

mother knows best

Two sets of parents of autistic children share with Koh Jia Ling why mothers should trust their instincts when it comes to their child's development



It is every parent's dream to have a healthy, happy and normal child. But when signs indicate otherwise, the next best thing to do is to spot the problem early and seek professional help so that your child has a better chance of leading a life that allows him to realise his potential.

In the case of Autism Spectrum Disorder (ASD), most children are diagnosed only when they are about three to four years old, which hinders the possibility of them recovering well enough, socially and mentally, to match their peers and cope in a mainstream school. Although a child slightly over a year old may display many red flags of autism, some developmental paediatricians are of the opinion that children so young may simply be working out the kinks of growing, and will eventually right themselves.

That was what happened in Jenna's* case, when she tried to seek help for her son Jackson* whom she suspected had a problem.

"Jackson was about one when I noticed that things just didn't seem right. He started doing repetitive movements with his head and he just kept on nodding his head constantly. And everything with him just seemed a struggle, like getting him to go from, say, a bottle, to drinking from a straw. I also noticed that he never actually paid attention to anything I was doing or what anyone else was doing; he just liked to do his own thing. When he was 16 months I took him to a developmental paediatrician

who told me he had a lot of red flags of autism, and suggested I look into putting him in an early intervention programme. At the same time, her attitude was that sometimes things just work out on their own, and six months later he might be fine."

After some time, when it was apparent that things were not going to work their own way out, she decided to take things into her own hands. She did some research on possible early intervention programmes that could help her son, and came across ABC Center Singapore's Infant/Toddler (IT) programme for children under the age of three who are diagnosed or 'at risk' of being diagnosed with ASD.

"Research has consistently shown that early intensive intervention offers the best chance for improving function and maximising a child's progress and outcomes," says Loh Hui Ling, M.A., BCBA, Site Administrator of ABC Center Singapore. "There is growing evidence to suggest that a small minority of persons with autism progress to the point where they no longer meet the criteria for a diagnosis of ASD. However, the age at which intervention begins for a child with ASD is critical."

Early Intervention

Knowing this, another set of parents, Faith* and Andy*, decided to enrol their son Kyle* in the IT programme as well, as they learnt from family and

their own research that early intervention and ABA (Applied Behaviour Analysis) is an effective form of therapy for children with ASD. They had been looking for more intensive programmes for their 16-month-old son, but met with great frustration as most therapists they saw were unwilling to enrol their son in the number of therapy hours they wanted for him, citing his young age. They also liked how the programmes at ABC were structured around ABA — the proven science of using interventions and stimuli to influence human behaviour, rather than explaining it away as internal constructs beyond our control — and the fact that ABC Center was a US-based company run properly by professionals with BCBA (Board Certified Behaviour Analyst) certification.

The IT programme in particular focuses on facilitating emerging skills such as initiation, eye contact, imitation, play, and responding to social reinforcement with children under three years of age, so as to increase the child's range of behaviour across different areas and situations, and help him or her eventually be successful in typical community environments. It started only last August in Singapore, but already, of the five children who have been enrolled in the programme, two of them have graduated and gone on to mainstream schools and are doing well.

Both Kyle and Jackson have improved much after joining the programme. After only three months in the programme, Kyle's eye contact has vastly improved, and he is interacting a lot more with his parents and has started speaking; while Jackson has shown great improvement in his skills after nine months in the programme.

Says Jenna, "When we enrolled Jackson in the programme, he couldn't do anything — he couldn't clap his hands, he couldn't wave... he really couldn't do anything. He's definitely improved immensely in his play skills, in his gross and fine motor skills, and also in following simple instructions."

Her advice to parents: "I always hear of mothers whose kids are not diagnosed until they're three or four. If you do think that you've got a problem with your child, or your child's got some bizarre traits, you should follow up and really push the paediatricians to listen to your concerns, because I too was told by the paediatrician that every kid develops differently. Trust your instincts, your gut feeling. The mother always knows best."

**Names have been changed*

FACTS OF AUTISM

What is autism spectrum disorder?

It refers to a range of pervasive neural developmental disorders that range from mild to severe, affecting how information is processed in the brain.

Causes:

The cause of autism is unconfirmed, but it is likely that both genetics (rare mutations, or rare combinations of common genetic variants) and environmental factors (such as the advanced age of parents, maternal illness during pregnancy, extreme prematurity and very low birth weight, exposure to high levels of pesticides and air pollution during pregnancy) combine to play a role. However, of the parents we spoke to for this article, none of them had a family history of autism.

Signs of autism include:

- Impaired social interaction: as early as infancy, babies with ASD may be unresponsive to people, focus intently on one item to the exclusion of others for long periods of time, fail to respond to their names and often avoid eye contact with other people.
- Impaired communication skills: delayed speech and language skills, failure to point or respond to pointing, uses few or no gestures.
- Impaired play skills: unusual interest or behaviours such as lining up toys or other objects, playing with toys the same way every time, like parts of objects (wheels, lids); may develop routines that might seem unusual or unnecessary (i.e., looking in every window that he/she walks by). Not being allowed to do these routines might cause severe frustration or tantrums.

When to seek help:

If your child is displaying the above signs, and is not meeting the typical developmental milestones of his peers, you should look for a developmental paediatrician to have him checked out.

