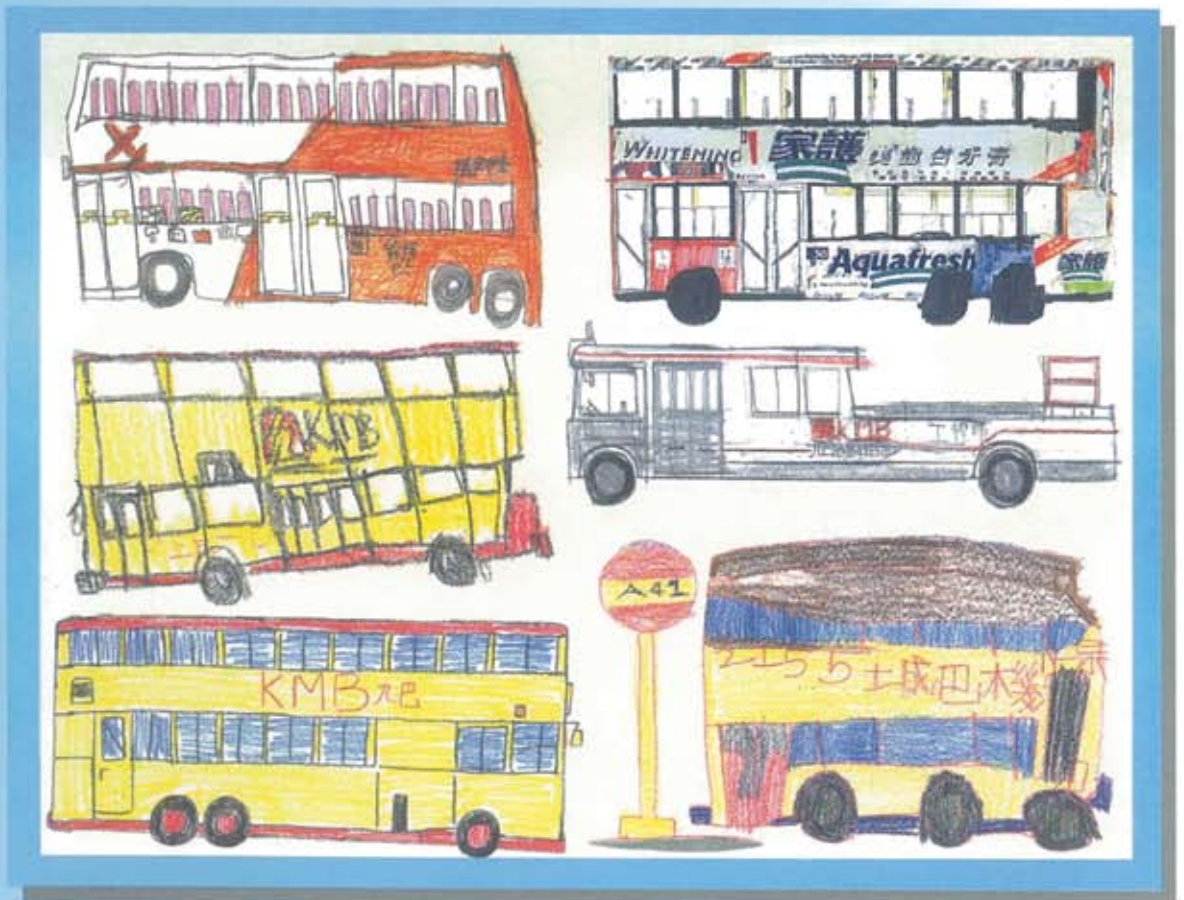


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# BRAINCHILD

The Official Publication of HKCNDP  
Autism Spectrum Disorders



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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**The Hong Kong Society of  
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**SPECIAL ISSUE ON  
ATTENTION SPECTRUM DISORDERS (ASD)**

<b>CONTENTS</b>	<b>Page</b>
Message from the President	1
Autism Spectrum Disorders – An Overview Stephenie Liu	4
Autism Spectrum Disorders – The Epidemic? Estella Woo, Stephenie Liu	6
Diagnostic Issues of Preschool Children with Autism Spectrum Disorders: Challenges for Clinicians Lorinda L Lam	9
Autism Spectrum Disorders – Strategy for Early Intervention Stephenie Liu	14
Local Services for Children with Autism Spectrum Disorders Rose Mak, Lorinda L Lam	19
Heep Hong Society's Holistic Training Approach for Children with Autism Spectrum Disorders May SP Leung	23
An Eclectic Intervention-Planning Model for the Development of Social-Communication Skills in Young Children with Autism Spectrum Disorders Irene T Ho, Lourdes MO Lam	27

