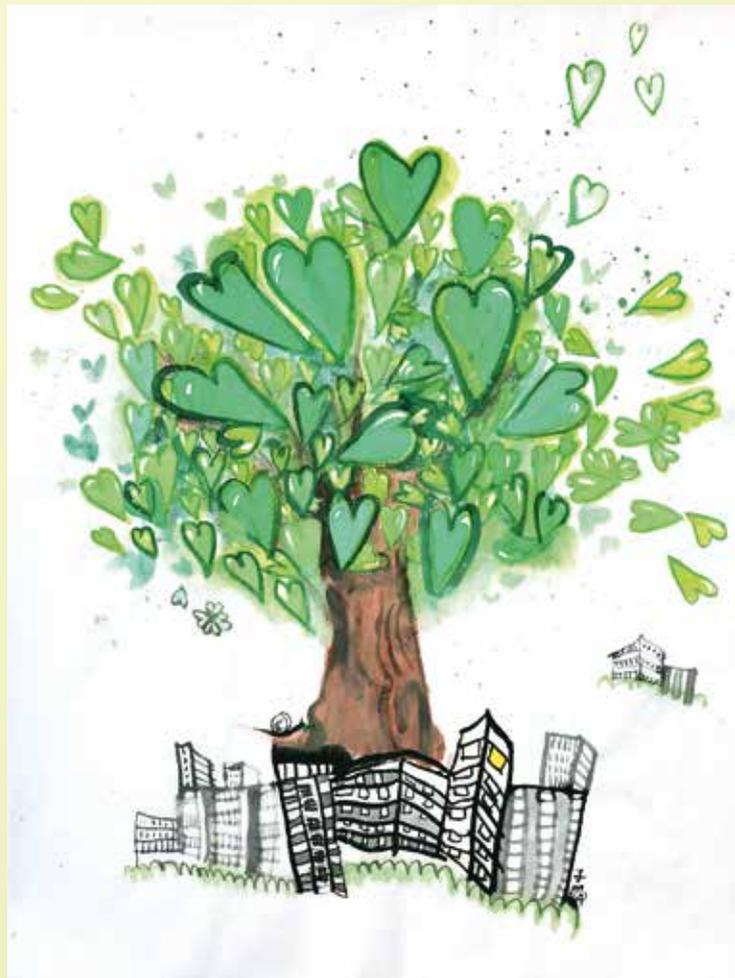


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Special Issue on Autism Spectrum Disorder



香港兒童腦科及體智發展學會
The Hong Kong Society of Child Neurology and
Developmental Paediatrics





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May 2021 Volume 20 No.1

Special Issue on Autism Spectrum Disorder

CONTENTS

	page
Message from the Editor-in-chief Dr Kwing Wan TSUI	1
New Conceptualization and Diagnostic Considerations of Autism Spectrum Disorder Lorinda LAM, Dr Catherine LAM, Wendy LAI	3
TEACCH & SCERTS – Good Friends in Enhancing the Learning and Social-Emotional Development of Children with Autism Spectrum Disorder Natalie YT TSUI	9
Overview of the JC A-Connect School Support Project – A School Support Project for Students with Autism in Hong Kong Mainstream Schools Hannah MY TSE, Kathy WONG	18
Employment Support for Youths with Autism Spectrum Disorder Vergo CHENG	23
What Did We Learn From the Grown-ups? A Decade On Chi-yan WONG	30
Emotional Problems and Psychological Treatment for Children and Adolescents with Autism Spectrum Disorder Sophie YY CHEUNG	36
從穩態失衡到理想穩態 — 自閉症譜系障礙動態發病機制與干預新理念 鄒小兵 汪瑜 李妍 朱繪霖	42
封面背後的成長故事 — 別低估自己的能力 子舜媽媽 Anita	52

The Hong Kong Society of Child Neurology & Developmental Paediatrics

EDITOR'S NOTES for the May 2021 Issue

BrainChild on Autism Spectrum Disorder – Editorial

Dr. Kwing Wan TSUI

In this issue of BrainChild, our Society will bring you articles on updates of Autism Spectrum Disorder (ASD).

The term “autism” was first used by a Swiss Psychiatrist Eugen Bleuler in 1916 when he was describing symptoms of schizophrenia. In 1940s, Leo Kanner and Hans Asperger adopted “Early Infantile Autism” and “Autistic Psychopathy” as diagnostic label for a group of children with abnormal communication, social interaction and rigid / stereotyped behaviour, respectively. However, many people still viewed autism as an early onset form of schizophrenia. It was not until late 1970s that consensus was reached to separate autism from schizophrenia and “Infantile Autism” was first published as a distinct diagnosis in DSM-III in 1980. Over the past decades, autism and its related disorders underwent various revisions in nomenclatures and diagnostic criteria. Most recent DSM-5 published in 2013 finalized a single term “Autism Spectrum Disorder” to describe children with difficulties in social communication and presence of restricted, repetitive behaviours.

Change of the diagnostic criteria and increased awareness might explain the progressively rising prevalence of ASD. CDC reported 1 in 54 8-year-old children of the USA was identified with ASD in 2016 and similar trend was observed in many parts of the world, including Hong Kong. Despite the recent advance in molecular genetics confirming the strong neurobiological basis in ASD, we have not yet identified a biological marker which can make diagnosis of the condition more straightforward. Like other neurobehavioural disorders, a multidisciplinary approach is often required for assessment and management of the associated neurophysiological impairments, physical dysfunctions and psychosocial difficulties. The multidisciplinary team involves child psychiatrists, paediatricians, clinical psychologists and educational psychologists, occupational therapists, speech therapists, physiotherapists and social workers. The process of care can be resource demanding and time consuming. The service provisions are also beyond medical and educational needs since vocational counseling and support are often needed for grown-ups with autism. Besides, we need a strong advocacy for education of public to understand the condition, timely access to diagnosis, assessment and management, provision of special needs in education and equal opportunity in opening employment.

Articles in this issue cover various important topics from review of neurobiology of ASD, new conceptualization of ASD, management in children and grown-ups, TEACCH as an evidence-based treatment of ASD core impairments, treatment of associated emotional problems to school and employment support. After reading these articles, I wish you will have better understanding of ASD in modern terms and support these children with your own field of expertise.

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I would like to thank all the authors who contributed to this issue of BrainChild and members of the editorial board who spent their valuable time and efforts to make publication of this issue successful.

Last but not the least, my special thanks to Anita, mother of a teenager with autism for sharing their story and allowing us to use her son's painting as cover picture of this issue of BrainChild.



Dr. Kwing Wan TSUI

President

The Hong Kong Society of Child Neurology and Developmental Paediatrics

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New Conceptualization and Diagnostic Considerations of Autism Spectrum Disorder

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The understanding of autism spectrum disorder (ASD) has undergone revolutionary changes from a severe psychotic disorder to the current view as a neurodevelopmental disorder which involves neurocognitive developmental factors including social and language impairments and a variety of compulsive, repetitive and stereotypic activities.^{1,2} These re-conceptualizations resulted from the expansion of an epidemiological approach in child psychiatry and developmental psychology, along with the growth in genetic and neuroscience research and findings.

In their review on issues related to the diagnostic classifications in ASD, Lord & Jones pointed out that despite past decades of effort in understanding the genetics or neurobiological underpinnings of ASD, findings on neurobiological causes for ASD remained diverse and lacking in specificity to behavioural dimensions of ASD. Given the lack of reliable biomarkers, diagnosis of ASD must be made based on behavioural manifestations.^{3,4}

Overview of the DSM-5 and ICD-11

Diagnostic and Statistical Manual of Mental Disorders (DSM) and International Classification of Diseases (ICD) are two major diagnostic systems internationally adopted in making diagnosis of autism. Over the years, researchers found that the previous categorical Autism Spectrum Disorder groupings in DSM-IV-TR or ICD-10 were not consistently applied across clinics and treatment centres, and the move from using previous clinical categorical diagnoses to unified dimensional descriptions of core features of deficits in social communication, restricted behaviours and cognitive flexibility was made to improve diagnostic accuracy and better reflect the state of knowledge about autism.³

Both classification systems have undergone review and new editions were made. The Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-5)⁵ was released in May 2013, whereas The World Health Organization (WHO) released the 11th revision of the International Classification of Diseases (ICD-11) on 18 June 2018.⁶ The two international diagnostic classification systems have made several major changes regarding the diagnostic criteria for autism in their new editions that reflect a reconceptualization about the disorder from a new perspective. In the following, we will outline the major changes of diagnostic criteria in DSM-5, followed by a comparison of DSM-5 and ICD-11.

Major changes in the diagnosis of ASD in DSM-5

i) Umbrella term

In the newly revised DSM-5, the diagnosis “Autism Spectrum Disorder” (ASD) has

been introduced to replace the prior category of “Pervasive Developmental Disorders” in the DSM-IV-TR. The various categorical diagnostic subtypes of Autism Spectrum Disorders, namely Autistic Disorder, Asperger’s Disorder, Childhood Disintegrative Disorder and Pervasive Developmental Disorder not otherwise specified (PDD-NOS), are now subsumed under the single umbrella diagnosis of ASD. The NOS Categories was removed as it was unspecific and often ambiguous for diagnostic purposes. Given its single-gene aetiology, Rett’s Disorder was removed from DSM-5, although an individual with this genetic condition would still receive an ASD diagnosis, probably with a specifier, if the diagnostic criteria for ASD are met.⁷

ii) Triadic to dyadic approach in diagnosis

In DSM-5, diagnostic domains were reduced from three to two, focusing on social communication and social interaction deficits (Criteria A), as well as restricted, repetitive patterns of behaviours, interests, and activities (Criteria B). Social communication and social interaction are combined into one category under DSM-5, in recognition that communication is necessarily social in nature.⁸ For a diagnosis of ASD, individuals must display all the three kinds of social and communication deficits listed under criterion A, and they are pervasive and sustained, and must be manifested across multiple contexts.

iii) RRBs and Sensory Processing Problems

Another major change in DSM-5 was that it has included atypical sensory responsiveness (hyper- or hypo- reactivity to sensory input) or unusual interest in sensory aspects of the environment as one of the four possible elements of which two must be met under domain of restricted, repetitive patterns of behaviour, interests, activities (RRB)⁸. Although atypical responses to sensory stimuli were also reported in people with intellectual disability and other neurodevelopmental disorders,⁹ these responses were more common in ASD group compared to the special educational need group. Occurrence of potential sensory abnormalities is now incorporated as behavioural symptoms in Criteria B. In validation study of proposed DSM-5 criteria for ASD by Frazier et al,¹⁰ adding sensory sensitivities and unusual interests as a RRB criterion improved sensitivity (0.81 versus 0.78) without substantially altering specificity. Sensitivity to high-functioning ASD could be maximised by including sensory sensitivities or unusual sensory interests.

iv) Age of onset

DSM-5 had eliminated strict age criteria that required delays in social interaction and communication to be apparent before age 3 years. Instead, the onset of these symptoms in the “early developmental period” was enough to fulfil the criteria. In DSM-5, it has emphasized that some symptoms may not be fully recognised until social demands exceed their capacities, or they may be masked by compensatory strategies in later life. Besides, diagnostic criteria may be met when restricted, repetitive patterns of behaviours, interests, or activities were clearly present during childhood or at some time in the past, even if symptoms had subsided at the time of diagnosis. This amendment has recognized that for

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some individuals, symptoms or characteristics may be prominent in early years but they improve at later development.

v) *Specifiers*

List of “Specifiers” includes recording the severity of cardinal symptoms, the current language and intellectual ability and the presence of concurrent genetic, medical or environmental condition to further describe the symptomatology or the subtyping of the population. By doing so, it helps to facilitate the formulation of the management plan to the individual with such heterogeneous nature.

Language impairment is no longer included in the diagnostic criteria, but is included as a specifier. This radical change is the recognition of language delay is not specific to ASD and the language abilities of children with ASD are found to be varied and highly correlated with other factors such as their intellectual functioning.³

The severity levels of cardinal symptoms are recorded through classifying the amount of support that the autism condition required in each of the 2 cardinal symptoms, which ranged from one to three on a scale. The three levels are namely Level 3: Requiring very substantial support; Level 2: Requiring substantial support; and Level 1: Requiring support.

The addition of a system of specifiers is a valuable contribution as it allows the recognition of essential shared features of the autism spectrum condition with various individualized characteristics.

Dual diagnosis:

Finally, in DSM-5, comorbidities with other neurodevelopmental, mental or behavioural disorders are recognised, thus, it is possible for an individual to receive dual diagnoses for ASD with another neurodevelopmental disorder (for examples, Attention Deficit/Hyperactivity, and Anxiety Disorders) if diagnostic criteria of both conditions are met.

Similarities and Differences of DSM-5 and ICD-11

Overall, the concepts of ICD-11 on autism are basically similar to that of the DSM-5. In ICD-11, similar to DSM-5, ASD is characterized as a neurodevelopmental disorder. It emphasizes that individuals exhibit difficulties from birth onwards and its cause is often situated neurologically at birth. The onset of the disorder occurs during the early development and persists but may not be fully manifested until later when social demands exceed limited capacities. Individuals along the spectrum may exhibit a full range of intellectual functioning and language abilities, and may have associated known medical, genetic or environmental factors or other neurodevelopmental, mental or behavioural disorders. Deficits or the presented core symptoms must be sufficiently severe to cause impairment in personal, family, social, educational, occupational, or other important areas of functioning.

Both manuals put autism, Asperger syndrome and pervasive developmental disorder not otherwise specified into a single umbrella category called ‘Autism Spectrum Disorder.’ Both highlight impairments in two broad realms — social communication, and restricted interests and repetitive behaviors as characteristic of the condition.

