



20 APR, 2025

Raising a child with autism

Sunday Star, Malaysia



OCCASIONAL SOAP BOX

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LIKE many parents and caregivers of autistic children, our story started when we first noticed differences in how our child was developing. Our son would bang his head, make repetitive movements, line up his toys obsessively, he wouldn't make eye contact, or call us "Mama" and "Papa".

Some parents and caregivers may be in denial at first, and that was my first response too. Despite that, we started exploring every possible way to support him, such as sending him to therapy sessions. From hospitals to centres to home therapy, we tried almost everything – occupational therapy, speech therapy, early intervention programmes, and applied behaviour analysis. At the same time, we made sure to send him to kindergarten so he could socialise with neurotypical children.

The diagnosis: Accept and act

Receiving a diagnosis can be overwhelming. I vividly recall the day I received a report from his therapy centre. "Autism Spectrum Disorder" was written on the cover. I wanted to believe that everything was fine – perhaps he just needed to attend a few more sessions. Eventually, though, I came to the realisation that I must accept the condition for the sake of my son.

Acceptance of the diagnosis is crucial so that parents and caregivers can seek appropriate interventions and support for their children.

In today's digital age, information is truly just at our fingertips. Apart from taking children for routine health check-ups to monitor their development, parents and caregivers can also get information on the condition, symp-

toms, and interventions online.

Therefore, if you notice any symptoms, act immediately – seek a doctor's advice, and start the intervention as soon as possible.

A day in the life

A typical day for our son begins with his attendance at the Integrated Special Education Programme provided by the Education Ministry in the morning, followed by sessions at the Ideas Autism Centre in the afternoon, after which he spends the rest of the day with family.

(The centre is run by Ideas, the Institute for Democracy and Economic Affairs think tank, as part of its efforts to develop a sustainable non-profit model that can be replicated to help those in need.)

Our son loves music and art. He enjoys playing musical instruments at home and at the centre, and they are always special moments for him and for us.

Despite the joy he brings, though, we do encounter challenges such as difficulty understanding his needs that can lead to tantrums, having to prepare meals to accommodate his tricky preferences, and managing his sensory sensitivities.

It is important to note that chil-

dren with autism exhibit a wide range of symptoms, and each child's experience is unique.

Financial constraints may be experienced by parents and caregivers. The costs of therapies and interventions are high. Recognising this struggle, the government introduced initiatives with Budget 2025 that focus attention on autism and the community around those who live with it. Many of the initiatives help lessen the burden faced by parents and caregivers.

Appreciate the wins

Celebrating our children's milestones is rewarding. Though our son rarely expresses his emotions, we make sure to show ours to him. When he receives awards at school or participates in school events, we are the first in line to support and cheer him on.

Despite practicing a lot for performances, he often refuses to perform in front of a large audience, so seeing him even stand on the stage is a win for us. We encourage any and all participation in activities at school and at the centre to build his confidence and allow him to slowly experience more and more of the wider world.

The support system

Caring for a child with autism is challenging, yet a strong support system can turn the challenges into manageable phases. While family serves as our core foundation, we have also been blessed with supportive friends, dedicated therapists, and compassionate special education teachers. This, I believe, is a reflection of how much more aware of autism society is becoming.

I'm also profoundly grateful to Universiti Tenaga Nasional (Uniten) for providing therapy support for my son. Besides Uniten, indeed, many parties are working on various initiatives to support people with disabilities (PwDs), and one of them is Universiti Malaya, which offers a fee reduction scheme for PwDs.

The support from various parties for the autism community is truly commendable.

A call for inclusivity

I am constantly inspired by my son and the community of autism. So much so that I decided to delve into the field of language and disability studies.

It is a rollercoaster ride having to balance family, work, and studies, but I am fortunate to have a strong support system – understanding family, friends, and colleagues, including my supervisor, Dr Ang Pei Soo, an expert in this field.

This month includes World Autism Awareness Day, marked on April 2, so I wanted to take this opportunity to share our story to do my bit to raise awareness and acceptance of autism in the hopes of one day achieving inclusivity as outlined in several of the United Nations' Sustainable Development Goals.

And also to give all parents and caregivers who are raising children on the spectrum this important message: You are not alone.

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Raising a child with autism

In Autism Awareness month, a mother shares what it's like bringing up a neurodiverse child on the spectrum.



Photo: Filepic/The Star