**The Hong Kong Society of Child Neurology  
& Developmental Paediatrics**

BRAINCHILD – FEBRUARY 2006 ISSUE

**Message from the President**

With the good control of infective illnesses and medical disorders, mental health is now the main focus in child health. This is well emphasized by the “*Millennium Development Goals (MDG)*” issued by the United Nations Summit Meeting in 1995, the WHO Initiative on “*Importance of Early Development*” in 2002, the Delhi Joint Declaration by WHO, UNICEF and IPA on the World Health Day at 8th April 2005 on “*Make Every Mother and Child Count*”, and the local health policy on “*Comprehensive Child Development Service (CCDS) 0-5 Years*” initiated by the Health, Welfare and Food Bureau in June 2005. All these major child health initiatives converged to emphasize the vital importance of mental health in child development. It is thus imperative that all professionals dedicated to the care of children should keep themselves abreast of the latest development in the management of children with such disorders so as to be in alignment with the secular trend and child health demands.

The current issue of *Brainchild* is devoted to “*Attention Spectrum Disorders (ASD)*”. This is a common disorder with prevalence of about 0.1 to 0.2% in the child population based on local figures. The Issue starts with an overview of the problem, followed by local epidemiology, diagnostic issues, early identification, strategy for early intervention, local available services, and concluded with an intervention model for the development of social-communication skills in young children with ASD. The series of paper aim to explore different facets of the disorder with clear indications and effective strategic measures on clinical approach to the management of the problems. Dr Stephanie Liu, the Issue Editor, and all contributors are to be commended for a good mission accomplished. I would also like to take this opportunity to thank Heep Hong Club, The Spastic Association of Hong Kong, The University of Hong Kong, and the Child Health Assessment Service of the HKSAR Government Department of Health for the immense contributions in allowing us to publish their valuable research data and statistics. The Issue is the first one of its kind exclusively dedicated to the care of children with ASD published in the domain of paediatrics and child health in Hong Kong. I am sure the information stated therein will remain novel reference in local child health archives!

The HKCNDP Annual Scientific Meeting on “*Neuro-muscular Disorder in Infants, Children and Adolescents*” was successfully implemented in November 2005 in Hong Kong under the *Course-Director* Professor Royden Jones, Professor of Neurology from Harvard Medical School and *Special Guest Speaker* Dr Lui Wai Ying, Consultant Child Neurologist from Winnipeg Children’s Hospital, Canada. The keynote lectures together with workshops and seminars contributed by local experts created a fertile platform for cross-pollination of expertise and served to pave directions for future development of services in this important area within the territory of Hong Kong. Concurrently, we also had a high quality free paper session whereby adjudicators had difficult time in recommending the best paper out of a constellation of six good papers all very elegantly presented during the session. I would like to

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take this opportunity to congratulate *Dr Sylvia Doo et al* for being awarded with the First Prize with the paper on “*Sleep Problems of Chinese Children with Pervasive Developmental Disorders in Hong Kong – Correlation with Parental Stress*”. Well done!

Also in the year 2005, we have hosted a Joint Meeting on Developmental Paediatrics between Hong Kong, Macau, and the Mainland of China on “*Update on Childhood Hearing Impairment*” on 30th October 2005 in Beijing with experts coming from major cities and special administrative districts sharing clinical experience on the early identification, diagnosis, intervention and rehabilitation of children with hearing disorders. The Meeting was well attended by more than 200 experts with favourable comments at the conclusion of the function.

