

By Dr Lian Wee Bin

"Mummy, I need a friend..."



This went on in my clinic yesterday.

"So, are you enjoying school?"

"YES!" (Resoundingly, in a high-pitched tone.)

"And, do you have any friends – can you name them?"

"YES! There's Zhiyong, and Timothy, and Suzie, and Masturah ..."

"Wow, so you have lots of friends ... what do you do with them?"

"PLAY!" (Excitedly.)

"Yes, but what do you play?"

"Oh, CAPTAIN'S BALL!" (Almost shouting.)
"You throw the ball around and if you catch it, you get one point!"

"And what else?"

"And FRISBEE! You throw the FRISBEE and if you catch it, you also get one point! Yes, EVERYTHING you throw and catch, you get one point!"

Then, mom interjected over the up-and-down tone of her 10-year-old son, "Actually, he doesn't

really know how to play with the other children. He has no friends of his own. These were only played during structured game sessions organised last week by the special education teacher recently sent to the school."

The isolated child – sometimes you see them, even more often you hear about them: the awkward child who does not fit in; the clumsy child who few want to befriend; the one who stands alone every recess time; the one who gets jeered at or bullied. How one's heart aches for them. Yet, such is the reality of life.

SHE EATS ONLY 'YELLOW FOODS'

Another mother came with her child to see me after an anxious six-month wait upon referral from the polyclinic and told me how difficult it was to feed her child. She described how her 4-year-old girl would only eat yellow foods. She would take *nasi briyani* but not white rice; french fries but not lighter-coloured potato chips; yellow noodles but not rice noodles or *char kuay teow*; yellow banana milk but not regular full cream or fresh milk. Food fad or rigidity? As it

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turned out, this young girl also had difficulties in communication and social interaction, and a host of stereotypic behaviours and restricted interests (the last to which the ‘yellow foods’ phenomenon belonged) – the triad of impairments that satisfy the criteria for a diagnosis of an autistic spectrum disorder (ASD).

Developmental and behavioural disorders can certainly present in various different ways. This umbrella terminology includes a wide variety of disorders ranging from

- gross motor delay to cerebral palsy;
- fine motor delay to developmental coordination disorder or dyspraxia;
- isolated speech and language delay to communication disorders such as ASD; and
- learning disabilities and attention deficit/hyperactivity disorders.

The list goes on.

Children may present with some parental concerns as early as a few months old, usually with motor delay, or for developmental screening because of a tumultuous perinatal period. More often, the child is referred for assessment for a delay in the development of speech and language skills when they turn two years. A later phase of presentation occurs during the kindergarten years when the child encounters difficulty, or the preschool teacher detects delays in academic learning or inability to focus or concentrate. As parents become more educated and aware, they are also bringing their children in for issues such as difficulties with social interaction.

When the child comes for consultation, the developmental doctor will interview the parents and then explore the issues together with them,

as well as take the opportunity to observe the child and interact with him. A provisional diagnosis can usually be made after that initial visit, although at times, it can be complicated and issues may need to be re-explored at a second visit or further subsequent visits. We then provide feedback to the parents on our impressions and make our recommendations for further assessment, intervention and schooling needs.

Generally, our role extends beyond the usual medical model of ‘the doctor provides treatment and cure’. We play more often, the role of advocator for the child’s needs, and case manager to assist the family and coordinate the various needed interventions and care that will be provided by a number of professionals on the team. These include the physiotherapist, occupational therapist, speech and language therapist, psychologist, nurse and medical social worker. For children transitioning to primary school, the educational facilitator is also involved. We also help to liaise between the team members and external agencies (such as schools, learning centres and private therapists) to coordinate strategies and management of the child. Certainly, the role of medicating the child who requires it also remains our domain. Furthermore, as parents struggle to accept the diagnosis for their special-needs child, we strive to point them towards the right resources and provide ongoing educational updates for the condition, knowing that cure is most likely not available for this group of children. It will be a life-long journey for many of the families.

“THIS CANNOT BE HAPPENING”

In Elizabeth Kübler-Ross’ book, she outlined the ‘5 Stages of Grief’. Although first described for terminal patients, we see these stages so frequently in our patients and their families. First, comes the denial – this cannot be happening to my child! Then comes anger – the whys! A period of bargaining may follow – if I do this, will my child be okay? As reality starts to sink in, depression is often experienced – this is hopeless, how is he ever going to make it? Finally, acceptance will spur them to see how they can help their child. The stages are not isolated and well defined. Parents can get stuck at one phase for a long time. They can also slide to and fro between stages. They may skip stages and only revert to an earlier stage at odd times of their journey with their child. It is an interesting process and invariably, the parents become stronger over time.

Sometimes, it can be hard to tell where they are, and being stuck at a particular stage can cost



En route to Pulau Besar, the family stopped at Malacca for a holiday shot. (From L-R) Paul, Dr Peter Ang, Joan, Dr Lian Wee Bin and Simon.

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the child many golden years of opportunities for intervention. I have a family who remained on my follow-up for five years before coming to terms with their child's condition. A simple low-income family, his parents 'accepted' the initial diagnosis of global developmental delay calmly at the age of 1 year, but never turned up for any therapy or any early intervention programmes that were arranged. “No need,” was the simple reply when asked why they failed to turn up time after time. “He'll be better. He's just slow.” Two years later, it became more apparent that the child was likely cognitively impaired. At the age of 3-and-a-half, he was not walking or talking at all. He was simply lying in the stroller and looking around. An attempt was made to organise a psychological assessment for special school placement. Despite encouraging, coaxing, counselling, threatening, arranging financial support and a variety of other methods, his parents did not yield. “It's ok. We will look after him.” To the statement that as gradually aging parents, we would not be around to look after our children forever, the immediate reply was that his brother and sister will look after him when they (parents) were gone “They have a duty – they are his siblings.” Sigh!

