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Journey of raising a special child

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Page 1 of 2

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COMMENT
by Maslinda Md Yusof

THE journey of raising a child with autism is unique – it is filled with joy, challenges and learning experiences. Like many parents and caregivers, our story started when we noticed differences in the development of our son.

He displayed symptoms such as banging his head, making repetitive movements, lining up toys, having limited eye contact and not calling “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, centres to home therapy, we tried almost everything – occupational therapy, speech therapy, early intervention programme and applied behaviour analysis. At the same time, we sent 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 previous therapy centre. “Autism Spectrum Disorder” was written on the report cover.

I wanted to believe that everything was fine – perhaps he just needed to attend a few sessions. Eventually, I came to the realisation that I must accept the condition for the sake of my son.

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

In today’s digital age, information is 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, symptoms and interventions online.

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

A typical day for our son – he attends Program Pendidikan Khas Integrasi in the morning, followed by sessions at IDEAS Autism Centre in the afternoon and spends the rest of the day with the family.

Our son loves music and art. He enjoys playing musical instruments at home and the centre. Despite the joy he brings, we sometimes encounter challenges such as difficulty understanding his needs that can lead to tantrums, preparing meals to accommodate his preferences and managing his sensory sensitivities.

It is important to note that children with autism exhibit a wide range of symptoms and each child’s

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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 in Budget 2025 that focus on the community of autism. These initiatives can help lessen the burden faced by parents and caregivers.

Celebrating wins

Celebrating our children’s milestones is rewarding. Despite rarely expressing his emotions, we show ours to him.

When he received school awards or participated in school events, we would be the first to support and cheer him on. Why? Because we are together in this.

We encourage his participation in activities at school and the centre to build his confidence and let him experience the world.

Despite practising a lot for his performances, he often refuses to perform in front of a large audience. But seeing him stand on the stage was a win for us.

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 been blessed with supportive friends, dedicated therapists and compassionate special education

teachers. The society is also becoming more aware.

I am profoundly grateful to Universiti Tenaga Nasional (Uniten) for providing therapy support for my son. Besides Uniten, many parties are working on various initiatives to support people with disabilities (PwD), and one of them is Universiti Malaya (UM). The university offers a fee reduction scheme for PwD. The support from various parties for the community is truly commendable.

Call for inclusivity

I am constantly inspired by my son and the community of autism that I decided to embark on my journey in the field of language and disability studies.

It is a roller-coaster ride having to balance family, work and study but I am fortunate to have a strong support system – family, friends, colleagues and supervisor Dr Ang Pei Soo, an expert in this field.

Let us continue to raise autism awareness and acceptance, and strive for inclusivity as outlined in the United Nations’ Sustainable Development Goals 2030.

To all parents and caregivers who are raising children with autism: you are not alone and you are never alone.

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