In the upcoming year 2006, the Society will continue its work in Specific Learning Disabilities (SLD)/ Dyslexia. Encouraged by the triumph of having SLD officially included into the Rehabilitation Programme Planning (RPP) by the Rehabilitation Advisory Council of Hong Kong, the Society has convened a Forum on 28th July 2005 at the Queen Elizabeth Hospital whereby local experts on SLD from different sectors, professions, disciplines and institutions gathered to exchange experiences and share knowledge on the subject in serious and conscientious manner. Thanks to the effort of Dr Catherine Lam, the Society has successfully prepared a document on “*Specific Learning Disabilities and Dyslexia in Hong Kong: 2006 Position Paper on Future Direction*” duly approved by experts present at the Forum. The Society is very much indebted to the effort of all experts for their contribution because this is the second consensus documents issued by the Society on the subject. The first one was published on 2nd December 1999 on “*Specific Learning Disabilities (SLD): Position Statement and Papers*” whereby local experts unanimously agreed on the *Definition of SLD*: a feature even professionals from developed counties are unable to achieve up to this day. *It is no easy task!* We are proud to have well motivated and initiated professionals dedicated to the welfare of our children and working via their selfless devotions. We are confident that the current 2006 Position Paper is going to be an important document for use by the HKSAR Government and professionals in Hong Kong for policy making, healthcare finance planning, programmes setting, technical formatting, project implementing and outcome measuring in the future. Also in the area of SLD, the Society Working Group will strengthen its exiting activities with professional partners including the *Pathways Foundation*, *Association for Specific Learning Disabilities (ASLD)* and the *Focus on Children’s Understanding at Schools (FOCUS)* to wider, uncovered and practical levels. We shall endeavour to focus on three major areas including *public health education* on the concept of equality (joint effort with the *Equality Opportunity Commission*), *promotion of intrinsic talents* of children with SLD (the HKCNDP Talents Exhibition for Children with SLD in Hong Kong to be hosted in mid-2006), and *job opportunities* for SLD after school leaving (activities with the Hong Kong Vocation Training Council). We shall stress more on the positive assets SLD rather than just stressing on their disabilities for sympathy and compassionate consideration of others. We aim at promoting better understanding of SLD amongst public both at school and in the community for better acceptance of the disability by the society.

*The HKCNDP Working Group on ADHD* established by the Society Council in October 2005, consisting of Professor Patrick Leung (CUHK), Professor Tatia Lee (HKU), Professor Shiu Ling Po (CUHK), Mr Joseph Lau and Dr Stephanie Liu (Child Assessment Service), Dr Catherine Lam and Dr Chok-wan Chan (HKCNDP). The Group is charged with the terms of reference to equip local professionals in child health with most up-to-date information and knowledge on the subject so

that their work and services can converge well with our child psychiatrists at tertiary and quaternary levels (service system recommended by Dr Ernest Luk, Convenor of the Task Force for Mental Health Service for Children in Hong Kong). The Group has met three times to discuss practical approach, do mapping of local experience and literature, and set recommendations for management of this disorder in Hong Kong. As our target, we shall formulate a position paper to set directions for future services in our locality. In order to bring cutting-edge information to Hong Kong, the Society will host its 2006 ASM in November 2006 on ADHD. The Course Director will be *Dr Drake Duane MD* of the Institute for Developmental Behaviour Neurology, Arizona State University, Scottsdale, Arizona, USA. Dr Duane is an experienced child neurologist cum developmental paediatrician currently ranked as top world expert in the area of childhood ADHD in private practice which is appropriate and relevant to upgrade local service standard for ADHD in the private sectors and at primary care levels. We also intend to invite experts from the Asia-Pacific Region to participate at this AGM for benefit of experts from our region and for promotion of effective knowledge transfer.

It is obvious that there are lots of activities to be launched by the Society in the coming twelve months. Please stay tuned! We look forward to your support and participation at these activities which are always vital to their ultimate success. I thank you once again for your ever-unfailing patronage to our Society. *Finally may I wish you all reading pleasure and best of health in the Year of the Dog!*



Dr Chok-wan CHAN  
 Editor-in-Chief, *Brainchild*  
 President, The Hong Kong Society of Child Neurology & Developmental Paediatrics

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## Autism Spectrum Disorders – An Overview

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Autism Spectrum Disorders (ASD) consist of a group of clinical behavioral syndromes characterized by impairment in reciprocal social interaction and communication, and the presence of stereotyped behaviors, interests, and activities. Qualitative abnormalities are pervasive, affecting several streams of development, as well as the individual's functioning in all situations. Abnormalities are deviant relative to the individual's developmental level or mental age, and are usually evident in the first three years of life.