Although both new editions have advantages over the old one in terms of improved specificity and sensitivity by removal of the separate diagnoses, much concern has been raised if individuals who do not fully meet the current revised DSM-5 or ICD-11 diagnostic criteria may be denied of necessary support, especially in countries where specific medical diagnosis is required for intervention. However, DSM-5 explicitly states that individuals with well-established DSM-IV diagnosis of autistic disorder, Asperger’s Disorder, or pervasive developmental disorder not otherwise specified, should be given the diagnosis of autism spectrum disorder.¹¹

In the DSM-5, there is a diagnosis of Social Communication (Pragmatic) Disorder which may include individuals who only present symptoms on the domain of social communication deficit (Criteria A), but do not present symptoms of restricted patterns of behaviours, interests and activities (Criteria B). For the ICD-11, it also includes a category characterized mainly impairment in pragmatic language under the section on developmental language disorder which echoes the DSM-5 Social Communication (Pragmatic) Disorder.¹¹

Regarding the differences between the two diagnostic systems, the ICD-11 diverges from the DSM-5 in significant ways. One major discrepancy is that ICD-11 makes no mention of sensory abnormalities such as over- or under sensitivity to sound and tactile, whereas the DSM-5 has included them under the core diagnostic criteria (Criteria B), given its high prevalence rate among individuals with autism.¹¹

On severity classification, the ICD-11 listed eight subcategories of autism to specify whether an individual with autism has comorbid disorder of intellectual development, together with the level of functional language and impairment. It is similar to the DSM-5 specifiers but provides greater detail. This system of specifiers enables the recognition of essential shared features of the autism spectrum condition while also attempting to individualise diagnosis through dimensional descriptors.¹² As such, a single categorical diagnosis will be complemented with a clearer symptom description and impairment measurement.

Validity of ASD as a unitary concept

A large body of research has emerged over the past decades to inform our understanding of how behavioural, cognitive, social and emotional competencies emerge and change across development trajectories. Much is also known about their underlying neurobiological bases, and how they can go awry and manifest as psychopathology.

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The validity of a unity concept of ASD with co-occurrence of separate subdomains of impairment has been argued in view of the current state of ASD research findings which reveal the disorder's heterogeneous clinical presentations and aetiologies vary across individuals, developmental trajectories and outcomes.¹³ Genetic architecture of individuals with ASD differ from one individual to another, requiring further refined analysis of individual variations in connections between brain and behaviour.¹⁴ Complex combinations of multiple genetic and environmental factors needed to be resolved. Heterogeneity of risk factors, brain impairment and non-diagnostic symptoms in ASD individuals remain to be explained. Moreover, understanding the high rate of comorbidity (e.g. anxiety disorders, mood disorders and Attention Deficit/Hyperactivity Disorders) in ASD also remains limited. This high level of comorbidity could be attributable to similar or associated risk factors, or the occurrence of one disorder increasing the risk of another disorder (i.e., sequential comorbidity). As such, support for the neurobiological and construct validity of ASD diagnostic criteria and ASD spectrum features has been increasingly called to question.¹⁵

In 2008, the National Institutes of Mental Health (NIMH) proposed a Research Domain Criteria (RDoC) initiative which aims to understand complex mechanisms of linkages between brain-behaviour association and time courses of mental health disorders, including ASD, through observable behaviors and neurobiological measures that are dimensional in nature.^{16,17,18} It provides a research classification approach based on neurobiology and observable behaviour, and integrates different levels of information (from genomics and circuits to behaviour, and self-report) to explore basic dimensions of functioning that span the full range of human behaviour from normal to abnormal.^{19,20}

Under the RDoC framework, the current definition of ASD is a somewhat arbitrary and ill-defined clustering of symptoms that is not necessarily closely related in terms of neurobiology, given its phenotypic heterogeneity. Specific brain regions have been found to be associated with deficits in social perception, cognitive impairments and still others have been linked to circumscribed interests.²¹ Similarly, some neurobiological bases might be shared among other disorders but then go in different developmental courses. A number of RDoC constructs are relevant to impairments that are common in ASD, including social processing (e.g., social communication, social attention, joint attention, perception and understanding of others), negative valence systems (e.g. fear, anxiety, and reward circuitry dysfunction), positive valence systems (e.g. initial and sustained response to rewards), and cognitive control (e.g. executive functions, such as response selection, and inhibitory control). The long-term goal of the RDoC initiative is to establish a research database that will allow for multimodal dimensional classification of traits related to psychological and biological systems, and to foster research into the development of novel and effective intervention approaches that target these dimensional traits.^{21,22}

With the parallel developments of RDoC for understanding ASD and the revised conceptualizations DSM-ICD diagnostic classification systems, large-scale research

programmes on ASD may be scaffolded and cascaded. A biologically valid, reformulated classification, instead of categorical diagnoses may help guide the discoveries of the neurobiological basis of psychopathology, and ultimately help diagnosis, prevention, treatment, and cure.

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TEACCH & SCERTS – Good Friends in Enhancing the Learning and Social-Emotional Development of Children with Autism Spectrum Disorder

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Introduction

With difficulties in social communication, emotional regulation, learning and adaptation to new environments, it has always baffled educators how to teach children with Autism Spectrum Disorder (ASD). In recent decades, the Treatment and Education of Autistic and related Communication handicapped CHildren (TEACCH) and Social Communication, Emotional Regulation, Transactional Support (SCERTS) models have been used world-wide as educational frameworks to support the learning and overall development of children with ASD¹⁻³. Acknowledging that no one single approach can meet the diverse needs of children with ASD, Heep Hong Society has been adopting a combination of models and strategies, including TEACCH, SCERTS, DIR Floortime, Social Story, Sensory Integrative Therapy and Picture Exchange Communication System (PECS) in training children with ASD. Nevertheless, TEACCH & SCERTS are the two major models that have been widely and mostly used in our centres. In this paper, the effectiveness of these two models in helping children with ASD to learn will be reviewed. Frontline challenges on how to implement these two models in Special Child Care Centres (SCCC) and Early Education and Training Centres (EETC) will also be discussed.

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The Difficulties of Learning with ASD

Autism Spectrum Disorder (ASD) is a developmental disorder that poses various challenges to individuals living with it. Children with ASD show deficits in both verbal and nonverbal social communication, understanding and developing social relationships⁴. Furthermore, they demonstrate different degrees of severity in repetitive behaviours, restricted interests, rigidity, and hypersensitivity or hyposensitivity to sensory stimuli⁴. The word ‘spectrum’ in ASD implicates diversity in the type and severity of symptoms people experience. The variety of symptoms and levels of difficulty further pose challenges to teachers on handling children with ASD. In Hong Kong, children with ASD who are aged two to six with comorbidity in other special needs are often admitted to special education settings such as SCCCs and EETCs^{5,6}, depending on the severity of their symptoms.

The TEACCH system

To provide a framework for educators in helping children with ASD to learn, The University of North Carolina has introduced the programme TEACCH2. TEACCH is a ‘system’ that helps children with ASD to better comprehend, adapt and learn individually in class. The design of TEACCH is based on the idea that individuals with ASD have their unique ‘culture’ in thinking and acting⁷. This includes their relative strengths in processing

visual information, their difficulties in understanding time passage and sequencing of activities, their frustrations in handling changes in routines and environment, as well as their deficiencies in social communication. Through structured teaching and design of the environment, TEACCH provides children with ASD an easier way to understand what they have to do and learn independently⁸.

The three core components of TEACCH

TEACCH can be categorized as having three core components, which are listed in the figure below:

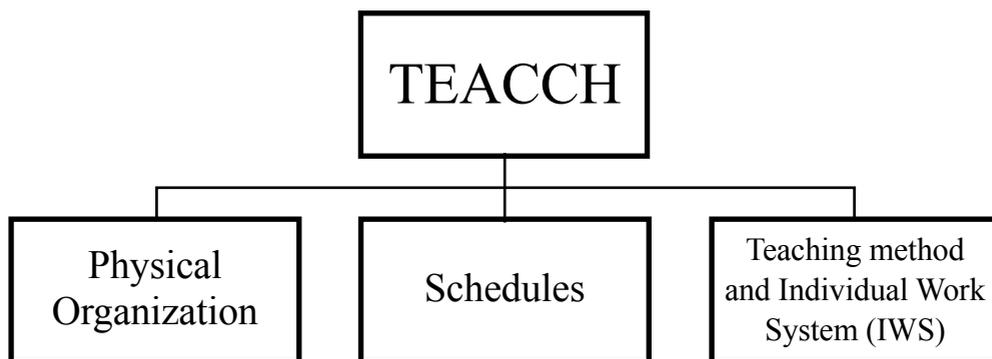


Figure 1. The Three Core Components of TEACCH

Physical organization refers to the design of a structured learning environment². In TEACCH, there should be clearly defined physical and visual boundaries between different corners in a classroom⁹. All teaching materials should be placed at their specific locations with visual cues all year round so that changes are minimized¹⁰.

Schedules in TEACCH illustrate the activities or lessons that children are going to have on a school day². They help children understand what activities to expect at different times of the day so they are being informed earlier about the changes that are going to take place. In class schedules, miniatures, photos, pictures or word cards may be chosen to represent an activity depending on the cognitive and literacy level of children¹⁰ (Figure 2).



Figure 2. Class schedules with different levels of difficulty (From miniatures to words)

Teaching method in TEACCH refers to the principle that teachers have to give clear instructions on ‘what to do’ and ‘how to do’². Children with ASD are usually more receptive to visual cues instead of auditory cues¹¹. Therefore, teachers should make sure they deliver their instructions in ways that children understand, such as using precise verbal prompts with clear visual cues.

Individual work system (IWS) in TEACCH helps children develop independent working skills by delivering their tasks in a structural and organized way². Teachers can make use of the IWS to design jigs (Figure 3) for children to consolidate various concepts and skills. In each jig, children should easily understand (1) what they are expected to do; (2) how many tasks or items they are expected to finish; (3) the sequence of tasks; (4) the criteria of finishing each item and (5) what they will gain upon the completion of all tasks¹².



Figure 3. Jigs in Individual Work System (IWS)

The use of TEACCH in SCCC and its effectiveness

Similar to what other researches suggested¹³⁻¹⁵, TEACCH yielded a very positive response from teachers and great effectiveness in helping children with ASD to adapt to their learning environment and follow routines. First, with clear physical boundaries and settings, children were able to explore different corners on their own. Second, schedules were helpful in helping children to understand the transitions going to take place in their school day. It reduced the discomforts children faced during transitions at school. Third, the structured teaching methods, especially the use of IWS, proved to be very effective methods in providing children opportunities to work on their own.

Filling in the gap – the addition of SCERTS

At frontline, it is indisputable that TEACCH has been a very effective approach in helping children with ASD to learn routines and work individually. However, teachers find children with ASD still struggling with social difficulties and behavioural problems sparked by their weak social communication skills and poor emotional regulation ability. To aid teachers in tapping on the social-emotional needs of children with ASD, the SCERTS model has been introduced.

SCERTS is an educational framework that can embrace various approaches, including TEACCH, PECS, Social Story and the Hanen Program¹⁶. While TEACCH focuses primarily on structured teaching to help children learn and work effectively, SCERTS is a much broader framework that aims to enhance children’s social communication skills and emotional regulation abilities¹⁷. In ‘SCERTS’, ‘SC’ stands for ‘Social Communication’, ‘ER’ stands for ‘Emotional Regulation’ and ‘TS’ stands for ‘Transactional Support’¹⁷. To help local teachers of SCCCs and EETCs better grasp the concepts of SCERTS, a flower pot diagram representing the general framework of SCERTS has been designed by Heep Hong Society:

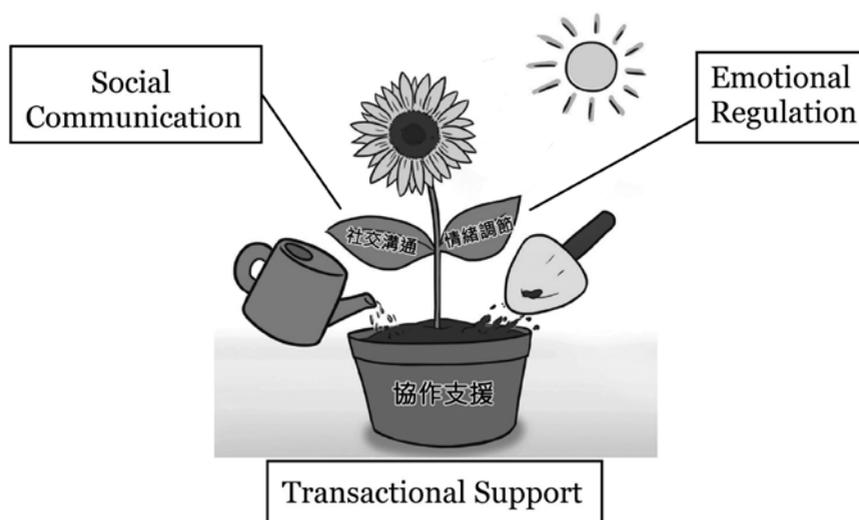


Figure 4. The SCERTS flower pot diagram of Heep Hong Society

In Figure 4, the sunflower represents each child with ASD, with two leaves representing the two core needs – SC and ER. Teachers, through transactional support such as interpersonal support and learning support, provide water, sunshine and soil to the flower so it can bloom¹⁸.

Social Communication (SC)

In SC, children with ASD show difficulties in two major areas – (1) joint attention and (2) symbol use¹⁷. Joint attention is an essential prerequisite of meaningful communication¹⁹. It refers to the ability to share attention on the same object or topic with others so as to achieve a meaningful interaction²⁰. Children with ASD usually have weaker joint attention than their same-aged peers²¹. Thus, their ability to engage in purposeful conversation with others is hampered.

Symbol use refers to the concept that children and teachers are using symbols they both understand to communicate with one another, such as the use of signs, vocalizations, pictures and verbal language¹⁷. When children can use symbols to communicate with others more effectively, they can expand their communication goals from simply requesting to sharing, inviting, commenting and more. Moreover, they can express their feelings using symbols instead of socially-inappropriate physical acts.

Emotional Regulation (ER)

Regarding ER, SCERTS focuses on helping children to regulate their emotional arousal. Furthermore, emotional regulation also covers maintaining an optimal level of arousal to help children stay focused in their learning¹⁷. Children can use visual aids or language to name the emotion they are experiencing and learn various coping strategies to help them regulate their emotions.



Figure 5. SCERTS Visual cue – ‘Emotion Ring’

Transactional Support (TS) - Interpersonal Support (IS) and Learning Support (LS)

TS refers to the support adults can provide to help children grow in social communication and emotional regulation. Under the SCERTS model, there are two major types of TS – Interpersonal Support (IS) and Learning Support (LS)¹⁷.

IS refers to any adjustments in the interactive styles adults can make in response to the needs of children with ASD¹⁷. Such adjustments can be found in the change in tone, diction, emotional expressions and social interactions with children¹⁷.

LS refers to the modification adults can make in the physical setting of children’s learning environment as well as the design of activities¹⁷. For instance, teachers can provide visual supports in children’s learning environment to foster their independence in communicating with others. They can also design activities that children find meaningful and engaging so as to improve their joint attention¹⁸. Besides IS and LS, support for families and support among professionals and other service providers are included in TS as well¹⁷.

