

COMMENT by Dr Sunitha Sivakumaran

Collaboration key to autism support

AUTISM awareness has grown steadily over the past decades through advocacy, research and policy reforms.

Globally, it is estimated that around one in 100 children are on the autism spectrum, reflecting both increased awareness and improvements in diagnostic practices.

Yet, despite this progress, many families still navigate fragmented systems of support while schools and service providers struggle with limited resources. Too often, autism support operates in silos.

A Unicef study on disability and inclusive education systems highlights that fragmented services remain among the biggest barriers to effective support for children with developmental conditions, resulting in duplication of effort, gaps in care and missed opportunities to create sustainable systems of care.

Effective autism support depends not on the presence of services but on shared understanding across families, schools and communities. In Asean, however, services remain unevenly distributed.

For example, a 2021 study in Singapore found that some autistic individuals and caregivers still found services inaccessible because of distance, way-finding difficulties and environmental bombardment on public transport.

In Malaysia, nearly 60,000 children with autism were registered as of May 2025, with numbers continuing to rise. While better awareness and diagnosis account for part of that rise, some parents still delay seeking diagnosis due to cultural beliefs or social pressure, leaving many children without timely support.

Collaboration enables diverse expertise and resources to converge into systems that follow children across classrooms, clinics and communities. Without it, families experience gaps and instability, undermining the very continuity of care that children need most.

Progress without listening is growth without roots

Traditional measures of autism support often fixate on programme counts, funding levels or service expansion and not lived family experience.

The Global Burden of Disease study highlights persistent inequalities in autism diagnosis and intervention across Southeast Asia, with rural families facing the greatest barriers.

In Malaysia, this gap is both geographic and financial. A 2025 Universiti Malaya study found that the key public services, including hospitals and government offices, remain largely unequipped to meet the needs of persons with autism and their caregivers, leaving families in underserved areas with nowhere to turn.

True progress is not measured by the number of programmes launched. Collaboration reframes progress as connective tissue linking schools, NGOs, healthcare providers and communities into unified systems of care.

Without it, interventions may exist on paper while families remain invisible in practice.

Empowerment without engagement is policy without people

Organisations can design programmes but without listening, policies risk becoming monologues. Research shows that families often feel isolated while navigating autism support systems, balancing caregiving responsibilities, work commitments and social stigma.

For some families in Malaysia, that isolation carries a financial weight too. A 2025 study found that autism-related costs often exceed RM4,000 a month, against the national median household income of RM7,017, barely half of what rural families typically earn.

Government assistance covers only a fraction of this gap. Services remain concentrated in cities and many mothers leave employment to become full-time caregivers. The system, as it stands, is not reaching families that need it most.

Engagement helps bridge this gap. When parents, teachers and community

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stakeholders are included in decision-making processes, they shift from passive recipients of policy to active contributors of solutions. Empowerment must be cultivated through ongoing dialogue, not treated as a checkbox.

Innovation without conscience is intervention without direction

Assistive technologies and therapy models hold enormous potential but without ethical grounding, they risk amplifying disparity.

In Singapore, researchers have developed an AI-powered wearable device that tracks physiological signals to detect early signs of distress in children with autism.

In Malaysia, the “Play Home” application developed by the researchers from Universiti Teknikal Malaysia Melaka uses machine learning to support cognitive and sensory development in children with autism, with real-time feedback that makes learning more personalised and adaptable.

Yet, a 2025 study by the Education Ministry found that even advanced assistive technologies produced minimal gains without individualised customisation, sustained teacher coaching and reliable infrastructure – barriers that are most acute in rural and under-resourced schools.

Without strong ethical safeguards

and equitable access, innovation risks deepening the very inequalities it aims to address.

This is where collaboration becomes most critical. Technology does not replace the human systems around it; it requires them.

Call to action

Autism support must evolve meaningfully. The next step is not coordination but true collaboration – one centred on dialogue, shared responsibility and collective action. That means policymakers embedding family voices into every decision; schools, clinics and NGOs sharing data and strategies openly, not in silos; and funders investing in connective systems, not standalone projects.

Autism support must not be a patchwork of disconnected services. Families deserve systems that listen, schools deserve partners that sustain them and children deserve classrooms where their potential is nurtured without interruption.

Fragmentation is no longer acceptable. Our answer must be collective action.

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