Since the first description of "Infantile Autism" by Leo Kanner in 1943, the diagnostic criteria for Autistic Disorder have broadened considerably in the past sixty years. In the current edition of the American Psychiatric Association's Diagnostic and Statistical Manual, the DSM, (APA, 1994),<sup>1</sup> five diagnostic subgroups are included under the term of Pervasive Developmental Disorders (PDD). These are Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) including Atypical Autism. In the World Health Organisation's Classification of Mental and Behavioral Disorders,<sup>2</sup> PDD has eight diagnostic categories, which include Childhood Autism, Atypical Autism, Rett's syndrome, Other childhood disintegrative disorder, Asperger's syndrome, and others. Wing in 1981 proposed a dimensional approach instead of categorical approach in classifying this group of disorders: the concept of a continuum or spectrum of autistic disorders.<sup>3</sup> The autistic continuum is similar to though somewhat wider than the DSM/ICD category of Pervasive Developmental Disorders. It is not divided into diagnostic subgroups, and the impairment can vary in severity from the most to the least severe. Autism Spectrum Disorders (ASD) is now an "umbrella term" that embodies the continuity between Autistic Disorder (AD) and related disorders.

The diagnostic features of ASD include three aspects: (1) abnormalities in communication; (2) abnormalities in reciprocal social interaction; and (3) restricted, repetitive and stereotypic pattern of behavior, interest and activities. The abnormalities are deviant relative to the individual's developmental level and mental age, and significantly affect the individual's daily function. There are a number of associated features including uneven cognitive profile, hyper- or hypo-reactivity to sensory stimuli, gross and fine motor clumsiness, presence of some savant skills, and behavioral difficulties (e.g. hyperactivity, short attention span, impulsivity, aggressiveness, temper tantrums, self-injury).

The prognosis of Autistic Disorder is generally accepted to be poor, and it is a lifelong affliction for more than 90% of affected children.<sup>4</sup> Approximately 80% of children with Autistic Disorder function cognitively in the range of mental retardation,<sup>5</sup> compared to 26% to 40% of individuals with other disorders in the spectrum.<sup>6,7</sup> The children's cognitive ability is closely associated with the severity of their autism.<sup>8</sup> The disorders are three to four times more common in boys than girls, with girls more likely to function in the range of severe mental retardation than their male counterparts.<sup>9</sup>

Much research shows that the ASD are biological in origin. Co-occurring medical conditions exist in 6-10% of individuals with ASD.<sup>10</sup> Among them, seizures and some syndromes such as Fragile X and

Tuberous Sclerosis, were found to be strongly associated with ASD. However, a coherent biological theory of the ASD still waits to be developed despite the large literature on genetic and various neurological abnormalities associated with the disorders. The only exception is Rett's disorder, which, in the majority of cases, is due to mutations in the MECP2 gene on the X chromosome.<sup>11</sup> The recurrence rate for isolated ASD in subsequent siblings was found to be at about 5%.<sup>12</sup>

Autistic Disorder was once thought to be rare. However, there is a dramatic rise in the prevalence of the whole spectrum of disorders in recent years. In a recent epidemiological study, the prevalence of ASD was reported to be at 90/10,000.<sup>13</sup> The cause of this dramatic rise is still disputed and will be further discussed in the next paper.

To make an accurate diagnosis of ASD is sometimes very challenging for the physician. These pitfalls in diagnosis will be addressed in the third paper. The strategy for early intervention of children with ASD and their scientific evidences will be further elaborated in the fourth paper. Finally, the scope of local services in Hong Kong and the work of Child Assessment Service, the intervention programs provided by the two big non-government organizations, The Heep Kong Society and The Spastics Association, will be addressed in the last three papers.

5

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## Autism Spectrum Disorders – The Epidemic?

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### International Statistics

Autistic Disorder was once thought to be rare since their first description sixty years ago. However, the prevalence of Autism Spectrum Disorders (ASD) has increased continuously from 4-5 per 10,000 children in studies published before 1985<sup>1-4</sup> to 90 per 10,000 in a recent international epidemiological study.<sup>5</sup> The cause of this dramatic rise is probably multi-factorial, and the possible interpretation of this apparent epidemic included the following:<sup>6</sup>

- The definition of ASD has broadened over the last decades (from DSM-III to DSM-III-R to DSM-IV);
- The difference in methods used for case finding in surveys;
- Referral statistics have been used to evaluate trends over time, but these data are confounded by changes in factors such as referral patterns, availability of services, public and professional awareness, age at diagnosis, and diagnostic concepts and practices;
- Diagnostic substitution may occur (i.e., more children are diagnosed as ASD rather than associated conditions such as mental retardation);
- Real increase in incidence of ASD, due to unknown factors.