The three partner stages of SCERTS

As individuals with ASD varied in their abilities and severity of symptoms, they can be categorized into three partner stages according to their language ability under the SCERTS

model. The three partner stages are (1) Social Partner Stage; (2) Language Partner Stage and (3) Conversational Partner stage¹⁵.

Social Partners are children who communicate through pre-symbolic nonverbal means¹⁷. The SC goal of social partners is to strengthen their initiation in communicating with others²². Teachers can teach them to use signs or gestures to communicate with others. For ER, the goal is to regulate emotions through behavioural strategies used by parents and teachers²².

Language partners refer to children who are communicating through early symbolic means, such as using verbal language of one to two-word¹⁷. The SC goal is to enrich their communication by broadening their bank of vocabulary and lengthening their speech²². For ER, language partners aim to employ behavioural strategies by themselves to regulate their emotions, such as choosing the coping strategy of ‘drinking a cup of water’ from the ‘emotion ring’ (a visual cue card with different coping strategies) when they feel angry.

Conversational partners can express themselves in sentences and conversational level discourse¹⁷. However, they may still be weak at turn-takings in conversation and following social etiquette. Therefore, the SC goal for conversational partners is to broaden their communication intents, as well as paying attention to paralanguage²². Concerning ER, conversational partners aim to employ behavioural, verbal and metacognitive strategies by themselves to regulate their emotions¹⁸.

The use of SCERTS in SCCC and EETC and its effectiveness

SCERTS is first promoted through a case-based approach. With the help of educational psychologists, teachers in SCCC and EETC select two children each year as ‘SCERTS cases’. Prior to the first SCERTS meeting, educational psychologists have to conduct class observations, whereas teachers, parents and therapists fill in different forms¹⁷ to gather information on the children’s background and level of communication.

In the first SCERTS meeting, psychologists, teachers and therapists discuss and review the needs of the cases. Next, they prioritise the goals and needs of each case and select relevant ‘SCERTS goals’ from the ‘Frequently Used Objectives & Transactional Supports’ list¹⁷. After selecting all the relevant ‘SCERTS goals’, the team brainstorms what practical strategies can be used under TS.

As each SCERTS case involves an in-depth analysis and close-monitoring of the child from a multidisciplinary professional team, it proves to be a largely effective way to enhance children’s SC and ER skills. More importantly, it provides teachers with fresh eyes to examine children with ASD. Rather than the traditional way of seeing children as a ‘trouble-makers’ and aiming to eliminate the problematic behaviours, teachers begin to see children as lacking skills and ways to appropriately express themselves. In recent years, this case-based approach has gradually faded out with the replacement of teachers trying to integrate SCERTS directly into their lesson designs.

Challenges of promoting the use of TEACCH and SCERTS to teachers and ways to tackle them

As TEACCH is a relatively straightforward and structured system, teachers find it easier to understand the concepts and integrate them into the school routine. However, different from the visible and structured TEACCH, SCERTS is a much more abstract framework that highly demands teachers' sensitivity and soft skills. To promote the use of SCERTS in centres, various strategies have been employed over the years, including (1) regular on-site support from the 'SCERTS Team'; (2) video-guided feedback and video-sharing; (3) regular trainings and knowledge exchange and (4) the launch of the implementation guide and the activity guide to help teachers integrating SCERTS into lessons.

Regular on-site support

To promote the use of SCERTS in centres, a 'SCERTS Team', which comprised of educational psychologists, speech therapists and occupational therapists, was formed. During the monthly visit to centres, team members conducted class observation and provided on-site support to teachers who were responsible for the selected SCERTS cases.

Video-guided feedback and video sharing

SCERTS accentuated the importance of a wide range of soft skills, which were very difficult to convey on paper or lectures. Teachers were encouraged to film their lessons for easier discussions. These videos were extremely useful in helping teachers view their interaction with the children clearly from a third-person perspective. They were also useful in another way that psychologists and SCERTS team members could provide video-guided feedback to teachers. The use of video-guided feedback came from the concept of Video Interaction Guidance (VIG), which had been proved to be an effective approach in helping individuals to reflect on their soft skills and make necessary changes²³. When promoting SCERTS in centres, SCERTS team members often selected clips that showed the effectiveness of using TS in achieving students' objectives so as to motivate teachers using such strategies in class.

Regular trainings and knowledge exchange

To ensure the implementation of both TEACCH and SCERTS are sustainable in centres, regular trainings to therapists and teachers who are new to teaching children with ASD have been conducted. Moreover, to keep up with the latest practices in both models, multi-disciplinary teams which included psychologists, therapists and SSCCW were sent to both USA and UK to learn the newest practices in both approaches.

Integrating SCERTS into lesson designs – The Implementation Guide and The Activity Guide

During the promotion of SCERTS in centres, many teachers held the misconception that SCERTS was a 'specific lesson' with its strategies only being used within a particular session. Therefore, an implementation guide (Figure 6) presenting the outline of using

SCERTS in class and an activity guide covering 60 activities have been published to provide teachers with ideas on how to integrate SCERTS within various lessons^{18,24}.

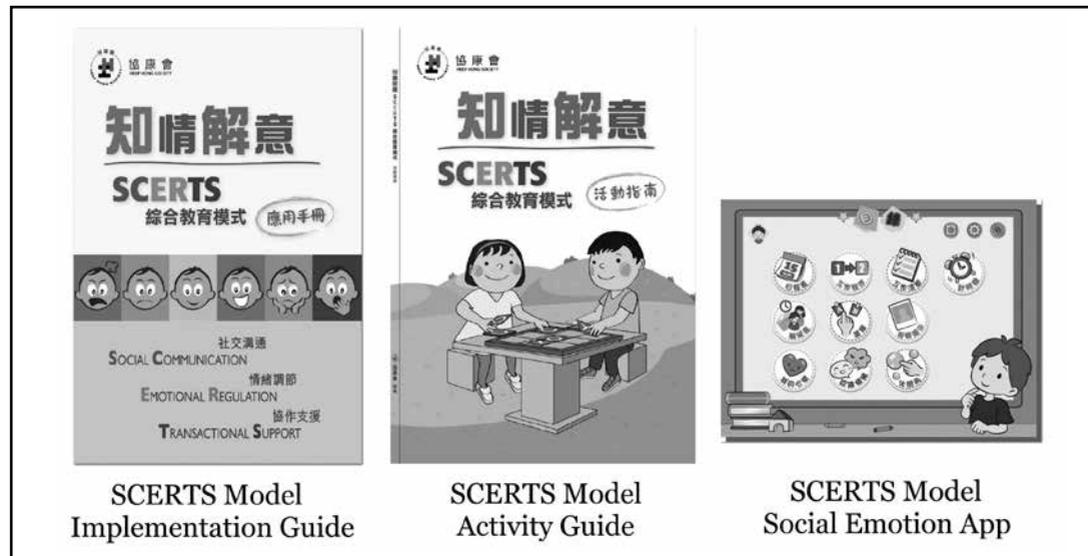


Figure 6. Resources on SCERTS published by Heep Hong Society

Conclusion

Both TEACCH and SCERTS have proved to be equally important models in helping children with ASD, with the former helping them to adapt to routines and changes, and the latter helping them to communicate meaningfully and learn to regulate their emotions. Promoting the use of both models in special settings is no easy tasks. Regular on-site support, cultivating a culture of video-taking and video sharing, integrating both models into the settings and curriculums are helpful to ensure their sustainability and effectiveness.

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Overview of the JC A-Connect School Support Project – A School Support Project for Students with Autism in Hong Kong Mainstream Schools

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Background

The number of people diagnosed with autism spectrum disorder (ASD) has increased rapidly throughout the world, and a similar trend has been observed in Hong Kong. The number of students with high-functioning ASD studying in Hong Kong mainstream primary and secondary schools is also increasing—from 7,713 in 2015/16, to 8,871 in 2016/17 and to 9,947 in 2017/18—i.e., an approximately 13% increase per year.

With this rising number of students with ASD, schools have expressed the need for more resources and expertise to provide support to these students, including small group training by personnel experienced with their needs, professional support for teachers and parents on how to help these students, and activities for the peers of these students to promote their understanding and acceptance.

Because of these service demands, we obtained funding from the Hong Kong Jockey Club Charities Trust to launch the JC A-Connect school support project (the Project) in September 2015. We aimed to enhance mainstream schools' support for students with ASD by implementing the Project with a three-year timeframe, i.e., from 2015 to 2018, through collaboration with the Education Bureau (EDB) and six non-governmental organizations (NGOs), namely, Caritas – Hong Kong, Heep Hong Society, SAHK, the Salvation Army, New Life Psychiatric Rehabilitation Association, and Tung Wah Group of Hospitals.

In view of the positive endorsement by and overwhelming demand from schools and parents, the Project has been extended for another three years to a second phase, i.e., from 2018 to 2021. We collaborated with two more NGOs, Hong Kong Sheng Kung Hui Welfare Council Ltd. and Hong Kong Young Women's Christian Association, in this second phase.

Since launching, the Project has provided training to more than one-half of the students with a confirmed diagnosis of ASD in approximately 50% of mainstream schools. For instance, in 2018/19, we served 7,764 students (of which 80% had a confirmed diagnosis of ASD) as well as their teachers and parents from 503 mainstream schools.

Project Features

The Project aims to enhance mainstream schools' support to students with ASD and to improve the capacity of the key stakeholders. The implementation of our Project is based on the latest practice guidelines for children with ASD^{1,2} with the following features:

1. Introducing the expertise of NGOs to schools by providing school-based services;
2. Providing supplemental training to a critical mass of students with ASD so that a significant number of schools would experience its benefits. The training is delivered in a small group format using evidence-based methods, where needs assessment and training goals are highly individualized. These training goals are critical for school adaptation, namely, skills in the social, emotional regulation and learning domains;
 - a. Requiring school personnel to assist in the group training, so they can observe the skills taught and help to facilitate transference in schools;
 - b. Providing teacher consultation and training seminars to facilitate support for students with ASD in the classroom and playground;
 - c. Providing parent consultation and training to foster home-school collaboration in supporting student development;
 - d. Conducting activities to promote inclusion in school;
3. Providing training and developing resources for participating NGOs and teachers to enhance their expertise to provide quality support to students with ASD.

19

School-based group training

Small group training is the backbone of our service delivery. These small groups are run by NGO-qualified trainers with at least 2 years of experience working with children with ASD. Each group has four to six students with at least 18 training hours per year. Our Project requires the same NGO to perform the training over these three years so that the training goals are planned in a spiral approach, and the systematic monitoring of student progress is conducted to continuously inform about programme effectiveness and the need for improvement.

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Before the group training, teachers complete the Student Profile Checklist for School Adjustment (“SPCSA”)³ to assess the learning, social and emotional skills of the participating students. Training objectives are set based on the needs of the students, as reflected by the SPCSA and from discussions with teachers and parents. The trainers would then set group goals based on the training objectives of different students in the group and customize individual goals for each student. The SPCSA is also used as a post-training measure for the continuous monitoring of students' progress and the revising of training objectives. By comparing the difference between pre- and post-training SPCSA ratings, both primary and secondary students are shown to have the most improvement in higher-order thinking, prosocial behaviour, social thinking and social problem solving.

Under the 3-tier support model (Figure 1) promoted by the EDB to support the diverse special education needs of students, our small group training serves as support at the tier-2

level. Using the tier-2 level as an entry point, with the support from the experienced trainers from NGOs, together with the capacity building of stakeholders in supporting students with ASD, support for students with ASD at tiers 1 and 3 will also be enhanced.

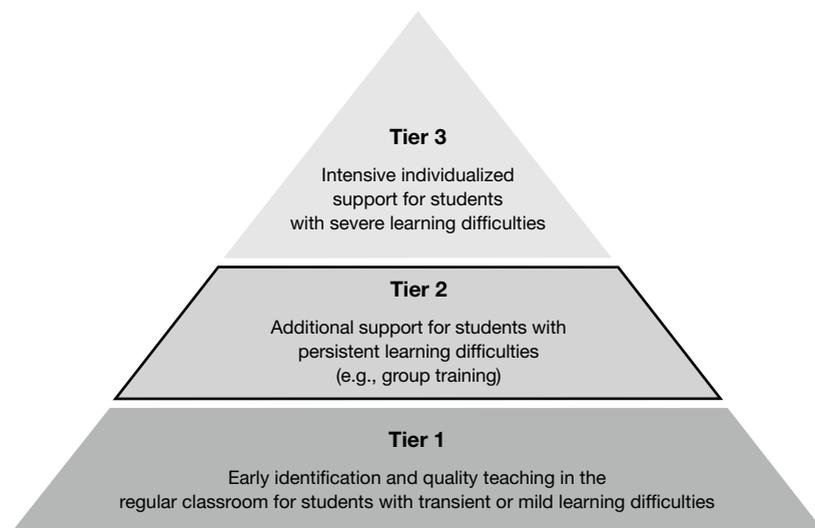


Figure 1. 3-tier support model adapted by the EDB⁴

20

Capacity Building

Another goal of our Project is to enhance the skills of teachers, parents and NGOs and strengthen their collaboration in supporting students with ASD. Capacity building for these stakeholders is essential for the effective transference of skills from training groups to daily life and to sustain support for students with ASD in the long run.

Schools and Teachers

Participating schools are required to dedicate one school staff member, usually a teacher or teaching assistant, to assist in the group training so that the school staff member can observe the skills used by the trainers during the training and help encourage the students to generalize the skills learned in the school environment. The trainers also provide consultation or staff development to school teachers to facilitate knowledge transfer to the organization level, i.e., the school. The Project team also conduct teachers' training workshops on supporting the needs of students with ASD for teachers who may or may not have joined this project.

Parents

The trainers also provide consultation to the parents of the students in their group through individual meetings or groups. Hence, the parents become familiar with what is taught in the training group within the context of their school.

NGOs

Similarly, we build capacity for NGOs in supporting students with ASD by working closely with the trainers and their advisory teams. The educational psychologists from our

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Project team and the EDB provide support through meetings, group observations and reviews of lesson plans. Workshops are also conducted on goal setting and the adoption of evidence-based strategies in group training.

Resource Development

The Project also aims to share the knowledge and experience gained with NGOs, teachers and practitioners in Hong Kong. We have developed numerous resources for supporting students with ASD.

Student Profile Checklist for School Adjustment-Short Form (SPCSA-S)

The SPCSA developed by the EDB comprehensively describes a list of 135 expected behaviours to assess the learning, social and emotional skills needed for the students to be adaptive in the classroom, which would be time-consuming for teachers to complete. Therefore, we developed the Student Profile Checklist for School Adjustment-Short Form (SPCSA-S) with local norms to help quickly inform intervention priorities and monitor training progress.