ABC Center Singapore is the newest centre in the ABC (Applied Behavior Consultants) global family, established in Singapore on January 2010 to provide specialised ABA services for children and adults with autism and other developmental disabilities. It is located at 318 Tanglin Rd, Phoenix Park Office Campus 01-57 to 59, S247979. Tel: 9423 6248 Email: admin@abccentersingapore.com. Website: www.abccentersingapore.com



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CHANGE OF HABIT

AUTISTIC CHILDREN CAN BE TAUGHT NEW SKILLS AND WAYS OF DOING THINGS THAT WILL HELP THEM INTEGRATE INTO SOCIETY. SUNUJA NAIDU FINDS OUT HOW ONE CENTRE DOES THIS

I remember talking to someone whose son was autistic some months ago and sensed a tinge of sadness in her voice when she spoke about him. All parents wish to have their child be normal, yet as some parents have discovered, having an autistic child is not the end of the road.

Autism is a spectrum disorder, meaning the abilities of autistic kids range from mild to severe, from low-functioning to high-functioning. Not all children will have the exceptional abilities of the Dustin Hoffman character in *Rain Man*; in fact, very few will. But many of them do manifest the social shortcomings of that character. Most

autistic children lack social skills. They do not make eye contact, lack greeting skills and are unable to interact with others. "Most children with autism prefer to be alone," says Ms Hui Ling Loh, Senior Behaviour Analyst, ABC Center Singapore.

They are also deficient in play skills and are unable to pretend play or play appropriately with toys. They tend to line up their toys or repeatedly play with the same toy in the same fashion, are unable to engage in turn taking, sharing, imaginative or substitution play and are unable to functionally communicate what they want or need.

"Children with autism in general are unable to take in natural stimuli in the environment to learn the way other children do. They are enclosed in their own world and are sensitive to certain variables in the environment such as light, sounds and texture," says Hui Ling. ABC Center employs a method called Applied Behaviour Analysis to help these children function more effectively in society.

The first thing the centre does is to meet parents to discuss their concerns and goals and to assess the child's current skills level. Various strategies are then employed to help the child learn new skills. One of them is to place the children in a restricted environment with few distractions so that they are not overwhelmed by external stimuli and are better able to receive information. Once the child has acquired the skill in this structured environment, the next step is to teach generalisation, where the child is taught to generalise the skill across stimulus classes, settings and time, to natural environment and social community. On developing the child's programme, the child's daily routine is factored in where all the activities are broken down to small manageable steps and taught to mastery. These steps are then chained together and integrated into the natural routine.

The centre provides training programmes for parents to empower them to teach their children. Many parents, points out Hui Ling, have difficulty managing the everyday life of their autistic children. Her advice to parents in this situation:

- Find out what autism is and how it affects your child; look for scientifically proven methods that are effective in managing him or her.
- Teach and encourage independence in daily routines.
- Create goals for your child and introduce these goals systematically through structured teaching.

According to one parent, Irene Tan (not her real name), ABA helps her son express himself, manage his behaviour and motivates him to do things. "He is doing well academically, but he needs a support teacher to help him to focus and be attentive to lessons and instructions. Also, socially he needs encouragement to communicate and interact with his peers."

Whether a child is able to join a mainstream school depends on the child's skills level and how well the child learns in a natural environment. The child could also go to school with a classroom shadow to give him the support he needs in integrating into the school environment. The autistic child can be taught skills but transferring those skills requires some pre-planning on the part of parents, school and the behaviour analyst working with the child, advises Hui Ling.

A SILVER LINING

Alan (not his real name) was 18 months old when his parents noticed that he was not making much eye contact, pointing at objects or babbling. He was also prone to tantrums. His worried parents took him to see a paediatrician who referred him to the Child Development department at Kandang Kerbau Hospital. He was given speech therapy before being formally assessed by a psychologist at Kandang Kerbau Hospital at the age of two years seven months.

Shares his mother, Mrs Lim, "Although we suspected he had autism, it still came as a hard blow when the developmental paediatrician at Kandang Kerbau Hospital confirmed our suspicion. The informal diagnosis was autism with global developmental delay. No words could describe the pain that followed: Why did it happen, why him... It was just too painful to see your beloved child having such a bad start in life. From anger to sadness, helplessness to fear for his future... these feelings and thoughts just kept haunting me throughout the months. It is a tough and painful journey I wish no parents would have to go through."

She enrolled him in speech and occupational therapy and also in an intensive ABA programme by ABC Center. At ABC Center, he clocks an average of 25-30 hours a week. This is supplemented by home-based teaching by his mother.

"I spend many hours a day doing one-to-one teaching, playing turn taking games with him, teaching him self-help skills and keeping him engaged in meaningful activities, such as playing his toys appropriately, hugging his sister, story time and music time. TV time is limited to half an hour a day. He is also on the GFCF (Gluten free, Casein free) diet as he suffers from wheat, dairy and egg allergy."

Mrs Lim is very pleased with the progress Alan has made at the centre. "He is now talking in two to three-word sentences, has good eye contact and responds to all greetings spontaneously. He is also imitating a lot. His play skills are also emerging quickly. He now seeks my husband and I for a game of chase, tickle, a hug, pat a cake game and he calls for mummy if he doesn't see me nearby. He spontaneously requests his favourite snacks and food and will say 'hi' to his younger sister."

"Academically, he can read at least 100 words and has no problem naming A-Z and counting 1-20. He can even sing 'Twinkle twinkle little star'. His tantrums have subsided and he has been shown more appropriate ways to make requests. He plays with his toys better, pulling his Thomas train around the tracks and not throwing them around."