

Promoting evidence-based care for children and adolescents on the autism spectrum

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Autism spectrum disorder (ASD) is a neurodevelopmental disorder that has been increasing in worldwide prevalence,¹ including Singapore. In this latest issue of the *Annals*, we share the latest Singapore Clinical Practice Guidelines (CPG) for Autism in Children and Adolescents, discussed by Wong et al.² This is the culmination of the tremendous effort of cross-sectoral professionals coming together to generate recommendations of practice for the community, aspiring in goals of using high-quality evidence to promote high-quality care for families and children on the autism spectrum. The first CPG on Autism Spectrum Disorders in Preschool Children was published in March 2010,³ and the current updated version presents an opportunity to extend the guidelines to adolescents, as well as bring together more professionals within other non-health sectors to participate in its shaping. We highlight some of the key features of the CPG in tandem with evolving and important issues pertinent to practitioners in Singapore in the field of ASD.

The CPG emphasises the role of developmental surveillance and the need to seek immediate specialist care in the presence of any concerns of ASD without adopting a “wait-and-see approach”. This area of ASD is one that is evolving rapidly with evidence being generated for ASD surveillance in young children, so that early intervention can be timely and appropriate. In primary care, various local studies have started evaluating and validating culturally-relevant ASD-specific screening tools within child developmental visits, paired with clinical assessment of children. Ten years ago, the psychometric characteristics of the Modified Checklist for Autism in Toddlers (M-CHAT) was evaluated.⁴ The M-CHAT has since evolved to the Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT R/F), which holds promise as a feasible, practical, valid and acceptable screening tool in primary care, based on a recent large-scale study among well-children aged 18 months.⁵ In parallel, and in line with the shifts towards an inclusive childhood

ecosystem, equipping teachers in the early years in detection of young children with symptoms will be equally important. Additionally, what remains to be studied would be the acceptance of local parents towards developmental surveillance and screening and their cultural attitudes towards action—as we are still seeing delayed seeking of help due to varied responses to an ASD positive-screen or ASD diagnosis. Worldwide, evidence suggests that low-income children or children with lower-educated parents are also more likely to be missed⁶ as they commonly do not attend developmental surveillance visits at primary care, or because parental awareness is low. Our developmental surveillance and screening for ASD would need to reach them, as they are at highest risks of missing time-sensitive periods of early intervention.

An ASD diagnosis in a child has enormous impact on the parent and family. Most critical to parents would be “What can I do to help my child?” Their urgency, mixed with desperation, is usually met with vast options of programmes, treatments and claims of quick fixes. Parents and professionals may be confused by the myriad of offerings of newer trials and non-evidence-based practices. A section of the CPG of interest to practitioners will be that on Complementary and Alternative Medications (CAM) in ASD. The current guidelines serve as a quick reference, containing updates on an array of CAM that elucidate current and graded evidence regarding controversial treatment modalities and investigations in ASD. Nutraceuticals, gluten-free casein-free diets (GFCF diet) and neurofeedback remain popularly explored by parents and patients locally. Evidence-grading revealed that many of these more popular treatments are still based on limited evidence without well-conducted trials. Use of such treatments were hence not supported in the CPG, which also highlighted some of these as having potential for harm. What remains the “grey zone” would be what constitutes agreed “evidence” for parents—who are happy to buy

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any hope for improvement or cure based on anecdotal evidence or observational studies. Physicians should uphold professional standards and serve to gatekeep against unsafe, ineffective and costly, or unethical business-driven practices in CAM, so that parents can draw informed decisions.

The CPG also offers evidence-based reviews and recommendations on newer pharmacological treatments in co-occurring conditions, as well as in the treatment of core symptoms. What is encouraging within the past 10 years is the proliferation of newer drugs and pharmacological trials, based on theoretically hypothesised mechanisms in the treatment of ASD. What is disappointing is that many of these studies are inconclusive or as yet of insufficient evidence and can only be explored on a research basis or on selected patients, than larger populations. However, in the spirit of science—we must bear continued hope of emerging research—where initial empirical evidence can be combined with good pathophysiological explanations for newer treatments. This is especially important in children with severe features.

Timely with the publication of this CPG is the Singapore government's announcement of an expansion of early intervention services for young children who have been found to have ASD and development needs.⁷ Although the CPG has outlined various evidence-supported developmental and behavioral approaches—very often parents will still bring a query of “which therapy is better” and “is my child's therapy enough?” These questions will never be well answered because many of these therapies have not been compared, and often it is not possible for these studies to be directly comparable at all. Because ASD is a complex disorder and each child's intervention requires setting unique goals—it is rather impossible for a single metric to demonstrate a single program's superior efficacy or improvements.⁸ Instead, we should balance the ramping up of services with providing professionals with training in many of the evidence-based approaches—so that the quality of care we provide to children is always of high quality. This should happen across government and privately-run early intervention centres, and it is our duty to the children and families that we do so.