Resource Packages for the Group Training of Students with ASD

Together with our six partnering NGOs in the first phase, we published two resource packages—one for primary school and one for secondary school—in 2018. Each resource package consists of 13 books, including 12 resource books, each covering one domain on adaptive skills that students with ASD needed support with group training, 1 guidebook to provide an overview of how to use the resource books and implement the training programme, and 1 CD-ROM that contains the assessment tools and training materials. The resource books emphasize the use of evidence-based strategies in the training plans. They also cover the needs of ASD students in that domain and training plans that would help teachers and NGOs adapt and develop their own. The resource packages were distributed to all mainstream primary and secondary schools in Hong Kong. To facilitate the teachers in understanding and using the resource packages, we have been providing workshops by domain for school personnel. The feedback from schools has been very positive.

Chinese Writing Packages

Both schools and parents report that students with ASD need help in their academic learning, yet they find it difficult to develop training materials dedicated to learning due to a lack of resources and expertise. We, therefore, initiate the development of a training group on Chinese writing, which is an area in which students with ASD often face great difficulty and is crucial for school success and later school transition.

Our team of educational psychologists and Chinese teachers adopted the Self-Regulated Strategy Development (“**SRSD**”)⁵⁻⁷ model in developing our Chinese writing packages. The SRSD model is a cognitive strategy instruction approach developed to help students with learning disabilities improve their writing through six stages of instruction: 1. develop and

activate background knowledge, 2. discuss it, 3. model it, 4. memorize it, 5. support it, and 6. independent performance. It was shown to be effective in helping students with ASD⁸.

Two writing packages—one for senior primary school students focusing on narrative essays and the other for junior secondary school students focusing on argumentative essays—were developed and piloted in two primary schools and two secondary schools. The initial responses from teachers were positive. We are currently running a trial study of the writing curriculum in 11 primary schools and seven secondary schools. The curriculum will be published and distributed to all mainstream primary and secondary schools in Hong Kong in 2021.

Conclusions

With the funding support from the Hong Kong Jockey Club Charities Trust, our Project helps primary and secondary school students with ASD better adjust in mainstream schools. Given its success, the EDB will regularize the small group training upon our Project completion in 2021. Combining the capacity we build on individual levels (parents, teachers and NGO trainers) and organization levels (school and NGOs) with the training resources developed, it is hopeful that the support for these students will not only be maintained but also continue to improve.

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Employment Support for Youths with Autism Spectrum Disorder (ASD) in Heep Hong Society

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Introduction

Autism spectrum disorder (ASD) is a kind of neuro-developmental disorder. The manifestations vary among different individuals and also vary at different stages. Scientists found no single cause, but they believe that genetics and environment might have an interactive contribution to ASD¹. Two diagnostic criteria are listed in the Diagnostic and Statistical Manual of Mental Disorder (DSM-5), (i) persistent deficits in social communication and social interaction across multiple contexts; and (ii) restricted, repetitive patterns of behavior, interests, or activities². Broadly speaking, individuals with ASD have weak social reciprocity. Deficits in theory of mind (ToM) and central coherence contribute to their tremendous challenges in social communication. In simple language, people who have poor theory of mind have a hard time understanding others from others' perspective. On the other hand, weak central coherence suggested the limited ability in seeing a big picture or to process context-dependent information³. Public often find individuals with ASD challenging to work with, they are also perplexed by their behaviors and communication style. However, as the name suggested, individuals with autism do not have just one phenotype. Each person with autism has a distinct set of strengths and difficulties. Some require significant support in their daily lives, while others may need less support and, in some cases, live entirely independently⁴.

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ASD Youth and Employment Support

Challenges individuals with ASD encounter could be different at different ages⁵. Among the diverse needs, independent living, in particular employment, remains one of the top concerns. Some early studies on youth employment in western countries found that only about 8-22% of individuals with ASD were employed, and even a lower percentage of them pursued or completed higher education⁵. Even being employed, they still face various challenges. Hitches include but not limited to prioritizing job tasks, regulating emotions when receiving criticism, communicating with supervisor or colleagues, and reacting to sudden change of duties. In 2018, Heep Hong Society conducted a survey on "Employment Condition of Youths with ASD". The survey revealed that fewer than 50% of the interviewed ASD youths could keep their job for more than a year. 44% of the employers who hired ASD youths reported their inadequate understanding on ASD. Therefore, professional support for both the youth and the employer are crucial to create efficacious employment.

Jockey Club STAR Resource Center (JCSRC)

Heep Hong Society, being the leading education and rehabilitation organization, commits to helping children and youth with diverse needs. There are three units operated by Heep

Hong Society for youths: Support Centre for Persons with Autism (SPA), Jockey Club STAR Resource Center (JCSRC) and the Community-based Support Centre at the Integrated Service Complex (ISC). Each center has different service schemes to support youth with autism spectrum disorder. The Jockey Club STAR Resource Center will be introduced in this article.

The Jockey Club STAR Resource Center (JCSRC) at Oi Man Estate was established in 2015. It is funded by The Hong Kong Jockey Club Charities Trust (HKJC). The Centre has a variety of facilities catered for different training purposes such as a computer room for IT training, a simulated office for clerical training, a Star Café for catering training, a bedroom and washing machine for housekeeping training. JCSRC is the first one-stop comprehensive service center for children, youth, young adults with ASD and their parents. The word STAR is an acronym for four core values: Support (S), Training (T), Acceptance (A) and Respect (R). We believe that acceptance and respect are essential qualities to bring the society nearer to true inclusion.

24



With the premises and the sponsorship from the HKJC, we launched the “Employment Support for High Functioning Individuals with ASD and Their Parents / Caretakers” (星亮職訓) program, which benefitted 152 young people with ASD aged between 15 and 35 years of age. The project team has actively expanded the network of employers and employment opportunities for the participating young people. In view of the positive outcome, The HKJC continues their support and allowing JCSRC to launch another three-year project - “CHEER30” (飛悅30). In CHEER30, participants receive guidance in discerning their

career paths. Job-expo, company visits, and internship are arranged. Pre-vocational courses and specific vocational skills training workshops are designed for personal development. In addition to employment support, JCSRC also aims to help ASD youth by fostering their self-esteem, developing their potentials, enhancing their quality of life. Quality of life for individuals with ASD was found to be lower than that of typically developed individuals⁶. A positive employment experience is definitely a building block for a glow and shiny journey.

CHEER30 Project at JCSRC

The project consists of two working teams. An adolescent team that serves individuals age 6-15, and a youth team that serves individuals age 16-35. TEACCH® Autism Program led by Dr. Laura Klinger (UNC) and PEERS® by Dr. Elizabeth Laugeson (UCLA) are two core approaches we adapted to support youths with ASD. Heep Hong Society advocates the importance of support by a multi-disciplinary team, thus a collaboration effort from Clinical/Educational Psychologist, Occupational Therapist and Social Worker is readily available in CHEER30. The youth team's services consist of four components: Star Plus (星亮加油站), Star Club (星Club同樂會), Star Studio (星亮夢工場), and Star Net (星亮網絡).

Star Plus (星亮加油站)

Pre-vocational and vocational training programs are designed to improve their job skills, adaptive abilities, and prepare them to overcome obstacles arisen at work. To give more personalized and comprehensive support, CHEER30 admits 20 to 25 individuals as intensive cases. Youths who experience difficulties in sustaining their job and/or transiting from study to employment will be admitted with higher priority. Youths joining the intensive case support will be assessed on their communication skills, work motivation, problem solving ability, emotional stability, executive functions, motor skills, work skills, and occupational orientation. An individualized inclusion plan (IIP) will be co-generated by the multi-disciplinary team. Other support includes job-matching, conducting on-site job visits, hosting mock interviews, and liaising with the employer etc.

Star Club (星Club同樂會)

Star Club provides our youths with diversified leisure activities. We aim to develop their interests, facilitate them to establish friendship, and enhance their quality of life. Activities include but not limited to hiking, movie sharing, board game gathering, karaoke, and museum visits. Our youths have high participation in Star Club activities. They find it joyful not only because of the activity, but also for the fact that it is an occasion through which they could hang out with peers that share common interests. In addition, JCSRC locates freelancers or parents to host interest classes. Popular interest classes include but not limited to magic class, ukulele class, chess class, kendama class, yoga class, and latte art class. These interest classes often attract members across a wide age range and background. Many youths demonstrated high potentials in the classes. On the whole, Star Club is not merely for leisure, it is also a suitable and secure platform to refine our youths' social communication skills and emotion regulation ability.

Star Studio (星亮夢工場)

JCSRC also values the youths' voices. Star Studio is designed to build-up their self-identity. Self-Advocacy Group, Star Ambassador, Mentorship Program are examples of services. Self-Advocacy Group acts like a student council. The group will launch educational or leisure events for all the members. The group will also publish statements or stories to convey special messages to the public, aiming to raise the society's awareness on ASD. Two of our star ambassadors were arranged to share in an SEN Exhibition organized by University of Science and Technology (UST) on their views on romantic relationship. Through the participation in community education work in Star Studio, we hope the public can understand and recognize our youths' ability more. We also wish the youths could find out their own strengths and interests.

Star Net (星亮網絡)

As a parent resource center, JCSRC has a Resource Library allowing parents to borrow books, audio-visual materials, and board games for their children. They can also join Parent Peer Support Group and STAR Café Parent Volunteer Group to share their concerns and wisdoms with one another. In addition, parents can join stress reduction activities like Chinese Calligraphy and Yoga class; or mentoring event, like STAR Café Chef Tutor. At times, JCSRC will invite guest speakers to share in parent workshops or seminars on specific topics, for instance, “如何與青年子女談兩性相處” or “提升青年抗逆力”. We reckon parents are valuable resources. Empowering the parents allow them to enhance capacity for their own and create benefits of the youths.

Roles of Professionals

Successful strategies for employment support often come from multidisciplinary collaborative efforts^{7,8}. This is an advocate of Heep Hong Society, from the pre-school service to the young adult service. There are two social workers, one occupational therapist, two clinical/educational psychologists and one project assistant working in the youth team.

Social Worker

Social worker (SW) holds a significant role. SW serves as the case managers for each intensive employment support case. The SW has to familiarize with the job market and maintain stable network with various employers. SW also acts as the job coach for the youths, providing assistance and guidance. SW also works closely with parent to support the mezzo-system of our clients.

Occupational Therapist

Occupational therapist (OT) is mainly responsible for work skills related affairs. OT will conduct standardized tests to assess youths' motor ability as well as their vocational skills or occupational interest. OT will also host training groups targeting specific work skills, such as clerical class, or cooking class. Moreover, if OT is invited to an on-site job visit, she will put emphasis on the youths' skill set and the ability-task matching.

Clinical / Educational Psychologist

Clinical psychologist (CP) and/or educational psychologist (EP) serves the role of consultants. In individualized inclusive plan (IIP), they will oversee the holistic development of the case. For instance, the psychologist will give suggestions to the team and facilitate collaborative decisions on how to integrate the youth's personality, ability, interest, family dynamics and market vacancies. Psychologists also contribute in evaluating youths' communication ability, work motivation, and emotion stability. If a youth has emotional disturbance from work or at work, the psychologist will need to step in and support the case.

Benefits and Challenges of the Employment Support Project

With the support service from our professional team, youths become better equipped and more ready for employment. They also have clearer picture of their career path and development. The youths' stability of staying in a job has generally enhanced with the provision of vocational assessment (for identifying the youth's vocational interest and ability), internship, appropriate job matching, on-job coaching and support, as well as strengthened communication with the employers and/or the colleagues. One successful example is a youth who used to stay in jobs for no more than two months get employed as Project Assistant in the Educational University of Hong Kong. He came with low self-esteem and high anxiety in social communication yet became motivated and confident to take up IT tasks. He also develops skills in programming and coding. Another youth with an accounting degree had multiple negative working experience causing low self-confidence sustained his work at Food for Good as an Assistant Accounting Officer for more than two years after receiving training and counselling.

In the light of good fallouts of the employment support scheme, HKJC has continued their sponsorship on the employment projects at JCSRC. Nonetheless, the Project does not proceed without obstacles or hitches. The team has experienced three major challenges (i) employers' knowledge and attitude, (ii) the insufficient resources for job coach; and (iii) the difficulty in reaching the unidentified ASD youth.

Maintaining communication with potential employers is more difficult than one could imagine, not just because of the multiple returns of messages or phone calls, but the effort and time to educate them about the characteristics and way of communication of ASD people. In many cases, our youths got laid off not because of their job skills, but their coarse communication style. Some of the companies express their willingness to hire youths with special educational needs, but lack the knowledge and skill to support them. Some underestimate the required efforts and have little persistence and patience to embrace them in the squad. After all, the team discovers that job matching and skills training are important, but a good employer is somewhat the most critical factor for sustained employment.

With no doubt, social workers play a very important role in employment support. Yet, their heavy work load prohibits them to do more, especially the role as job coach. Even for

the intensive individual cases under Star Plus, the social workers could not manage to follow through the progress of each youth closely. Basically, it's almost impossible for our social workers to accompany them to work during the first week of employment. Yet, we know the first week of new employment life or transition of environment is the most challenging for our ASD youth. With inadequate manpower, we cannot effectively create a good tiered model in supporting our ASD youth with different level of needs, especially for those who need more support.

Another challenge encountered was recruitment difficulty. Fewer applications were received than that of the previous year, which gives us fewer choices to select for intensive case support. It was probably due to rising competition for youth participants as a result of the growing number of ASD projects for young adults in the market. However, we do see a large group of youth with ASD or other SEN in post-secondary settings. Youth with mild ASD symptoms and higher intellectual ability are not eligible for shelter workshops or supported employment. This group of individuals is the population that we are looking for. They certainly need some kind of help or boosters before they can gain employment in the open market. More promotion and recruitment work have to be done to reach this group of people.

28

■ Future Direction

To be fair, many companies and employers hire our ASD youth with good intentions. However, they often give no particular accommodation to them and expect them to perform well like typical individuals. It is undeniable ASD youths have their strengths. Yet, companies need to create a person-job fit environment, which allows the ASD youths to demonstrate their strengths. Making good use of their talents and strengths can increase the productivity of the company. Instead of hiring and treating them as an additional staff, we hope to see more employers treating them as an asset for the companies. There ought to be a paradigm shift in the market for true inclusive employment. Enhancing employers' inclusive employment readiness remains the top priority in our future work. Psycho-education on our youths' characteristics and tips on communicating with our youths will definitely help. Employers should also learn about the importance and benefits of giving accommodation for youths with ASD.

