

CASE REPORT

A Mother's Resilience: Navigating the Uncharted Path of Neurodivergence

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ABSTRACT

Autism spectrum disorder (ASD) is a complex neurodevelopmental condition affecting communication, behaviour and social interaction, with limited awareness and access to early intervention in Malaysia placing substantial strain on caregivers. This case report describes a 5-year-old Malay boy diagnosed with ASD at four years of age, presenting with delayed speech, poor social interaction, repetitive behaviours, feeding difficulties, echolalia and delayed toilet training. Developmental concerns were recognised by his mother as early as age two. Financial constraints restricted access to private services; however, the family utilised available public speech and occupational therapy and implemented structured routines at home. Despite initially slow progress, consistent intervention resulted in observable improvements in behaviour and learning. This case highlights the emotional, financial and societal challenges faced by caregivers of children with ASD, while underscoring the critical role of caregiver resilience, early diagnosis, structured intervention and accessible support services. Strengthening caregiver education and community-based support may improve outcomes for children with ASD and promote family resilience.

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INTRODUCTION

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that affects about 1 in 100 children worldwide, though the prevalence can vary across different studies and settings. In Malaysia, the prevalence of Autism Spectrum Disorder (ASD) is about 1.6 per 1,000 individuals, while in the USA, it is 14.7 per 1,000 children aged 8, or one in 68. This rate has been increasing over the years (1,2). It is marked by difficulties in social communication, restricted interests, and repetitive behaviours (3). These challenges extend beyond the individual and significantly impact caregivers, often requiring them to adapt to unexpected situations and navigate unfamiliar care systems. Parents raising children with ASD frequently face emotional, financial, and societal hurdles (3,4). This case sheds light on how early diagnosis, tailored interventions, and a change in mindset can help caregivers embrace and manage these challenges effectively.

CASE REPORT

This report focuses on a 5-year-old Malay boy who was diagnosed with ASD at the age of 4 after presenting with

developmental delays. His mother noticed concerns as early as 2 years old when his speech was delayed, and he showed limited responsiveness to social cues. He met the DSM-V criteria for ASD through symptoms such as delayed speech with echolalia, poor attention span, challenges in social interaction, and repetitive behaviours like hand flapping. Additionally, feeding issues, including an extreme preference for specific foods and difficulties with toilet training, added to the complexity of caregiving.

The boy was referred to speech and occupational therapy services, but progress was initially slow. His mother, a teacher and caregiver to five other children, faced significant challenges in managing his needs, compounded by financial limitations that restricted access to private therapy.

Specific interventions included picture exchange communication system (PECS) for communication, sensory integration therapy to address hyper-reactivity to noise and texture, and play-based tasks to improve joint attention and imitation. The mother reported initial resistance but noted gradual improvements in turn-taking, alphabet recognition, and basic self-care tasks.

Over time, she adjusted her approach, focusing on creating structured routines and working closely with available therapy services. These efforts helped the child improve his ability to participate in therapy, develop basic

self-management skills, and learn to recognize alphabets and numbers.

DISCUSSION

Caring for a child with ASD can be an overwhelming experience for many families, as it involves navigating behavioural, emotional, and societal challenges (4). In this case, the mother experienced significant stress due to the demands of caregiving, financial struggles, and the emotional toll of managing her child's needs. Despite these challenges, she demonstrated resilience by seeking out resources, committing to therapy routines, and shifting her perspective on parenting a child with ASD. This approach helped her adapt to her child's unique needs and fostered significant developmental progress over time.

Therapy interventions such as occupational and speech therapy were instrumental in addressing the child's specific challenges (5). The importance of structured routines, consistent therapeutic engagement, and emotional support for caregivers was evident in this journey (5). This case highlights that while the uncertainties of raising a child with ASD can feel daunting, they can also lead to growth and positive outcomes when caregivers are empowered with knowledge and resources.

Building on this, several further reflections from this case may be highlighted regarding early recognition, caregiver involvement, and the wider support needed for families. The mother first noticed concerns when her son was only two years old, which shows how important it is to pick up early signs of developmental differences. Unfortunately, the diagnosis only came two years later, reflecting the common delays families face when trying to access developmental services in Malaysia. Greater awareness among healthcare providers and stronger referral systems could help shorten this gap and give children the chance to benefit from early intervention.

This case also shows how a parent can play the role of a co-therapist. By setting up daily routines, using simple reinforcement strategies, and practising speech activities at home, the mother was able to extend what was taught in therapy sessions into everyday life. This not only helped her child progress but also gave her confidence and a sense of control in caring for him.

Finally, managing ASD is not only about the child's therapy. Families also need emotional, financial, and social support to sustain their role as caregivers. Access to counselling, peer support groups, and community acceptance can make a real difference, as the well-being of the caregiver is closely linked to the progress of the child.

CONCLUSION

Raising a child with ASD involves navigating a journey filled with uncertainties and challenges. However, with early diagnosis, tailored therapy, and a supportive family environment, these challenges can be managed effectively. This case highlights the critical importance of resilience, structured routines, and access to therapy in achieving progress for children with ASD. It also underscores the need for comprehensive caregiver support to ensure the well-being of families managing neurodivergence.

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