Not till the age of 7 when the primary school authorities told them to go to special school did they turn up at my clinic to request a referral! Yet, interestingly, they had never defaulted a single medical follow-up visit. Why? I do not have an answer. Perhaps, they come from the old school of thought that you must see the doctor, but the rest are not important. Yet, as always, and even more so in developmental medicine than other disciplines, the doctor cannot and must not work alone. It is a team effort and the team should include the parents and care-givers as members.

HELPING HANDS

Another example of how care-givers should be included in management would be the need for strategy implementation across different environments for the special-needs child. The child with ASD or a communication disorder, who is non-verbal, requires an alternative mode of communication such as the Picture Exchange Communication System (PECS). This is essentially a method in which the child is taught to initiate communication through the use of picture cards. Although not predominantly designed for imparting speech skills, it has been

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found that large proportions of children who use PECS actually do start to talk somewhere midway through the modules.

The PECS cards therefore function as the temporary 'voice-box' for the child. Just as you do not leave your voice-box at home when you go out, parents should also be encouraged to bring the PECS cards out with the child. This ability to use cards to communicate widens their expressive ability and lowers their frustration levels, hence reducing temper tantrums and raising their self-confidence.

Therefore, all care-givers, including family members as well as teachers, handling the child should learn and use that method so that consistency is present for the child. Imagine how confused you would be if your voice-box works at one place and not at another! Think also how the availability of a voice-box can affect your social interaction and play skills amongst your peers.

When children with ASD grow older, they require help with structured management and scheduling to manage daily routines. As they cope poorly with transitions, these children benefit from visual strategies such as cue cards, board schedules and social stories to prompt them and help them anticipate and prepare for disruptions, which happen so often in daily life. Teachers and parents therefore play an important role in this aspect. It makes their lives easier and the child's view less complicated. All round, everyone is less stressed when these aids are in place, both within the classroom and at home.

Yet another example would be the management of a child with an Attention Deficit/Hyperactive Disorder (ADHD). Typically, a child with AD/HD may have predominant problems with attention and focusing (ADD – Attention Deficit Disorder) or could additionally be impulsive and hyperactive for those with the combined and the hyperactive type (ADHD). Medication, as shown by the Multimodal Treatment Study of ADHD (MTA), first published in 2001 with a follow-up study in 2004, is the cornerstone

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of treatment, superseding isolated behavioural treatment. Medication together with behavioural treatment has a slight advantage over the use of medication alone. Therefore, the administration of medication and implementation of behavioural management would necessarily involve both home and school care-givers. Observations for response to medication must also be made by both parents and teachers, for feedback to the doctor for drug titration for best efficacy. Behavioural management with the use of time-out measures for misbehaviour, star charts and reward tokens for positive reinforcements and timers for time management must be consistently used both at home and in school for best effectiveness.

“I NOT LAZY”

Many times as a doctor, we hear parents rant about how lazy their child is. It is important at such times that our developmental antennae goes up. Always remember to be an advocate for the child – check to see if the child in question is appropriate for his milestones. Check to see if the difficulties encountered by the child are a result of real deficits in skills or shoddy behaviour. Inquire about interaction and play skills. Ask about the home environment and the school environment as well as the supports provided for the child. A child who is of normal intelligence and yet continues to fail in school may not be so much lazy as often tired at the end of each tough day, during which he has been struggling with a learning disability. Once, in asking a child to read the word ‘cat’, the child shook her head to indicate that she did not know how to read it. Yet, later when asked if she could spell ‘cat’, she nodded vigorously and proceeded to write, with somewhat untidy handwriting – ‘tac’. She then went on to spell ‘dog’ – ‘god’!

Another child shared that she had devised a method to remember which ways numbers faced when writing them. She said wisely, “All numbers (besides ‘0’) face the west, where the sun sets, except for ‘5’ and ‘6’ which face the sun rising in the east.” For a child who needs to decode very letter and word that he reads, is it then any wonder that he would be tired out and start to have task avoidance behaviour?

The child with the ‘Number Rule’ went on to struggle for three years in primary school, before her parents finally came to terms and got her to be formally diagnosed to have dyslexia, one of a number of learning disabilities. Oh, the trials that some of our children go through.

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Let us therefore increase our own awareness of the special-needs child, to be a champion and an advocate for him, especially in a society that is largely still in its infancy on the road of support for these children. Certainly, it has improved in recent years in Singapore. We have the National Child Development Programme, launched officially in 2003. This provides subsidies for centre-based intervention for special-needs preschoolers under the Child Development Units in KK Women’s and Children’s Hospital and the National University Hospital. The former is serviced by paediatricians from the Department of Neonatal and Developmental Medicine, Singapore General Hospital, as well as Department of Neonatology, KK Women’s and Children’s Hospital whilst the latter is serviced by in-house paediatricians. The Child Guidance Clinic, under the umbrella of the Institute of Mental Health, also assesses and provides intervention for children in their school-going years.

Inter-ministerial committees are now exploring issues surrounding the provision of support for these children both at preschool and primary school levels. Teachers are starting to receive training for classroom management of the various developmental disorders. Special schools, although with long wait-lists, continue to be upgraded and built. Support groups, though still limited, are slowly gaining recognition. Efforts must therefore continue to increase, so that resources for parents and children can multiply. As family physicians, the challenge is to provide all-round support and advocacy for the family with the special-needs child. Only then, can a special-needs child of today be nurtured into a truly functional adult of tomorrow. ■