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On the other hand, having well-trained job coaches to support work transition and early phase of employment is essential. We hope our experience could have positive influence for the government and the market to consider making job coach a regular job positions and develop a systematic training mechanism for more job coaches to support ASD youths' employment.

Last but not the least, the recruitment and promotion strategy might need adjustment. Given increasing intake of students with ASD or other SEN in tertiary institutes like the Vocational Training Council, we will try to establish network with these tertiary institutes or

high schools. Young adults with ASD or other SEN who are academic low achievers or who have dropped out are less competitive among their peers. This group of people definitely needs employment support or career guidance.

With appropriate adjustment, youths with ASD could perform as well as or even better than typically developed individuals, given their high concentration, self-discipline and loyalty. If the Society, especially the employers, have a more inclusive mindset, it can make huge difference in facilitating ASD youths' employment. We look forward to providing continual support to our youth and employers.

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What Did We Learn From the Grown-ups? A Decade On

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SAHK launched a pilot project, the Supportive Programme for Adults with High Functioning Autism (HFA; 「吾懂人情」高能力自閉症人士支援服務) in 2009. It was the first initiative of its kind in the community at that time. The service model was adopted by the Social Welfare Department and served as the basis for the later Support Centres for Persons with Autism (SPAs). SAHK opened the first SPA ('True Colours' SPA; 「真色珍我」自閉症人士支援中心) in 2016. Together with the other four operators, SPAs are providing regular services to people with autism in the community.

Over the years, the two services of SAHK together have served more than 800 adults with HFA. Most of them were young adults within the age range of 15 to 30 years old (72%). There were more males (78%) than females (22%). The male to female ratio was similar to the one reported by the Centers for Disease Control and Prevention in the US¹. Over 70% of the service users had attained post-secondary education qualifications. More than half of them (68%) reported being at work at the time of data collection but most of their jobs tended to be temporary and unstable. Consistent with the study results in Western countries, co-morbid psychiatric conditions were common (38%) with anxiety disorders and mood disorders being the highest reported conditions, followed by other special educational needs (SENs) such as attention-deficit/hyperactivity disorder (ADHD) and specific learning disorder (SpLD)². Contrary to public perception, many of the service users were in a relationship, and about 6% were married with children³.

The year 2019 marked the 10th anniversary of the first community service for adults with HFA in Hong Kong. Behind the demographic data are the 800 true stories of our service users. Their challenges, frustration and journeys through the helping process all provide valuable information to our service. This paper is to consolidate the experiences of our clients and our staff team with the hope of contributing to the good practices in the field.

Identification and Diagnostic Issues

'My son was always a high achiever. He excelled in many subjects, especially Maths. He won several competitions, and was given a scholarship to pursue his Ph.D. studies in England. Things changed drastically after he came back to Hong Kong. Working in academia has been his dream all along. The universities were impressed by his academic achievements, but it seems he could never get through the interviews. He turned to teaching positions in secondary schools, but was terminated prematurely. Similar things happened in several schools. He then took up freelance jobs in a learning centre. He told me that he was complained by some parents, but he had no idea of how the complaints came about, not to mention how to make improvements. He has very few classes now, and spends most of his time at home. He's getting very quiet, but may burst into severe temper tantrums suddenly.

I'm really worried about him. One day I saw a programme on high-functioning autism. I felt like it's talking about him! With lots of persuasion, he finally agreed to seek help. We went through the assessment, and he was formally diagnosed (with high-functioning autism). When I look back, it all makes sense now...'

(Mrs. Au, a parent)

Jasmine was admitted to hospital after a suicide attempt by jumping off a height when she was 22 years old. She recalled she started cutting her wrist when she was a teenager. Jasmine has a very good memory and can be unusually persistent. She is proud of her logical (or one may say 'critical') thinking style as well as her musical 'perfect pitch'. However, it is this special thinking pattern coupled with her rather arrogant presentation style that stains the already few friendships she has. Jasmine was diagnosed as having depression and borderline personality disorder, and was on medication for over 10 years. It took her another five years before her ASD was finally uncovered

(Jasmine is a young woman with HFA)

The above excerpts are the vivid experiences of our service users and their parents/caregivers. Apart from the tears and frustration behind the stories, these excerpts also point out the challenges clinicians face in the identification and making diagnosis of adults with HFA.

31

1. Masked Symptoms

High intelligence, good academic results, and relatively few serious behavioural problems are all 'protective factors' that can keep youngsters with HFA unidentified throughout the school years⁴. However, they are not without difficulties. Many of the service users recalled being bullied at school without receiving support. They struggled through the academic and social demands in their own ways.

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2. Female Profile

Research results have shown that females may present with different ASD phenotypes⁵. They were found to exhibit fewer repetitive behaviours, and use more compensatory strategies such as mimicking their peers or escaping into fantasy to cope with the social demands⁶. While the existing diagnostic tools were largely developed based on the male samples, females with different ASD phenotypes might be screened out from the services they need.

3. Psychiatric Co-morbidity

Co-morbidity of other psychiatric disorders such as anxiety disorders and depressive disorders were frequently reported among people with ASD, especially those in the high-functioning group². It is not uncommon to find people being known to psychiatric services and receiving medication for years while the underlying ASD went undetected. There are also individuals who have presented concerns about ASD, but their concerns were either rejected or not addressed by the service providers. Clinicians in different service settings may need to increase their sensitivity of ASD and competency in making diagnostic assessment.

A Developmental Disorder needs a Lifespan Perspective

Similar to other developmental disorders, ASD service began with children and had predominantly focused on skills training such as social communication skills, sensory integration and learning skills. It was not until recent years that the government has begun to notice the needs of young adults, but the main concern has been to help them find a job. However, for the high-functioning group, their biggest challenge lies beyond job hunting.

'I worked in ten different schools since graduation 6 years ago. I started with a teaching position in a secondary school. I was terminated prematurely for failing to meet the requirements. I changed to another secondary school, but it was no better. I tried to make a new start in a primary school thinking that the workload may be more manageable, but the result was the same. I'm now a part-time teaching assistant in a kindergarten. I was just informed that my contract won't be renewed, and I have to find another job again. Many of my classmates whose academic performance was poorer than mine are now panel teachers. I'm still struggling in the junior positions.'

(Clara, a young adult with HFA)

32

Steve has been working as a computer programmer for more than 10 years. He knows it's impossible for him to get a promotion. 'Even if I accept staying in the same position without a pay raise, the company doesn't want to keep me. It prefers new graduates with lower pay. I have no choice but to keep changing jobs every three to four years. I don't know how long this can work... No employer is willing to hire a middle-aged junior staff...'

(Steve is a mid-30s adult with HFA)

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In addition to the work-related frustration, people with HFA gradually come to the realization that there is an increasing discrepancy between the so-called 'normal development' of their peers and their own as they move along the developmental path. Social difficulties are manifested in intimate relationships which require advanced perspective-taking, as well as reciprocal and flexible communication. Most of them are unaware of relationship problems, but are severely pressured by the constant demands of their intimate partners.

'My husband and I have been seeing family counsellors for over 10 years. I was repeatedly told that guys in a long-term relationship were like this, and I was asked to lower my expectations of him... Well... Things are not like that. He knows... literally (with a bitter laugh) that I want to have a deeper communication with him, but we just can't get there. Even a simple chat can end up in a fight. He goes round and round about the details which are not the gist of the conversation. I find it really exhausting. When I try to redirect the focus, I'm accused of going off-trail. He said he feels stressed about constantly meeting my demands. I feel frustrated too... by the lack of intimate communication between us, and I know we'll never get there.'

(Mrs. Wong, wife of a middle-aged man with HFA)

Being a parent can be extremely stressful for people with HFA. The unpredictable baby cries, disruption of their own routines, intimate interaction with the kids, and demands from the spouses about caring duties are all taxing for individuals with HFA.

We know little about older people with HFA in Hong Kong. Studies in Western societies came up with different results⁷. Some suggested better outcomes as the elderly were more socially isolated in general. This lifestyle is not new to people with HFA, and for the first time in their lives, they are leading similar lifestyles to their more ‘normal’ counterparts. Others suggested retirement that came with less structure might be difficult for older people with HFA. Unique to Hong Kong is its limited living space. People with HFA who need their own space may find old age homes or facilities overwhelming. Their needs, and how the elderly services in Hong Kong can support people with HFA are yet to be explored.

Beyond Skills Training

We know that HFA is a neurodevelopmental disorder. The difficulties it brings to the individuals are persistent and significant. Skills training undoubtedly enhances the individuals’ adaptive functioning. It is, however, not enough to help individuals with HFA to survive in a world with most of their counterparts using a more complicated social communication system and flexible thinking style. Over-emphasis on skills training also gives the distorted impression to people with HFA and their parents/carers that their impairments can be ‘corrected’. When they finally realize that their difficulties may never go away no matter how hard they try, anger and hopelessness set in, and many of them develop serious psychiatric disorders².

‘I started attending different training classes when I was two years old. I remember everything about the social stories, emotion thermometer... So what? The bullying never stops! Even now in the office, I know no one likes me. I have been eating out alone since I joined this company...’

(Rob, a young adult with HFA)

Learning from the experience of our grown-ups, it is time to go beyond skills training and incorporate components that may address their lifelong concerns.

1. Resilience Building

The essence of resilience is self-understanding, building up coping resources, and preparing for uncertainties⁸. While ‘difference is a fact’, we need to teach our children early on that the differences do not undermine their self-value. Just like everybody else, people with HFA have their strengths and weaknesses. The only way to create a fulfilling life is to make good use of their strengths and work hard to improve their limitations. Each of them is a spokesperson for HFA. What they say and how they behave do indeed make an impact on the community. Nevertheless, there will be people who do not like them. All they have to do is to help these people get an accurate understanding of HFA. After all, unpredictability

is a fact of life, no matter how much effort they have put in to build up the order, routine and structure in their everyday lives. We need to teach people with HFA to plan ahead, predict possible difficulties, build up internal and external resources to cope with the difficulties, and above all, manage their anxiety and frustration. Last but not least, resilience building is the most effective if it starts with children and is taught by the parents. It can become the motto that helps them get through the many hiccups in life.

2. Lifelong Learning Mindset

As the world changes, so do the individuals with HFA. No matter how comprehensive the training programmes individuals with HFA have received in childhood, there will be things they have not encountered as they travel along the developmental path. The prolonged experience of being service recipients coupled with their weakness in generalization may add onto their difficulty in coping with new situations. To facilitate people with HFA to lead a truly independent life, parents/carers need to instill a lifelong learning mindset in their children early on and build up a system with them about how it works. Specifically, people with HFA need to learn when and how to identify their own needs, research information and explore options, as well as understand the resources they can use, and the way to expand their resource network.

34

3. Co-creating a Sustainable Ecosystem

Efforts made by people with HFA alone may not be possible to bring about substantial change. Different stakeholders in the community should work together to co-create a sustainable ecosystem. Initiatives are taking place in different parts of the world. Technology companies like Microsoft and SAP have made revolutionary changes to the traditional hiring process that often screens out people with HFA despite their special talents. Their hiring programme has become a model in the field. Meanwhile, parents are supporting their adult children to set up new business models. Specialisterne, starting off as a software testing project in Denmark, has become a global business, providing training and consultation services to enterprises to help find suitable candidates with HFA and talents in digital technology. Green Bridge Growers is another successful business initiated by an individual with HFA and his mother. It uses aquaponics to grow produce and has changed the work environment in a local community in the US. Diversity Works is an award-winning project in Scotland, UK. It provides services to enterprises and graduates with diverse needs including HFA to find internship. In addition to enterprises and tertiary institutions, the project has the support from the government to create internship opportunities that benefit the community at large, such as providing manpower to the vast number of heritage sites that have been lacking of resources. The project creates a win-win situation for different stakeholders, which is a core factor for sustainable collaboration. There are more successful stories to come. Will the next one be from Hong Kong?

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Emotional Problems and Psychological Treatment for Children and Adolescents with Autism Spectrum Disorder (ASD)

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Abstract

Autism spectrum disorder (ASD) is one of the common developmental disorders affecting children and adolescents. In this article, the emotional problems of children or adolescents with ASD were reviewed. Clinical recommendations on assessment and treatment of these emotional problems were summarized. Specific modifications and adaptations in implementing cognitive-behavioural treatment (CBT) programs were also listed.

According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), autism spectrum disorders (ASD) are characterized by persistent deficits in social communication and interaction across contexts, as well as the presence of restricted interest, and repetitive or rigid patterns of behaviours¹.

Ghaziuddin reviewed literature and summarized that around 40% of individuals referred for an evaluation of ASD also suffered from additional psychiatric problems². Mukaddes and Fateh investigated psychiatric comorbidities of 37 children and adolescents attending a private psychiatric clinic in Turkey, and found the majority (94%) had at least one additional psychiatric disorders. The most common comorbid psychiatric condition was anxiety disorders (54%), followed by disruptive behaviour disorder (48%) and mood disorders (37%)³.

Emotional problems of children or adolescents with ASD

As summarized by White and colleagues, among individuals with high functioning ASD, anxiety and depression are the most common co-occurring emotional problems⁴. To further look into the issue, results of some meta-analyses or systematic reviews were summarized.

White and colleagues identified 40 studies investigating anxiety in children and adolescents with ASD. Results of their systematic review indicated that between 11% and 84% of children with ASD experienced some degrees of anxiety⁵. Van Steensel, Bögels, and Perrin further conducted a meta-analysis with 31 studies that involved individuals with ASD who were up to the age of 18. Results indicated that 36.9% of children and adolescents with ASD had at least one comorbid DSM-IV anxiety disorders, with the most frequently reported anxiety disorder was specific phobia (29.8%), followed by obsessive-compulsive disorder (17.4%) and social anxiety disorder (16.6%; See Table 1)⁶. Results of moderator analyses suggested that studies with a higher mean age also reported higher prevalence rates for anxiety in general and generalized anxiety disorder; while higher prevalence rates of obsessive-compulsive disorder and separation anxiety disorder were associated with studies that reported a lower mean age.