Whether it is due to heightened awareness of the condition, variation of diagnostic criteria or other environmental influences is still being debated and investigated. However, there is lack of convincing evidence thus far to support the cause to be due to heavy metal poisoning, infection, or increased sensitivity to vaccines.

### Hong Kong Statistics

In Hong Kong, a population-based study has never been conducted to establish the prevalence of ASD. It was estimated to be at 5 per 10,000 population according to the Census and Statistical Department in 2000 but was probably an underestimation.<sup>7</sup> According to service statistics from the Department of Health's Child Assessment Service, the incidence of ASD in 2004 was 2.3 per 1,000 children aged 2-5, the same figure derived from special preschool enrolment and waitlist statistics of the Social Welfare Department in the same year.

In Child Assessment Service (CAS), a public service for children from birth to under 12 years old, the numbers of newly diagnosed cases of ASD have risen continuously in the past twenty years, from 48 new cases in 1985 to 388 new cases in 2004. This apparent increase in incidence of ASD in Hong Kong can probably be accounted by the following reasons:

- CAS had opened up more child assessment centers, from one in 1985 to seven in 2004 in order to serve the whole territory. As a result, the yearly referral number also rose exponentially from around 1,100 to about 6,000. Therefore, more children have the opportunity to receive assessment and being diagnosed as ASD;

- More professionals have been trained to diagnose ASD in CAS and other sectors;
- Broader diagnostic definitions were used (e.g., change from DSM-III to DSM-III-R);
- Heightened public and professional awareness due to efforts of parent and advocacy groups, increased media coverage of affected children and families, and more training and information for physicians, psychologists and other service providers;
- Availability of increased medical and educational resources and the possible benefit of early intervention have led to increase in the numbers of children classified as ASD;
- Availability of more sensitive and reliable screening tool (e.g. CHAT) resulting in earlier diagnosis;
- Real increase in incidence of ASD due to unknown cause.

### Child Assessment Service Statistics

In view of the significant rising number of newly diagnosed cases of ASD in CAS, an analysis of the epidemiological and clinical findings of those cases diagnosed from year 2002 to 2004 was conducted in order to aid better understanding of this group of children.

In CAS, the total number of newly diagnosed cases in the two years period (2002 – 2004) was 621. Of these, 40% (n=253) were diagnosed to have Autistic Disorder, whereas 60% (n=368) were diagnosed to have other ASD conditions. The peak age of referral was between 2.5 to 4 years old. The male to female ratio was 8:1, which is higher than the figure of 4:1 reported elsewhere.

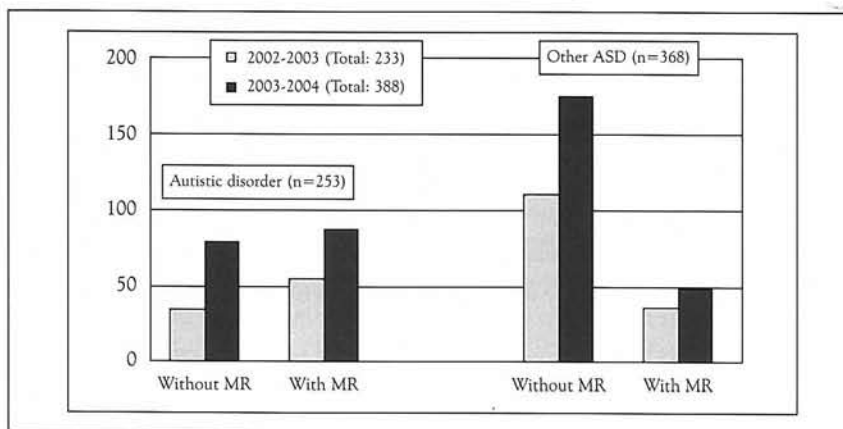
At presentation, two thirds of the parents reported gradual onset of abnormal symptoms, but one third did report some developmental regression. Fifty percent of parents became worried during the child's first year of life, rising to 90% when the child reached two years old. Almost all of them had a concern by the time the child was three years old. The referral reasons were mainly developmental delay, language delay, and behavioural and emotional problems. Common associated features were motor problems, hyper- or hypo- reactivity to sensory stimuli, and hyperactivity. Epilepsy was encountered only occasionally.

