vaccine. Ryan had also received the chickenpox vaccine. We went through a period of regret and, occasionally, we still do. Had we not given him those two vaccinations, could things have turned out differently? After all, he was progressing on track until those dreaded jabs. Or could it be due to the prolonged labour I had? Needless to say, we had more questions than answers. Our paediatrician had always maintained that such claims must be substantiated by statistics, of which there were none. (Recent research has debunked the connection with the MMR vaccine.) Notwithstanding all these, questions still remain: Is there a cure for autism? What do we need to do?

That period of our lives is best described as the "merry-go-round" phase. We saw numerous professionals – doctors, psychologists, homeopathy practitioners, occupational therapists, speech therapists, educational therapists, among others. Ryan was put through a variety of tests such as hearing tests, blood tests, stool analyses, hair analyses and food allergy tests. He was also treated for leaky gut and underwent psychological assessments. Some of the tests were not readily available in Singapore then, so the samples had to be sent overseas. Ryan was also put on a host of vitamins and supplements such as fish oil, taurine, L-Glutamine and probiotics, just to name a few. He even went on a gluten- and casein-free diet for a while. On top of all these, we also tried a variety of early intervention programmes such as the Applied Behaviour Analysis and the Glenn Doman approach.

Back then, the medical and treatment landscape was very fragmented, expensive and scarce. Parents like us had to rely on our own research, share costs, and struggle with the deluge of information and professional jargon in medical, psychological and therapy reports. There was really no single professional who could help us interpret all these data and develop a holistic plan for our child. We often wondered if a certain approach could be counter-productive to another. We were not sure; there were more questions than answers. Repeating our story to every professional we saw, we sounded like a broken record but always ended up with the same diagnosis. It was extremely frustrating and a drain on our finances.

We were navigating through a system which could not adequately support a child with autism. Private doctors and therapists were (and still are) very expensive, while at the public hospitals (which are cheaper), you had to wait months for an appointment. What was most frustrating at the public hospitals was the frequent turnover of professionals assigned to our case. With each personnel change, we had to repeat our story. Children with autism do not take to change well; it can be very traumatising for them. Just imagine the level of stress and frustration we experienced trying to access public services. Thus, to ensure that Ryan had as much early intervention as possible, we made the difficult decision to go to the private practitioners.

An evolving healthcare landscape

Singapore has definitely evolved. By God's grace, Ryan has come a long way too. There is now a lot more awareness and knowledge of autism, and services available to support people with autism have also increased. We are especially glad to see better support rendered at the early childhood stage – from diagnosis to early intervention. Of course, more can still be done. A good conversation to have is a discussion on how to narrow the gap between a doctor's clinical focus on developmental milestones and diagnosis, and a caregiver's need for advice on treatment and support services. Currently, there is still no unified approach to what needs to be done once a child is diagnosed with autism. Who can we look to as the clinical manager for the child?

Aside from early intervention, there is another area of concern – those above 18 are ageing out of our systems. This is a stage where most of us parents of children with special needs would call "falling off the cliff" – a bleak post-school horizon. I often refer to this age group as the "sandwich class". It is the age where almost 90% to 95% of those in Special Education Schools finish formal schooling. The rest of the cohort would continue with vocational training for another three years. For the former group, some would end up in day activity centres or sheltered workshops, but a vast majority would end up staying at home, facing unemployment and a high propensity for regression. This is also the group which Ryan is currently in. Even the services at the Child Guidance Clinic only cater to those below 18! Right now, there is no centralised transition plan for those beyond 18 years old, be it for education, employment or medical services.

When Ryan was approaching 21 years old, we discovered a new set of challenges. As he has moderate to severe autism, he needed help to manage most of his personal affairs

(eg, Central Provident Fund, SingPass, passport and banking matters, just to name a few). Therefore, we had to be deputised to manage Ryan's affairs through the Family Courts. When we approached the list of doctors under the Office of the Public Guardian for help with the medical report and affidavit, many were unfamiliar with deputyship for individuals with autism. Thankfully, through our collaboration with the National University of Singapore Pro Bono Office and a doctor who has a child with autism, we have been deputised to manage our son's affairs. Again, this highlights an area where we can work together to bring awareness and services, especially to those who have aged out of the system.

Nevertheless, local healthcare services for persons with special needs are changing, especially in recent years. Of course, as parents, we hope that the pace can be hastened and more can be done. For instance, it was only in late 2015 that we had the first of four dentists trained to handle geriatric patients and those with behavioural issues due to conditions like autism, cerebral palsy and intellectual disability. In March 2018, a new clinic under the Movement for the Intellectually Disabled of Singapore (MINDS) opened and offers specialised care for people with intellectual disabilities. Right now, services are limited to MINDS clients. Can such services be made available at the national level? Or perhaps, more GPs can be roped in to offer such specialised services?

Autism is a spectrum. It is a real challenge, especially to support those who are unable to articulate what is affecting them because they are less verbal or cognitively slower. Hence, if a doctor is unfamiliar with the disability or ill-equipped to communicate with persons with autism, these patients may not be provided with proper or correct treatment.

Currently, a lot of our resources are obtained from informal and closed support groups. We are really thankful that the caregivers in these groups are so generous in sharing their recommendations on medical professionals, treatment services, supplements, care, etc. Such networks are definitely a treasured resource, which we hope can be centralised and made available to more parents, especially those with children who are newly diagnosed.

Universal insurance coverage

The cost needed to support our child is a constant worry, especially finances for his long-term care when my husband and I are both no longer around. It weighs heavily on our hearts. Thus, it was a welcome relief when MediSheld Life was introduced back in November 2015, as it covers all Singaporeans and permanent residents, including those who have pre-existing conditions like autism. Prior to this, it was very difficult for them to get proper insurance coverage. However, a person with autism may need specific health services, such as speech therapy, occupational therapy and psychology treatments, which are recurring and not covered by the scheme. The costs of these services can be substantial, especially if they are required on a regular basis for a person to be functional. We hope that the scheme could cover some of these costs.

Continuous conversation

Healthcare is definitely an area in which we hope more conversations can take place. With better healthcare management, this journey of uncertainties could become one of possibilities, as caregivers like us can be more at peace that their maturing special children will be well taken care of. ◆


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Legend

1. Ryan (middle) and his siblings in 2004

2. A patchwork wall-hanging Christmas tree designed by Ryan

3. Posing for a family photo

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