Meta-analysis	<i>k</i>	Prevalence(%)	CI (95%)	<i>Z</i>	<i>Q</i>	<i>P</i>
ANX						
Fixed	20	34.8	32.3-37.2	28.032		<.001*
Random	20	39.6	29.7-49.6	7.798		<.001*
Homogeneity test					293.662	<.001*
OCD						
Fixed	12	12.5	1.5-14.6	11.916		<.001*
Random	12	17.4	10.3-24.6	4.772		<.001*
Homogeneity test					120.366	<.001*
SOC						
Fixed	15	13.4	11.5-15.2	14.261		<.001*
Random	15	16.6	12.0-21.3	7.056		<.001*
Homogeneity test					74.403	<.001*
SPH						
Fixed	16	24.6	22.3-26.8	21.538		<.001*
Random	16	29.8	21.5-38.1	7.028		<.001*
Homogeneity test					194.823	<.001*
GAD						
Fixed	14	9.8	8.2-11.5	11.944		<.001*
Random	14	15.4	10.2-20.5	5.873		<.001*
Homogeneity test					105.075	<.001*
SAD						
Fixed	13	3.5	2.5-4.5	6.807		<.001*
Random	13	9.0	5.5-12.5	5.021		<.001*
Homogeneity test					85.022	<.001*
PAN						
Fixed	10	0.2	-0.1-0.5	1.074		.283
Random	10	1.8	0.6-3.0	2.979		<.003*
Homogeneity test					34.861	<.001*
AGP						
Fixed	5	9.2	6.4-12.0	6.422		<.001*
Random	5	16.6	6.7-26.5	3.290		<.002*
Homogeneity test					42.305	<.001*

Table 1. Results of the meta-analyses for the prevalence of anxiety disorders in children or adolescents with ASD⁶

Note: * $p < .01$; k = number of studies; CI = confidence interval; ANX = at least one anxiety disorder diagnosed, or impairing anxiety level above clinical cut-off; OCD = obsessive-compulsive disorder, SOC = social anxiety disorder; SPH = specific phobia; GAD = generalized anxiety disorder; SAD = separation anxiety disorder; PAN = panic disorder; AGP = agoraphobia.

Depression is another common coexisting psychiatric condition. Wigham and colleagues conducted a systematic review with 19 studies investigating depression in children and adults with high-functioning ASD⁷. Among the 11 studies where depression was measured with diagnostic interview or informant-report, the rates of comorbidity ranged from 2.5% to 29%. Among the 8 studies where depression was measured with self-reported outcomes, the rates of comorbidity ranged from 1% to 47.1%. Based on another systematic review, depression is the most cited risk factor for suicidal attempt among individuals with ASD⁸.

In a local epidemiological study, the prevalence of ASD in Hong Kong was 16.1 per 10000 for children and adolescents aged 15 years or younger⁹. Based on the statistics released by the Hospital Authority, a significant proportion of patients attending child and adolescent psychiatric clinics are diagnosed to have ASD. Analyses of major mental disorders indicated that, among children and adolescents aged 0-5 years, 6-11 years and 11-17 years, the proportion of patients with the diagnosis of ASD in the year 2015-16 were 60.2%, 32.1% and 24.7% respectively¹⁰.

Since anxiety and/or depressive symptoms are prevalent co-occurring problems among children and adolescents with ASD, it is essential for primary care providers or frontline workers to keep in mind these co-occurring and impairment problems, in addition to the core deficits related to ASD.

Assessment and treatment of emotional problems in children or adolescents with ASD

In the United Kingdom, the National Institute for Health and Care Excellence recommended health and social care service agencies to provide age-appropriate psychosocial interventions for the core features of ASD, and psychosocial and pharmacological interventions for the management of coexisting mental health problems or other behavioural problems¹¹.

The Autism Speaks Autism Treatment Network/ Autism Intervention Research on Physical Health Anxiety Workgroup, a multidisciplinary team of clinicians and researchers with expertise in ASD, published the following clinical recommendations on assessment and treatments of anxiety in youths with ASD¹² (see Figure 1).

Recommendations for assessment of anxiety:

1. Performing a developmentally appropriate multi-informant (child, parent, and teacher) assessment, utilizing multi-methods.
2. Assessing specific anxiety disorders and anxiety symptoms related to the core symptoms of ASD.
3. Assessing and treating other psychiatric and medical conditions that may cause or aggravate anxiety.
4. Addressing psychosocial stressors or sub-optimal behavioural/ educational supports that may be contributing to anxiety.
5. Assessing the impairments.

Recommendations for treatment of anxiety:

1. Providing psychoeducation and coordination of care.
2. Modifying CBT techniques.
3. Considering medication.
4. Referring to mental health professionals if anxiety is extreme, impairing, or not responding to the interventions.

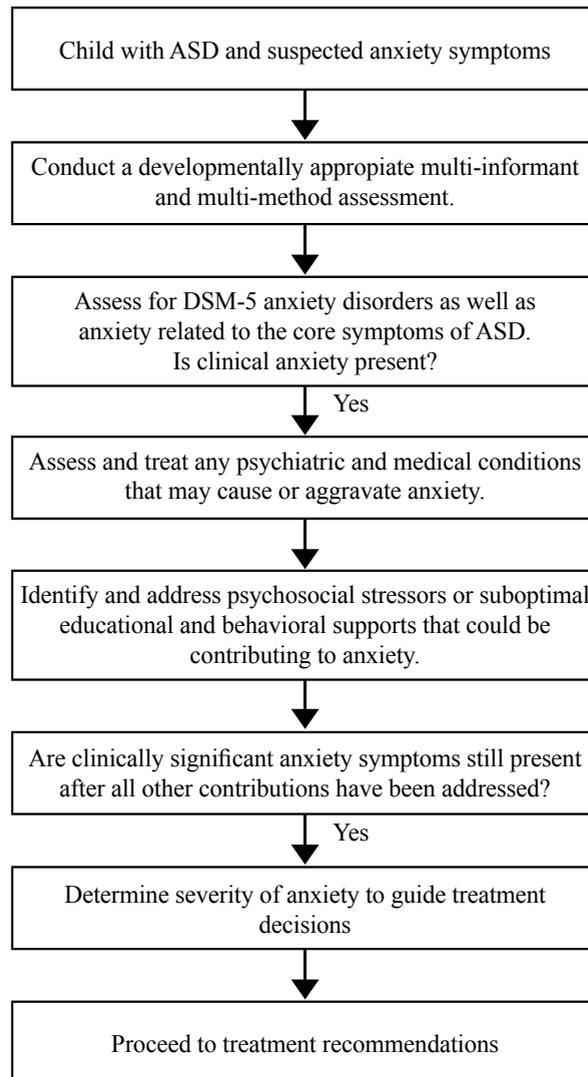


Figure 1: Assessment of anxiety in youth with ASD¹²

For typically-developed children and adolescents, the recommendations from the National Institute for Health and Care Excellence are to offer evidence-based psychological interventions with various intensities in the management of anxiety and depression^{13, 14}. Among these recommended psychological interventions, cognitive-behavioural therapy (CBT) is one of the most commonly applied psychotherapy.

Traditional CBT programs comprise assessment and treatment tasks like psychoeducation, cognitive restructuring and exposure. Aside from the deficits in understanding social communication and interaction across contexts, executive dysfunctions including impairments in verbal working memory, flexibility, planning and generativity likely impose them with greater difficulties in benefiting from these CBT programs¹⁵.

In fact, more researchers investigated the benefits of applying modified CBT to children or adolescents with ASD. Moree and Davis reviewed literatures about ASD children, and summarized four predominant modification trends for CBT in management of co-occurring anxiety¹⁶.

1. Using ASD specific treatment hierarchies, rather than solely focusing on comorbid problems like anxiety. For example, it is important to consider ASD specific problems like communication or social skills deficits in the assessment and case formulation, so that a broader hierarchy that also encompass ASD-specific problems could be used to guide the interventions.
2. Applying concrete and developmentally appropriate supports like visual tactics. Techniques commonly used in psychoeducation or cognitive restructuring include the use of emotion statements, picture drawings, visual worksheets, narrative and social stories, and role-plays.
3. Considering special interests of ASD children when appropriate, which would enhance participants' motivation and willingness to participate in treatment activities.
4. Strengthening parental improvements, which would facilitate generalization of therapy skills by allowing more home-practice.

With the considerations of the extra difficulties faced in the transition to adulthood, Kerns, Roux, Connell, and Shattuck raised the following issues in applying CBT in management anxiety and depression for adolescents and emerging adults with ASD¹⁷.

40

1. Providing disorder-specific psychoeducation. For example, providing these individuals with scientific information about prevalence and presenting problems of affective disorders and ASD can facilitate the normalization of experience and installation of hope. In particular, providing psychoeducation on the perpetrating and reinforcing cycle of anxiety and depressive symptoms also helps them understand the treatment rationale, as they understand more concrete evidence and treatment planning better than abstract concepts.
2. Simplifying and adding greater structure when cognitive strategies are introduced. The use of automatic thought records or cartoons with thought bubbles make abstract concepts more salient and concrete to understand. Examples of common cognitive distortions and coping thoughts are helpful for these individuals to generate alternative thoughts and practice using them. In-session role-playing, behavioural experiments, and video-modelling may be used to demonstrate and practice the alternative coping thoughts.
3. Restoring structure and increasing positive and rewarding activities in daily life. Adolescents or young adults may abruptly transit from a relatively structured and familiar school environment, where their social roles are well-defined, to relatively unstructured situations upon the completion of education. Therefore, by teaching these individuals various ways to restore structure in their daily lives, setting up routines, and regularly attainable goals may improve their sense of accomplishment.

Actually, most existing research on ASD focused on applying CBT to reduce the co-occurring anxiety, while relatively fewer studies on other clinical problems, including depression, anger, or emotional dysregulation⁴. Weston, Hodgekins, and Langdon conducted meta-analytic reviews to look into the effectiveness when applying CBT to people with high-functioning ASD. Overall speaking, positive treatment effects were observed. By comparing magnitudes of effect sizes in terms of Hedges' *g*, studies focused on reduction

on anxiety ($g = 0.32$ based on self-reported measures; 0.80 based on informant-reported measures; 0.86 based on clinician-rated outcomes) appeared to be more effective than those focused on reducing other clinical problems ($g = 0.24$ based on self-reported measures; 0.66 based on informant-reported measures; 0.08 based on clinician-rated outcomes)¹⁸.

Conclusion

In conclusion, children and adolescents with ASD display high rates of co-occurring psychiatric disorders. Symptoms associated with ASD impose these individuals with greater difficulties in attending treatment programs developed for typically developed children and adolescents. Health care service providers or frontline workers are suggested to conduct a comprehensive assessment and make necessary adaptations or modifications to help them fully benefit from psychosocial interventions.

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從穩態失衡到理想穩態 — 自閉症譜系障礙動態發病機制與干預新理念

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自閉症譜系障礙（autism spectrum disorders, ASD）以社交溝通障礙為核心特徵，對患者身心健康影響巨大。長期以來ASD歸屬於精神障礙範疇，近年來被歸類為神經發育障礙。過去的二十年，醫學和生物學領域對ASD開展了廣泛和深入的研究，取得了一批重要成果，已明確基因變異或遺傳易感性在ASD病因中扮演了重要作用。儘管多數學者均認同環境因素與遺傳因素相互作用，導致ASD發生，但迄今並未發現確定的環境致病因素。隨著ASD發病率的不斷上升，其所受到的重視程度也達到了空前的地步，社會學、教育學、倫理學和人類學領域學者的介入，ASD人士親屬的關注，尤其是ASD人士自宣導活動的興起和發展，對ASD的認識，在呈現巨大的爭議的同時，也浮現出一些全新的思路，環境教養因素被重新提出。本文作者擬對遺傳和環境、教養因素研究現狀進行回顧，在此基礎上，提出ASD個體遺傳與環境初穩態（early homeostasis, EH）、穩態失衡（impaired homeostasis, IH）和理想穩態（optimal homeostasis, OH）概念，並據此提出ASD干預三原則。

42

一、ASD的遺傳易感性

近二十年ASD研究最令人振奮的是遺傳和基因致病因素的發現。1999年Huda Zoghbi首先發現Rett綜合症存在Mecp2基因突變¹，2008年Weiss LA等報導了16p11.2微缺失和微重複與ASD的相關²，2014年Bernier R發現CHD8基因變異可導致ASD³⁻⁵，其他主要發現包括Shank3、SCN2、Pten等基因變異。迄今已經在超過10%的ASD人群中發現了新發（de novo）或遺傳性（inherited）的單基因異常或拷貝數變異（copy number variation, CNV），逾百個基因被認定為ASD致病基因，還有上千個基因被認為屬於ASD致病候選基因^{6,7}，這充分說明了ASD基因異常的異質性。這些基因異常的發現以及相繼開展的動物模型實驗大大增進了我們對ASD遺傳機制的理解，為全面揭示ASD遺傳病因和發病機制打下了一定的基礎。然而，上述單基因異常導致的多為綜合症性ASD（syndromic autism），綜合症性ASD患者除了具有ASD特徵，也同時存在不同程度的全面發育遲緩或智力障礙、特殊外貌等，與所謂經典ASD（classical autism），在此也可命名為非綜合症性自閉症（Non-Syndromic autism），多數具有正常外貌，多數（50%-70%）不存在智力障礙和全面發育遲緩有很大不同⁸。研究發現經典ASD的遺傳異常可能源於多個基因常見變異（common variations），如單核苷酸變異（Single nucleotide variations, SNV），包括新發的和遺傳性的，這些變異過去認為“不致病”，沒有明確臨床意義，但目前推測可能以數量性狀遺傳或加性效應（addictive effect）方式增加個體ASD的遺傳易感性⁶。其中一些基因作用較大，稱為主效基因（master gene），一些基因作用小，稱為微效基因。如果個體變異的基因數量大，或者包含了主效基因異常，則遺傳易感性大，反之亦然。目前多基因遺傳性疾病研究技術尚不成熟，尚不能對ASD診斷和干預提供足夠的支援，但不遠的將來，結合全基因組測序和人工智慧、機器學習和大資料分析發展起來的多基因風險評分（polygenic risk score, PRS）技術可能在揭示ASD遺傳機制方面發揮重要作用⁹。

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ASD在人群中患病率為1%，同卵雙生子高達80%到90%的ASD同病率^{10,11}，異卵雙生和同胞18%的ASD同病率¹²，ASD特徵與廣泛孤獨症表型（broad autism phenotype，BAP）存在明顯家族聚集性，遺傳因素在ASD病因中所扮演的重要作用不言而喻¹³。

