

Finding the Village for Autism Care in Singapore

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"It takes a village to raise a child, but where is the village?" These were the words spoken by one of my patient's caregivers in frustration during a clinic session. Many parents of individuals with special needs echo similar sentiments at various stages of their caregiving journey. The sheer magnitude of their responsibilities often takes a toll on their physical and mental health. Their frustration stems not only from the demanding nature of caring for a child

with special needs, but also from the isolation and lack of support they often face. For parents of children with autism spectrum disorder (ASD), the absence or lack of awareness of this "village" of support can be disheartening.

Autism spectrum disorder is a neurodevelopmental condition characterised by difficulties in social communication and repetitive behaviours. According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders, ASD encompasses what were previously known as autistic disorder, Asperger's syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified.1 The prevalence of autism is striking: the US Centers for Disease Control and Prevention estimates that one in 68 children is affected, with a male-tofemale ratio of 4.5 to 1.2 In Singapore, the estimated prevalence is one in 150 children as of 2016.3 Signs of ASD can emerge as early as six to 12 months of age; without early intervention, it can significantly impact speech, learning, social and emotional development.

The role of physicians in ASD care is critical. We have the unique privilege of identifying early signs of autism, right-siting and/or coordinating care, and managing co-occurring medical and psychiatric conditions. Early detection and intervention can make a substantial difference in a child's development, and physicians play an essential role in guiding families through this process. But despite the vital medical aspect,

managing autism is not just the responsibility of the attending doctors and parents - it truly requires a "village" of support from multiple sectors of society including healthcare, education and the broader community.

Challenges in detecting ASD and co-occurring conditions

Autism spectrum disorder can often first be suspected in primary care settings, typically due to parental concerns or observations made during routine developmental check-ups. Early signs may include delayed speech, poor eye contact, reduced social smiling, or regression in previously acquired communication skills. As children grow older, more prominent features such as sensory sensitivities, restricted dietary preferences or difficulties in adapting to changes in routine may emerge.1 These behaviours are sometimes misinterpreted as simple defiance or behavioural issues, rather than indicators of a neurodevelopmental condition.

Complicating matters further, ASD often co-occurs with other psychiatric conditions. Studies have shown that up to 70% of youths with ASD experience conditions such as anxiety disorders, mood disorders or attention deficit hyperactivity disorder. In cases where ASD is coupled with intellectual impairment, diagnostic overshadowing - where symptoms are incorrectly attributed to autism - can delay the diagnosis and treatment of these additional conditions.4

Misunderstanding and discrimination in schools and society

Children with ASD often face misunderstanding and discrimination, especially in schools. Educators and peers may mistake their need for routine or their challenges with communication as rude or defiant behaviour. For example, a child with autism might be perceived as "weird" or "difficult" due to his/ her inflexibility in thinking or social interactions. This can lead to isolation, as these children struggle to form relationships with their peers and may even become victims of bullying.

Outside of school, the challenges continue. In public, children with autism and their caregivers frequently face judgement when children display behaviours that do not conform to societal norms, such as meltdowns in overstimulating environments. These reactions from others can discourage caregivers from participating in public activities with their children, perpetuating feelings of isolation and reinforcing problematic behaviours through lack of exposure to diverse social environments.

A collective approach to autism care

Given the complex and multifaceted needs of children with autism, their care must go beyond the efforts of parents or healthcare professionals. A concerted "village" effort encompassing medical care, educational support and social services is required. Parents and caregivers should work collaboratively with healthcare providers to make informed decisions about their child's care, considering factors such as age, cognitive ability and autism severity. Support required can be divided into four broad areas: (1) Early intervention and therapy, (2) education support, (3) mental health support and (4) caregiver support.

Early intervention and therapy

Early intervention is crucial for young children with autism, as it helps them acquire essential skills like communication, social interaction and functional living abilities. In Singapore, early intervention services vary based on the child's needs, ranging from shortterm support in preschools to more intensive one-on-one therapy sessions

at specialised centres. These services are typically delivered by multidisciplinary teams that include speech therapists, occupational therapists and other allied health professionals.

Educational support

Education is another critical area where support is needed. Some children with autism also have intellectual disabilities, which require specialised educational settings. In Singapore, special education schools operated by MINDS and APSN cater to children with autism and cognitive impairment, while schools such as Pathlight School and St Andrew's Mission School offer education for children with autism who have average cognitive abilities. Mainstream schools are also increasingly equipped to support children with special needs through specialised education and counselling services.

Mental health support

As shared above, mental health conditions and behavioural challenges are common in children with autism. Nonpharmacological interventions, such as functional behavioural analysis, can help address these issues by breaking down challenging behaviours and developing appropriate preventive or response strategies. Collaboration between caregivers, educators and healthcare providers is essential to ensure consistency in behavioural support across different settings.

Caregiver support

Finally, caregivers themselves need emotional, social and financial support. Caring for a child with autism can be overwhelming, with parents experiencing grief, anxiety and stress at various points in their journey. They may also face additional financial burdens, such as the cost of therapy or specialised education. Support for caregivers can come in the form of psychoeducation, counselling, support groups and respite care.

Concluding thoughts

Autism is a complex, lifelong condition that affects not only individuals but also their families and the larger community. To effectively support individuals with autism, a collective, well-coordinated approach is essential – one that involves healthcare providers, educators, social services and the community at large.

Only through this "village" effort can we create an environment where individuals with autism can thrive and reach their fullest potential, and where caregivers feel supported and understood in their journey. •

References

- 1. Tonge B, Brereton A. Autism spectrum disorders. Aust Fam Physician 2011; 40(9):672-7.
- 2. Sanchack KE, Thomas CA. Autism Spectrum Disorder: Primary Care Principles. Am Fam Physician 2016; 94(12):972-9.
- 3. Wong CM, Aljunied M, Chan DKL, et al. 2023 clinical practice guidelines on autism spectrum disorder in children and adolescents in Singapore. Ann Acad Med Singap 2024; 53(4):541-52.
- 4. Reaven J, Wainer AL. Chapter 2 Children and Adolescents with ASD and Co-occurring Psychiatric Conditions: Current Trends in Intervention. Int Rev Res Dev Disabil 2015: 49:45-90.

For information on early intervention and therapy

- Enabling Guide by SG Enable Life Stages and Transitions: https://bit.ly/3ZXFHZJ
- Early Childhood Development Agency – Supporting your child. A parent's guide for young children who need early intervention: https://bit.ly/4eBHJTF
- Enabling Guide by SG Enable Service Directory: https://www.enablingguide.sg/ service-directory

For information on mental health support

· Child Guidance Clinic, Institute of Mental Health: https://bit.ly/400rVFF

For information on education placement and support

Ministry of Education Special Education Needs: https://bit.ly/4dEf675

For information on social, emotional and financial support

- · Enabling Guide by SG Enable -Caregiver Learning Roadmap: https://www.enablingguide.sg/ caregiver-learning-roadmap
- · Enabling Services Hubs: https://bit.ly/4eCh5Kq
- · Caring SG: https://www.caring.sg
- ARC Learning Academy: https:// learningacademy.autism.org.sg/