Despite all our national efforts, resource-limitations remain for professionals serving the children, and the state, requiring newer government efforts to ramp up capacity and increase subsidies.⁹ Additionally, even if professionals adopt high-quality evidence programmes—no good can be done if our services continue to lag behind

demand and there is inequity in service access. In addressing these treatment gaps, we could shift towards equipping parents with core skills, or parent-mediated ASD intervention for core symptoms in young children with ASD. Delivery models can also address treatment gaps, and novel models—e.g. adopting modalities including telehealth—can fill in intervention dosing gaps and can address long therapy wait-times and could also be cost-effective.¹⁰ These solutions are also now part of further evaluative studies in Singapore. Additionally, efforts have been invested in looking at the global functional outcomes of children receiving early intervention¹¹—so that we can understand better their clinical progress and measure accurately the child and the family's functional outcomes. Hopefully the future will hold promise on how different children with different clinical trajectories can allow the care and intervention goals to be more customised, with a view to better adult outcomes.

A lifespan perspective to supporting ASD individuals and their families is highlighted as important in the CPG—including transition planning for adolescents to adulthood and community living. Additionally, holistic needs of these individuals across the entire lifespan need to be addressed, including adaptive functioning and emotional wellbeing, in addition to academic achievement. This will maximise the quality of life of the individual on the autism spectrum in the long run. The latest Enabling Masterplan 2030, which is a roadmap to support persons with disabilities to enable their inclusion and contribution—mirrored the need for these recommendations to be implemented through a few strategic themes. For example, a new taskforce will study community living models for these individuals, as well as employment options for them in adulthood. The College of Family Physicians in Singapore is also equipping general practitioners through a course in caring for individuals with intellectual disabilities and ASD. Special education schools continue to expand in capacity, equipping children with the necessary skills for adulthood, while mainstream schools will be better resourced for manpower and specialised interventions for children with additional needs.¹²

Our work on an inclusive society towards individuals with ASD is not done. This latest CPG, commissioned by the College of Pediatrics and Child Health, reveals the continued passion and compassion of clinicians and professionals to drive the sector collectively and progressively. These guidelines should not simply be an evidence document, but hopefully become actively adopted and implemented in our services and care for these children and families.

Keywords: adolescents, autism spectrum disorder, children, clinical practice guidelines, evidence, paediatrics

Disclosure

No conflict of interests to declare.

REFERENCES

1. Zeidan J, Fombonne E, Scora J, et al. Global prevalence of autism: A systematic review update. *Autism Res* 2022; 15:778-90.
2. Wong CM, Aljunied SM, Chan DWL, et al. 2023 Clinical practice guidelines on autism spectrum disorder in children and adolescents from the Academy of Medicine, Singapore. *Ann Acad Med Singap* 2024;53:241-52.
3. Ministry of Health, Singapore. Autism Spectrum Disorders in Pre-school Children: AMS-MOH Clinical Practice Guidelines 1/2010. https://www.moh.gov.sg/docs/librariesprovider4/guidelines/cpg_autism-spectrum-disorders-pre-school-children.pdf. Accessed 6 April 2024.
4. Koh HC, Lim SH, Chan GJ, et al. The clinical utility of the modified checklist for autism in toddlers with high risk 18-48 month old children in Singapore. *J Autism Dev Disord* 2014;44:405-16.
5. Zheng RM, Chan SP, Law EC, et al. Validity and feasibility of using the Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F) in primary care clinics in Singapore. *Autism* 2023 Oct 26 [Epub ahead of print].
6. Kuo AA, Etzel RA, Chilton LA, et al. Primary care pediatrics and public health: Meeting the needs of today's children. *Am J Public Health* 2012;102:e17-23.
7. Ministry of Social and Family Development, Singapore. Committee of Supply debate—Strengthening early intervention and special education support, 6 March 2024. <https://www.msf.gov.sg/media-room/article/budget-2024>. Accessed 6 April 2024.
8. Volkmar FR, Reichow B, Doehring P. Evidence-Based Practices in Autism: Where We Are Now and Where We Need To Go. In: Reichow B, Doehring P, Cicchetti DV, Volkmar FR, editors. *Evidence-Based Practices and Treatments for Children with Autism*. New York: Springer NY; 2011.
9. Ministry of Social and Family Development, Singapore. Enhanced early intervention: better support for children with developmental needs, 28 Jan 2019. <https://www.msf.gov.sg/media-room/article/Enhanced-Early-Intervention-Better-Support-for-Children-with-Developmental-Needs>. Accessed 6 April 2024.
10. Sia IKM, Kang YQ, Lai PL, et al. Parent coaching via telerehabilitation for young children with autism spectrum disorder (ASD): study protocol for a randomised controlled trial. *Trials* 2023;24:1-13.
11. Ministry of Education, Ministry of Social and Family Development, and Early Childhood Development Agency, Singapore. Developmental and psychoeducational assessments and provisions for preschool-aged children—Professional Practice Guidelines, 2021. www.ecda.gov.sg/docs/default-source/default-document-library/parents/guidelines-for-professionals-2021.pdf. Accessed 6 April 2024.
12. Ministry of Social and Family Development, Singapore. Enabling Masterplan 2030. [https://www.msf.gov.sg/docs/default-source/enabling-masterplan/emp2030-report-\(final2\).pdf?sfvrsn=8032eb4d_3](https://www.msf.gov.sg/docs/default-source/enabling-masterplan/emp2030-report-(final2).pdf?sfvrsn=8032eb4d_3). Accessed 6 April 2024.