The data on the children's intellectual function was analysed at two points, at diagnosis and at the pre-primary school review assessment (when the child was about six years old). Among children diagnosed to have Autistic Disorder, 55% (140/253) were found to have mental retardation at diagnosis. At the six years old review, 41% (49/121) of the children who had attended the review were diagnosed to have mental retardation of moderate grade or worse. For children diagnosed to have other ASD conditions, only 23% (83/368) were found to have mental retardation at diagnosis, and at six years old review, more than 90% (180/198) of the children who had attended the review was found to have normal intelligence or mild grade mental retardation only (see Graphs 1 and 2). These findings are consistent with the current understanding that the children's cognitive ability is closely associated with the severity of their autism.<sup>8</sup>

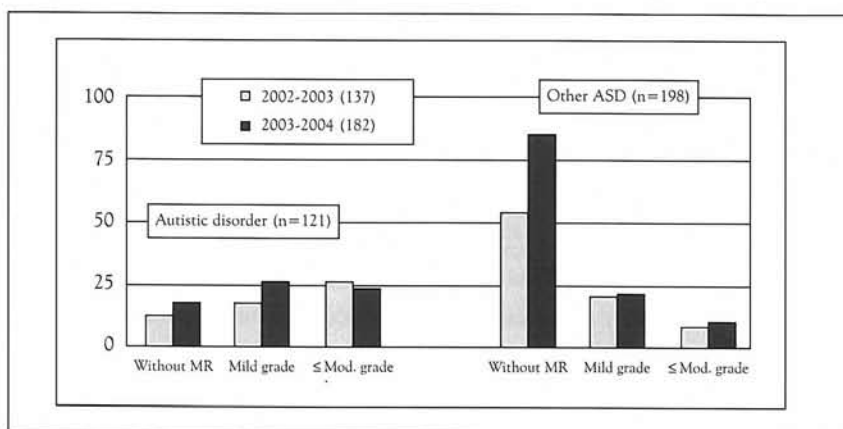
### Conclusion

It is evident from many epidemiological studies that there is a rising trend of newly diagnosed cases of ASD both globally and in Hong Kong. The cause is probably multi-factorial and needs further investigation. From the brief analysis of recent statistics in Child Assessment Service, we have observed

**Graph 1:** Intellectual functioning at initial assessment of pre-school children in CAS.



**Graph 2:** Intellectual functioning at reassessment before Primary One entry in CAS.



trends similar to those found elsewhere, the important ones being the rising trend of newly diagnosed cases, and the correlation between severity of autistic symptoms and mental retardation. In view of this rising trend, a local population based epidemiological study is worthwhile to establish the exact prevalence of ASD, so as to facilitate future service planning and policy making in Hong Kong.

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# Diagnostic Issues of Preschool Children with Autism Spectrum Disorders: Challenges for Clinicians

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Autism spectrum disorders (ASD) are complex developmental disorders, which pervasively affect the child's development and functioning. Early identification of ASD is recognized as important in contributing to early intervention and better prognosis of the condition. There has been recent progress in the earlier identification of children with ASD. However, this progress to earlier referral and diagnosis presents new challenges to clinical practice, including the accuracy and stability of early diagnosis, the use of standardized assessment instruments with young preschoolers, and the ability to indicate prognosis. It is the purpose of this paper to enhance clinicians' cautiousness when making a diagnosis of ASD in the assessment of preschool children.

## Diagnostic Classification Systems

ASD are a group of clinical *behavioural syndromes* characterised by impairment in reciprocal social interaction and communication, and the presence of stereotyped behaviors, interests, and activities. Such abnormalities are *deviant* relative to the individual's developmental level or mental age, and are usually evident in the first 3 years of life. In addition, the qualitative impairments are *pervasive*, affecting several domains of development, as well as the individual's functioning in almost all aspects of life.