二、環境致病因素

儘管遺傳因素是ASD研究的焦點，但學者們從來沒有忽視過環境因素的研究。綜合症性ASD，如Rett綜合症、脆性X染色體綜合症、結節性硬化等，由單基因突變導致，在遺傳方式上往往呈現出“全或無”，即患病或不患病，環境因素在致病中可能影響較小。而經典ASD，就目前的證據，還是多基因遺傳導致的遺傳易感性發揮作用，正如其他多基因因素影響的人類性狀（例如身高）和疾病（例如高血壓）一樣，環境因素也一定扮演了重要作用，就像身高與遺傳有關，但後天營養因素是實現個體身高不可或缺的因素，ASD，主要是經典ASD亦然也是如此，遺傳易感性提供了患病的可能性，而潛在的環境因素起到了觸發作用，使得可能性成為現實性。

縱觀ASD歷史，對環境因素致病的探索和爭議是如此之大，甚至對整個醫學領域都帶來了巨大的影響或衝擊。上世紀中葉，普遍認為ASD是由於母親冷淡造成，即“冰箱母親”理論，給家庭尤其是無辜的母親帶來的傷害人們現在還記憶猶新¹⁴；1998年Wakefield發表在柳葉刀雜誌的“麻風腮疫苗致病”假說¹⁵，儘管因為涉嫌學術造假而在2010年被撤稿，但卻造成了全球兒童傳染病計畫免疫率的顯著下降，麻疹、百日咳等死灰復燃；迄今，被提出、在探索、已否定的ASD環境致病因素不計其數，包括母親孕期病毒感染和細菌感染、免疫性炎症、孕期用藥（丙戊酸鈉、抗抑鬱藥）、葉酸缺乏、維生素補充不足、母親糖尿病、肥胖、剖腹產、各類圍產期併發症、以及一些與工業化、現代化和資訊時代相關的社會和自然環境因素，如環境污染、農藥、殺蟲劑、重金屬中毒、腸道菌群失調、父母（主要是父親）高齡生育、嬰幼兒過多使用電子產品、手機輻射、住高速公路旁等，均成為病因研究和調查的物件¹⁶。由於相對發展中國家和貧困家庭，發達國家和富裕家庭發病率更高，“發達國家”“高文化、高收入家庭”也成為高危環境因素。然而這些環境因素研究的結果多數是相關關係，研究結果往往也很難被重複研究所證實，上述環境因素並未得到普遍認可。

三、教養與社會環境因素

“冰箱母親”理論的錯誤教訓，讓談論父母養育與ASD的關係似乎是“禁忌”話題，但近年來有學者重新提出了這個話題。根據發展心理學理論，兒童行為與養育者行為之間存在極為密切的相互作用，養育行為影響兒童發展，兒童自身也對養育者的養育行為帶來影響¹⁷。ASD既然屬於行為疾病，理所當然受這一普適性兒童發展理論制約。Mandy提出，個體的遺傳易感性可直接導致ASD，也可首先導致ASD先兆（prodrome），表現為個體社交趣向（social orienting）降低，繼而引發親子交互作用的異動（perturbed interaction），親子異動導致ASD先兆特徵轉變為ASD表現或導致輕度表現向嚴重表現轉化¹⁶。這一假說與醫生臨床經驗高度吻合。作者認為，ASD兒童父母養育行為存在以下三種狀況：(1)多數養育者自然或習得的育兒技能往往無需特別關注兒童社交發展，她們天然缺乏養育一個存在社交趣向低下或已有ASD早期特徵的兒童的能力；(2)當嬰幼兒社交趣向降低，或表現為社交發育行為（如目光對視、喚名反應、依令指物、共同注意等）明顯延遲，或出現早期異常行為（如過度安靜、過

度活躍、經常看手），勢必對養育者帶來心理影響和非常規養育行為，養育者或表現為對嬰幼兒獨自安靜行為的忽視與放任，或表現為對嬰幼兒延遲出現的社交能力的焦慮；(3)如果嬰幼兒被懷疑或初步診斷為ASD，多數養育者會由於對ASD嚴重不良預後的極度恐懼出現“繼發性育兒失能”¹⁸，養育者自然的或習得的普通育兒能力也可能喪失，除非得到正確指導與干預，環境養育因素將出現惡化，不良相互作用將繼續發展，ASD遂由可能性變成了現實性，病情也可以由輕度轉變為中重度。此外，有研究證明，隨著兒童的成長，進入幼稚園、小學、中學乃至成年後，社會交往缺陷和狹隘刻板行為以及感覺障礙將使他（她）們面臨更加嚴峻的社會環境挑戰，會頻繁遭遇歧視、孤立、拒絕、排斥、欺凌等現象，個體與環境不良相互作用會繼續惡化ASD的問題行為，社交障礙繼續加重同時，內化性退縮、焦慮、抑鬱、雙向情感障礙、自殺意念乃至自殺問題，以及外化性多動、攻擊、破壞、滋擾性行為日益突出，成為青少年時期ASD的顯著特徵¹⁹⁻²¹。進入成年後，隨著相關特殊教育服務的中止，用世界衛生組織的話來說，他（她）們面臨“跌入斷崖”的危險，症狀繼續朝著更加嚴重的方向發展，逐漸喪失獨立生活、學習和工作能力，成為障礙人士。

我們在此提出問題：如果環境因素中的養育者養育行為恰當，環境支持和保護因素足夠，是否就可能降低ASD發生率或者減輕ASD嚴重程度呢？在回答這個問題之前，有必要認識一個新概念，自閉症譜系狀態（autism spectrum conditions, ASC）。

四、自閉症譜系狀態

與美國和世界多數國家不同，英國學者近年來已經逐漸使用ASC來代替ASD這一術語²²。一字之差，其意義不僅僅是為了消除“障礙”一詞給ASD人士所帶來的病恥感，更重要的是反映了目前對自閉症的全新認識。與相當長一段時間認為自閉症是“發病於嬰幼兒時期、罕見的、嚴重的、不可治療的、需要終生照料的精神障礙”²³概念不同，ASD現已成為常見障礙，發生率超過1%；ASD呈現譜系分佈。嚴重者，稱“障礙”並不為過；但也存在著輕度；還存在社交趣向低下但尚無明顯功能損害或障礙的群體；ASD並非均在嬰幼兒時期起病，在青少年，甚至成年期被首次診斷的ASD越來越多；孤獨症特質（autism traits）更是在多數人都或多或少存在²⁴；ASD可以導致殘障甚至嚴重殘障，但及時發現、包容接納、科學干預可以改善大多數ASD人士的預後；相當一部分ASD人士像其他普通人群一樣，帶著一定的特質（缺陷和優勢），獨立生活、學習和工作在我們這個世界。這些認識的獲得，歸因於人類學、社會學和倫理學的研究，歸因於ASD自宣導（self advocate）者發起的，並得到聯合國大會採納的“神經多樣性”運動²⁵。接受這樣的一種認識，那麼就有必要創新思考當前ASD的研究方向，需要對ASD的病因有一個重新思考，作者就此提出穩態失衡致病理論。

五、初始穩態、穩態失衡和理想穩態理論

最終被確診為ASD的兒童，多數都有一段“正常”發育階段，這個階段的長短與該患兒ASD症狀輕重有關係。在這個年齡階段，多數養育者或者不十分清晰、或不要求嬰幼兒展現什麼樣的社交溝通行為，其結果是低年齡ASD，由於其遺傳易感性，可能已經存在、或將出現先兆特徵，但一般不受關注，養育者按照普通發育兒童的養育方式帶養，嬰兒軀體發育和動作發育如常，具有ASD遺傳易感性的兒童個體與養育者之間關係平靜穩定，功能如常，相當於處在一個穩定平衡狀態，我們且稱之為“初始穩

態”（early homeostasis, EH），Flusberg對ASD高危兒父母養育的研究提供了佐證²⁶。儘管個體基因不會變化，但基因表達可以變化，同時環境也隨時間發生變化，因此初始穩態自然是一種動態平衡。

隨著兒童年齡的增長，家庭和社會逐步對兒童社交溝通有了明確要求，如果兒童沒有滿足這些要求，養育者就可能表達關注，或繼續觀察，或及時就醫，兒童可能遲早會被懷疑或診斷為“發育遲緩”、“社交溝通缺陷”或“自閉症”，如果養育者出現前述三種養育心態或行為和/或社會環境持續不友善，則這個具有ASD遺傳易感性的個體與其環境養育因素之間就可能失去初始穩態，發生穩態失衡（impaired homeostasis, IH），不當養育行為開始促使個體朝著異常發育軌跡（abnormal developmental trajectory）方向發展，如果這一進程未得到及時發現或阻斷，ASD特徵或症狀將逐漸明顯，先兆特徵將轉化為明確的ASD診斷，或原已診斷的ASD逐漸加重。這個過程，可視為養育行為和社會環境對兒童的直接影響，推測的神經機制可能是養育行為和社會環境通過對個體遺傳基因的修飾，即表觀遺傳學效應，影響兒童大腦的發育，體現在神經元數量、突觸數目、神經連接等方面的異常。反過來，兒童ASD診斷的確立，以及行為問題和症狀的加重，又將反作用於養育者、社會環境和養育行為，從而導致惡性循環。這就解釋了在ASD患者中常見的隨著年齡增大，症狀逐漸嚴重的現象。

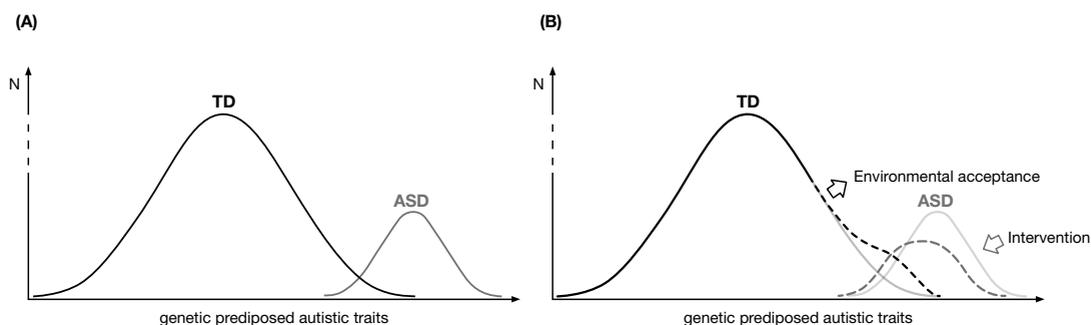
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如果ASD先兆或診斷發現及時，即使我們改變不了個體DNA順序和遺傳易感性，依然可以通過改善養育環境去應對，針對前述三個主要問題，教會養育者兒童社交干預技巧，不放任ASD先兆期和確診期兒童的社交孤立狀況，幫助養育者克服非理性的恐懼，在兒童加入幼稚園、學校乃至成年後，社會環境給予足夠的理解和支援，則可能不同程度恢復穩態平衡，換一句話說，具有ASD遺傳易感性個體與養育環境之間可以回復或重新建立理想穩態（optimal homeostasis, OH），個體就可能帶著ASD的缺陷和優勢能力，健康成長，成為社會的有用人才，甚至對社會做出重要貢獻。

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對ASD高危人群的相關研究支持OH²⁷。普遍認為，ASD不可治癒。但Fein通過分析和研究發現，存在著一定比例的ASD人士失去“ASD標籤”，獲得理想結局（Optimal Outcome, OO）²⁸，HeIt總結分析，發現比例為3%—25%²⁹。但OO概念主要根據患ASD兒童是否符合ADI-R和ADOS這兩個ASD診斷的所謂“金標準”評定ASD患者的結局²⁸，而事實上存在著一批符合ASD症狀診斷標準，但卻不出現功能障礙的群體，本質上就是獲得了OH的人群；作為一個橫斷面結局分析，OO也未能體現，隨著社會環境的變遷，ASD個體發育軌跡的走向。而OH概念則彌補了這個缺陷，OH不否認ASD人士部分特質的相對穩定性，但相信ASD個體出現的嚴重影響其功能的行為其實是個體遺傳因素與環境相互作用的結果，如果環境友善，則個體並不出現嚴重不良行為，因此OH理念事實上為我們合理解釋ASD預後提供了一個新思路。ASD個體發育過程中，是處在IH狀態，還是處在OH狀態，並非恒定不變的，如圖1所示，ASD發生與否與教養、社會、人文等環境有關。家庭、學校、同學、同事、社會對於存在社交能力缺陷個體的理解、接納、尊重可以幫助個體不發生ASD，或者發生，但程度減輕；相反，如果環境不能夠理解、接納、尊重，則這個個體就很有可能發展成為ASD，輕度者也可以發展成為中、重度，甚至在“正常範圍”的社交不足個體也可以發展成為輕度ASD；其次，科學干預可以改善ASD人士的社交缺陷和相關的情緒與行為

問題，可以讓圖中的曲線左移，部分患者可以因此不存在障礙，成為沒有障礙、具有“正常範圍”社交能力者（圖1黑色狀態分佈曲線）。在正常個體和ASD個體之間存在動態轉換可能，環境友好、科學干預可以讓ASD緩和改善或失去ASD診斷“標籤”；環境不友好、不給予幫助和干預可以讓ASD加重，甚至將處在閾值邊緣的正常個體也成為ASD。我們可以將ASD理解為個體先天特徵與環境之間“動態失衡”的結果（圖1A紅色正態分佈曲線），而將ASD的改善以及經由干預改善達成的理想結局視為“理想穩態”（圖1B）。