**Table 1:** The classification systems of Pervasive Developmental Disorders in DSM-IV and ICD-10

DSM-IV Classification		ICD-10 Classification	
299	Pervasive Developmental Disorders	F84	Pervasive Developmental Disorders
299.00	Autistic Disorder <ul style="list-style-type: none"> <li>- Early infantile autism</li> <li>- Childhood autism</li> <li>- Kanner's autism</li> </ul>	F84.0	Childhood Autism <ul style="list-style-type: none"> <li>- Autistic disorder</li> <li>- Infantile autism</li> <li>- Infantile psychosis</li> <li>- Kanner's syndrome</li> </ul>
299.80	Rett's Disorder	F84.2	Rett's Syndrome
299.10	Childhood Disintegrative Disorder <ul style="list-style-type: none"> <li>- Heller's Syndrome</li> <li>- Dementia infantilis</li> <li>Disintegrative psychosis</li> </ul>	F84.3	Other Childhood Disintegrative Disorder <ul style="list-style-type: none"> <li>- Heller's syndrome</li> <li>- Dementia infantilis</li> <li>- Disintegrative psychosis</li> <li>- Symbiotic psychosis</li> </ul>
299.80	Asperger's Disorder <ul style="list-style-type: none"> <li>- Asperger's syndrome</li> </ul>	F84.5	Asperger's Syndrome <ul style="list-style-type: none"> <li>- Autistic psychopathy</li> <li>- Schizoid disorder of childhood</li> </ul>
299.80	PDD NOS Pervasive Developmental Disorder Not Otherwise Specified ( <i>including atypical autism</i> )	F84.1	Atypical Autism <ul style="list-style-type: none"> <li>- Mental retardation with autistic features</li> <li>- Atypical childhood psychosis</li> </ul>
		F84.4	Overactive disorder associated with mental retardation & stereotyped movements
		F84.8	Other PDD
		F84.9	PDD, unspecified

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ASD are currently diagnosed according to the criteria set out by two major clinical classification systems, the World Health Organisation's International Classification of Diseases and related Disorders, tenth edition (ICD-10)<sup>1</sup>, and the American Psychiatric Association's Diagnostic and Statistical Manual, fourth edition (DSM-IV).<sup>2</sup> In addition to Autistic Disorder, both classification systems include diagnostic categories for individuals who show some but not the full complement of the impairments that characterise Autistic Disorder. The classification systems of ICD-10 and DSM-IV are illustrated in Table 1.

It is reckoned that, although the DSM-IV<sup>2</sup> and ICD-10<sup>1</sup> classification systems have provided a clear structure for categorising symptom clusters, problems arise when clinicians try to apply the criteria in clinical practice. Firstly, we are facing a heterogeneous group of individuals, each with a unique developmental profile. Secondly, the clinical picture of a child usually changes over the life span. In addition, some of the core features are not exclusive to ASD but even occur transiently in typically developing children.

## Diagnostic Issues

### (i) *Normalcy vs Abnormality*

Controversy regarding the precise definition of the ASD is largely due to its undetermined aetiology (e.g. without biological or psychological markers). In addition, we need to be very cautious in defining the normalcy and abnormality of the child's presenting behaviours while taking into consideration the developmental and chronological age of the child. For example, egocentric and ritualistic play behaviours are commonly found among children before the age of two and three. They "obsessively" cling to sameness and are resistant to changes. In language development, echolalia is common at around two years old when it is part of imitation or when a child is at a speech level with emerging single-word. Echolalic speech and immature play behaviour are also commonly found in children with speech and language delay.

Clinicians and parents should not be misled by a single behaviour (e.g. lining up toy cars) into thinking that the child's development is no longer typical. Rather, an all-encompassing preoccupation with these behaviours or the persistence of these behaviours beyond the age when they are expected should warrant our special attention. For example, hand regard that occurs from 4-6 months of age in typically developing children becomes 'abnormal' when it persists for many years in children with ASD. Arm flapping with excitement is normal in toddlers but again becomes 'abnormal' when it goes on for years in children with ASD and even continue into adult life.

### (ii) *Changing Developmental Trajectories*

Another important challenge to clinicians is the changing developmental trajectories of early autistic-like behaviors. It is not uncommon for children suspected to have autism are later found to resemble children with pure language impairment. The early symptoms of inflexible adherence to routines, limited imaginative play skills and weak social competence may no longer be present on later review. In the very young or very profoundly delayed child, differentiating autism with developmental delay from developmental delay alone may be difficult. Also, while the rigid behaviours of an autistic child may wane, social and communication interaction may be progressively more strange and awkward as ASD symptoms become more marked in middle childhood.<sup>3</sup>

Social impairment is the primary symptom. It is possible to distinguish ASD from other conditions (e.g. language disorder) by focusing on behavioural impairments in empathy and imitation,

indifference to social praise, and unusual or bizarre responses to the social environment.<sup>4</sup> Impaired make-believe play and peculiar speech patterns are also helpful in identifying ASD from other differential diagnoses.