46 圖1：遺傳易感性與環境接納、干預影響下的ASD動態平衡（黑色虛線部分表示環境接納下ASD數量減少，紅色虛線部分表示干預ASD病情減輕，數量減少）

我們認為社會人文環境，包括父母的恰當養育、教育和社會環境的理解、接納，也包括長期的教育和干預因素，在ASD發病中發揮重要作用。這個觀點與“冰箱母親”理論無關！我們旗幟鮮明地認同，ASD不是父母冷漠養育方式造成的，ASD有著明確的先天因素；ASD兒童的父母與其他普通發育兒童父母一樣，不缺乏對孩子的愛和恰當的支持，然而，由於普通發育兒童，甚至包括單純全面發育遲滯和智力發育障礙兒童（其核心障礙主要在認知、語言或運動領域），在社交方面並不存在障礙（或僅僅存在繼發性社交障礙），父母親或教育者無需對孩子進行社交能力干預和訓練，而針對認知、語言和運動落後的干預對父母和教育者來說，相對不陌生，甚至本能地具備一定的干預能力；傳統上，從事發育障礙領域干預的專業人員對認知、語言、運動干預也基本形成了較為成熟的理論和實踐技能。而相反，整個世界對ASD的認識相對落後，我國更加明顯，我們對於ASD干預，不僅在理論方面不夠成熟，在實踐能力方面更加滯後。這導致了一種現象，那就是無論是家庭教育者，還是專業人員，都習慣性地運用針對認知、語言和運動發育落後干預的方法去干預ASD兒童，他們本著愛，帶著耐心，去幫助ASD兒童，卻發現孩子要麼不配合，要麼出現逃避、對抗和哭鬧行為，很多家長會覺得無助，因此放棄。專業人員也許不放棄，但也感覺效果不佳。還有另外一個重要現象，我們且將其稱為“ASD的世紀詛咒”，即很多的家長和專業人員都相信ASD是“不可治療的嚴重精神障礙”，認為“ASD也許可以改善，但不可治癒”、“患者需要終身照料”，在這樣的認識下，很多家長存在極度驚恐心理，很多處在長期的焦慮或抑鬱精神狀態中，家庭功能也出現障礙，從而導致父母出現“繼發性育兒失能症”，如圖2所示，兒童發展是處在一個包含著個體、微系統、中間系統、外在系統、巨集系統以及時間系統這樣一個嵌套的生態系統中，各個系統都會對兒童發展帶來影響，當一個兒童出現ASD，同時又合併了家庭功能的損害，如果社會的關懷以及價值觀又對ASD兒童如此不利，生態系統失衡，這個患兒的發展所要面臨的挑戰之大不難想像，家庭干預無從談起，干預效果可想而知。

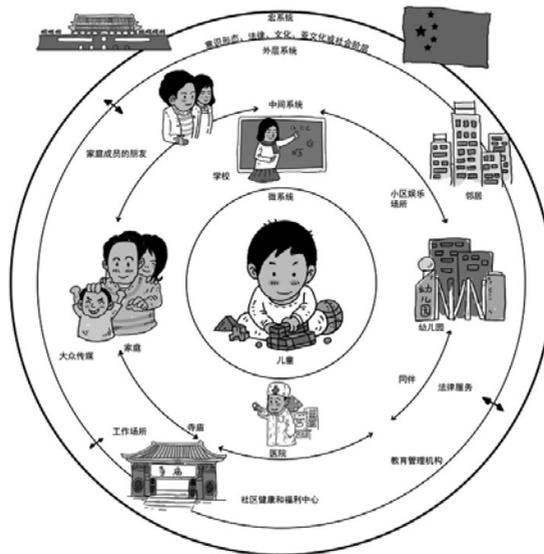


圖2 兒童發展生態系統

六、ASD教育三原則

由此，應該如何幫助ASD人士，目標就變得明朗，即讓ASD人士獲得“理想穩態”，也就是實現“環境友好、科學干預”。但殘酷的現實是，（1）包括我國在內，全球ASD群體生存環境嚴酷，由於缺乏診斷資源，嬰幼兒時期往往不能及時發現，同時存在父母和家庭對患兒的溺愛以及對存在問題的否認、忽略或不當照料；由於教育體制總體對ASD認識缺乏，學前期、學齡期、青春期的患者面臨被同伴和老師孤立、歧視、欺凌狀況；由於社交缺陷，成年期患者難以就業；（2）ASD科學干預方法，也許尚不完美，卻業已存在，但受制於診斷和干預資源的嚴重匱乏、科普教育不足、替代療法和偽科學氾濫、家長對ASD嚴重致殘觀念的極度恐懼，ASD科學干預現狀完全不能滿足這個群體的需求。（3）在我國，還存在著在引進國外診斷干預體系和方法時，高昂的智慧財產權問題以及文化不適應狀況。以上因素，共同導致ASD群體預後惡劣，嚴重者生活不能自理，需要家庭社會終身照料，成為嚴重殘疾，更多患者表現為包括焦慮、抑鬱、自殺、傷害行為等各類情緒障礙，不能不引起有關部門的高度關注。迫切需要我國專業人員通過努力，建立擁有我國自主智慧財產權、符合我國國情的ASD理論以及診斷干預體系。如前所述，環境接納與科學干預可以減輕ASD症狀，甚至獲得“摘帽”結局，作者提出ASD教育三原則。

1、理解、寬容、接納、尊重與賞識

ASD兒童帶著明顯的適應障礙、社交困難、問題行為的同時也伴隨著潛在的天生稟賦，也許人們已經比較充分地瞭解了ASD患者存在的問題行為，但對於ASD患者天生稟賦以及由此稟賦帶來的ASD文化需要更加深入的、虛心的討教和學習，一批ASD康復人士的自傳其實已經開始讓人們逐漸瞭解ASD的另外一面，那就是他們有自己的感知、認知和社交方式。需要理解、寬容和接納這種獨特心理特徵和文化的存在，尊重ASD文化具有的價值。

有了這樣的認識就可以避免一個最為普遍的錯誤：“把ASD兒童改造成和別的正常發育兒童一樣的兒童。”事實上，似乎也做不到這一點。因為從生物學角度來看，ASD並不可治癒，但並不意味著ASD兒童就不能在現今的社會環境下學習、生活和工

作，更別說不能生存了。重度ASD不僅需要幫助也需要包容，對於已經具備生存生活能力的ASD患者更加需要包容。凡夫俗子文化應該有包容他們的空間，就像今天的世界可以包容不同膚色、種族、語言人群的文化一樣，來包容一個ASD文化³⁰。家長要在一定程度上適應ASD兒童不夠恰當的交往；老師和同學應習慣和體諒ASD兒童一定程度的我行我素、自我中心的行為方式；社會要給予這些獨特人群與正常人群一樣的學習工作機會，就工作和創造性而言，他們可能不差於甚至優於那些凡夫俗子，只是作為同事，ASD患者不那麼好打交道而已；國家的政策和法律法規要給予ASD患者充分的權力，這才叫包容。只有今天的包容才能取得他們將來的回報。記住，不要試圖徹底改變ASD兒童，做不到也不必要，否則後果可能很嚴重。

無論是醫學專家，還是教育學家、心理學家、人類學家，也包括家長和教師對ASD的瞭解遠遠不夠。首先必須理解他們，應通過各種途徑（書籍、互聯網）獲取有關ASD的知識；參加相關的繼續教育活動；與專業醫生、老師以及其他家長建立起密切聯繫，互相探討和學習各自的經驗及教訓；可以明確的是ASD兒童的各類問題行為和天賦行為是與生俱來的。

無論是國內還是國外，今天的主流教育體系存在著一個普遍的現象或缺陷，兒童就像沙子，教育體系就是十分精細的濾網，所有的兒童都要放進這個濾網過濾，結果是普通兒童多數都漏掉了，而各類特殊兒童，無論是像ASD兒童這樣有缺陷的兒童，還是那些聰穎有個性的資優兒童，似乎都不容易通過這個精細的濾網，最後被主流教育體系所淘汰。現今的教育模式，幾乎讓ASD兒童陷於無處可學、無人願教的境地，是時候反思教育體系了。在主流教育中，應該有ASD兒童接受教育的地方；在主流教育之外，應該有教育的新思維，事實上，有學者早已經開始了這樣的嘗試，主流教育中的融合教育和資源課室；大型開放式網路課程（慕課，MOOC）；以自由、快樂、韻律、個性化為特徵的“華德福教育”³¹；居家學習和現代私塾；20世紀30年代在破損的公共汽車學校成才的“窗邊的小女孩”黑柳徹子的故事也早已為廣大教育者所熟知³²。在更大範圍實踐這種多元教育模式的時代到了。

就像接受還沒有見識過的外星人一樣，人們應該接受和尊重ASD患者以及ASD文化。即使在現代社會，依然有人生活在叢林中過著原始的生活，希望人類文明的成果能夠惠及他們，但是不能用暴力或強迫手段。應該尊重ASD患者“與眾不同的權利”³³。對兒童行為的要求不應該用某一個所謂“正常”的、統一的尺規或準則去衡量。否則，多樣的才賦、多彩的個性和豐富的創造力將被壓抑，長此以往，會損害了整個民族和人類的創造力和未來發展動力。

2、快樂、適度和巧妙地提升社交技巧和情緒管理能力，改善問題行為

然而，ASD兒童的父母就是凡夫俗子，包括醫學、教育及心理學等專業人員也是。ASD兒童因為“障礙”，會出現很多對其自身健康快樂成長不利的問題行為，這些問題行為就發生在父母、老師的面前，家長和教育者在充分堅持第一原則的基礎上，可以更多參與。事實上，教育學家和心理學家在過去的幾十年間，通過對包括ASD兒童在內的各種有障礙兒童的研究，已經逐漸建立了一些行之有效的幫助、支持和在一定程度上改變ASD兒童的方法³⁴⁻³⁷。通過家長-教師-醫務人員的互相溝通可以大大增進對ASD兒童的理解；在理解的基礎上，家長和老師在兒童教育態度和方法上的反思

與改變有時可以起到“化腐朽為神奇”的功效；有組織有計劃地針對ASD兒童開展“合作、競爭、對抗、分享、輪流、規則、對話”等社交遊戲和活動可以有效提升ASD兒童的社交能力³⁸⁻⁴¹；通過對兒童問題行為的“角色扮演遊戲”“問題行為（錄影）分析”或“正確行為示範表演”等形式可以在相當程度上教育兒童人際交流技巧，減少兒童在學校的外向性破壞行為³⁸；對兒童良好行為及時恰當獎勵和對問題行為的溫和與恰當的懲罰（不包括打罵），可以明顯改變兒童的在校表現；家長和老師在發出指令時，給予ASD兒童更多的“選擇權”，或更多商量的語氣可以明顯緩解兒童的對立違拗狀態，使兒童變得更加靈活而不固執和刻板；在學習和生活中盡可能程式化（每日按照比較固定的步驟進行學習和生活）可以顯著減少兒童的情緒紊亂；這些方法的特點具有非強制、非暴力、溫和、引導性。如果見效則堅持下去，但要注意改變應有度，不追求徹底改變，因為這是不可能的，並且可能導致嚴重的情緒反彈！如果無效則回到第一原則，評價的標準只有一個，是要幫助兒童快樂地成長，只有這樣才有利於個人的終生最優發展。

3、特殊興趣和能力的發現、培養和轉化利用

多數ASD兒童或多或少都有一些特殊興趣和能力⁴²⁻⁴³，這些興趣和能力的發現通常依靠家長敏感的洞察力、平靜的心態、積極主動的態度(被動應對、疲於奔命的方式不可取)、充足的時間和精力。

有眾多證據表明，部分ASD兒童成年後從事的就是與兒時的特別興趣和能力有關的工作，並且可以非常優秀^{42,44}。因此應對兒童的特殊興趣和能力給予一定的關注，並適當培養，然而更重要的是，將兒童的特別能力轉化及擴展到更加廣泛的學科和領域中去，這樣就可能在一定程度上促進兒童的全面發展。家裡應該準備足夠豐富的與教育相關的玩具、書籍或素材，家長積極主動參與到兒童的遊戲活動中去，並在大量的閱讀及遊戲活動中發現兒童的興趣所在，以此為基礎加以引導和培養。對於喜歡地圖的兒童，家長們可以和兒童從地圖開始玩起，從地圖談到國家、首都、森林、生物種類、動物、礦產、資源，又從國家談到人口、大小、距離、形狀等與數學有關的知識，還可以用英文對這些知識加以標注，這樣不僅在一定程度上促進兒童的全面發展，在語文、數學、英語的學習上均可獲益。如果兒童喜歡汽車，就從汽車開始與其交流和做遊戲，方法相同。如果轉化不成功，重回第一原則。不能強迫學習，以免適得其反。

對特殊興趣的發展和培養也許會導致ASD兒童發展的不平衡。然而，每一個人的能力發展都不均衡，只不過ASD的兒童在不均衡方面更加突出。從將來工作的角度來看，某些能力方面的不均衡影響遠不如想像的那麼嚴重。從發展或學習的最終目的來看，到達“羅馬”的道路不止一條，而且，也不是每人都想去“羅馬”。

誠然，人們對ASD還是所知甚少，有些問題還存在一定的學術爭議，專業人員能夠提供的幫助還非常有限，但醫生、教育者、心理學家應該和家長們共同努力，幫助這些特別兒童們克服缺陷，展現天生稟賦，實現最優發展。

本課題受國家自然科學基金面上項目（編號81873801）和廣州市科技專案（專案編號202007030011，201903010040）支持。

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封面背後的成長故事 - 別低估自己的能力

子舜媽媽 - Anita

子舜於歲半時出現自閉症特徵，6歲時確診自閉症及中度智障，學習能力非常薄弱，未能用語言表達。雖然我和子舜爸爸已盡力安排他接受不同的專業治療，可惜子舜8歲前都只能學會簡單的自理，既無法辨認1至10，也不懂分辨顏色。我們當時已作了最壞打算，子舜可能將會無語言，無書寫能力。

自閉症的黃金治療期瞬間過去，幸好我們沒有放棄，我們目標一致，對子舜的訓練有加無減，努力讓他接觸不同的事物，希望有一天找到開啟子舜一扇門的鎖匙。對於照顧子舜，我從不假手於人，子舜的訓練我都必定參與，也許這份積極，感動了身邊的家人和朋友，大家對子舜都很支持和愛護。

子舜8歲時，我們經朋友介紹，認識了一位繪畫老師Artin Wong女士。感謝她接受子舜，從零開始，悉心引導，發掘出子舜的個人風格。更奇妙的是，子舜在習畫後開始懂得寫字。

52

子舜並非天才畫家，單是分辨彩虹七色，老師已花上半年時間，簡單的一個心形，對子舜而言也並不容易。子舜用了很長時間仍未能畫出一個心形，於是老師想了另一個方法，先教他畫一個"m"字，再在下方加上一個"v"，

最終子舜畫出的心形非常可愛，實在令我們意想不到。

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子舜手部肌肉較弱，要完成一幅作品，需要付出很大力氣，後來老師建議子舜學習水墨畫。子舜喜歡用水墨繪畫在宣紙的感覺，慢慢找到屬於自己的線條，更開始在公開比賽中獲獎，令他得到自信，也開始著緊自己的創作。

現年19歲的子舜，畫風純真，線條跳脫，也許子舜的弱點成就了他獨特的繪畫風格。記得一位醫生曾經說過，一個只擁有60智商的人如果能善用他的能力，跟一個智商100但不思進取的人比較，前者可以活得更精彩。

編者後記：感謝子舜媽媽分享孩子的成長故事，並允許我們以子舜其中一幅畫作作為本期Brainchild封面。如想欣賞更多子舜的畫作，可瀏覽子舜個人網頁：www.alvinligallery.com