Of particular interest is the emergence of early pre-verbal social communication orienting behaviors as target behaviours for early identification.<sup>3,5-8</sup> These behaviours were identified from retrospective analysis of health records and home videos taken before the child was diagnosed to have ASD in the first two to three years of life. It shows that behaviors such as responding to name and monitoring gaze are present in nearly all typically developing infants by end of the first year of life, but are less frequent or absent in infants with ASD.

Among the early pre-verbal social communication behaviours, "joint attention" is considered to be a precursor of "theory of mind" in later development.<sup>9</sup> Deficit in the ability to initiate joint attention in the first two years of life is considered to be highly indicative of ASD.<sup>3</sup> Using these early pre-verbal social communication orienting behaviours in a screening procedure, the CHAT (Checklist for Autism in Toddlers),<sup>10</sup> in an epidemiological study of 16,000 20-month-old children,<sup>11</sup> it was found that infants with ASD showed very low frequency of empathic responding, gaze switching and imitation, in contrast to infants with language delay. It was also noted that two-thirds of the infants with ASD demonstrated functional play and some even pretend play. The corollary is that isolated examples of pretend play, or even gaze switching and imitative behavior, cannot rule out a diagnosis of ASD.<sup>12</sup> This is imperative for clinicians to note.

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### Accuracy and Stability of Diagnosis in Pre-school Years

Stability refers to the likelihood that a child will continue to warrant a diagnosis of ASD at follow-up. It has great bearing for clinicians who need to make decisions about when and at what stage to make a definite diagnosis and how to deliver the information and message to the parents in order not to cause unnecessary worries. Stone et al. made an insightful study on the stability of diagnosis across time in the clinical diagnoses within ASD.<sup>13</sup> It is found that there is good stability in a sample of 2.5-year-olds followed up one year later for the diagnosis of ASD, but a somewhat lower stability for an initial diagnosis of PDD-NOS: 4 out of 12 children received a non-ASD diagnosis at the review. On the other hand, one out of 8 children who had an initial diagnosis of a language disorder (with or without developmental delay), turned out to have a diagnosis of PDD-NOS when followed up at age 4 years old.

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There is consensus that the diagnosis of childhood autism is stable when diagnosed in the third and even the second year of life, and that experienced clinical judgment together with gathering of information from a multiple sources is more reliable than the use of a standardized assessment tools. Other than being usually 'difficult to test', we know that children with ASD typically perform well on structured testing even while they have enormous difficulties in daily life. Diagnosis of the broader range of ASD is less reliable, as has been found for older samples. Particularly, conditions with less severe or milder presentations may be misdiagnosed as developmental or language delay, especially in very young children.

Identification and diagnosis of high-functioning children with Autism, Asperger Syndrome or boarder phenotype of ASD (e.g. PDD-NOS) will also be a great challenge. The presentation of their social and communication impairments are usually subtler and might be masked by their compensatory skills due to higher cognitive abilities. These children might seek consultation at a later age, for example, at school age or even older, their milder features and possibly less debilitating symptoms having been missed in the early years. By then, even from a thorough developmental history, retrospective accounts by the informants might not be always reliable (e.g. regarding a history of

speech delay). On top of that, ASD children with higher cognitive functioning are often able to do well on standardized assessments in a one-to-one 'laboratory' setting, while their problems in real life situations persist. Naturalistic observations of children's behaviors in a group and across various settings might be more valid and reliable, but this is time-consuming.

## CAS Practice

The Hong Kong Child Assessment Service (CAS) adopts the ICD-10 classification and applies the research criteria for the PDDs<sup>1</sup> in making diagnosis. The multidisciplinary team for assessment of children with ASD usually comprises developmental paediatrician, clinical psychologist, speech therapist, and professional from other related disciplines, e.g. the audiologist will conduct a hearing test to rule out hearing impairment. CAS also works in close collaboration with the child psychiatric units in public hospitals under Hospital Authority in confirming the diagnosis and subsequent management.

In view of the challenges of diagnosis issues discussed above, clinical interviews with the parent and main caretakers of the child are conducted in order to tap a more detailed and thorough account of the child's early developmental history. This is accompanied by structured and unstructured clinical observations in order to evaluate the overall developmental and functional competence of the child. Intellectual functioning and social adaptive functioning are clinically determined by standardized intelligence tests and reports from multiple informants, including school personnel. The tools that CAS will make reference to in making diagnosis include: the CHAT (Checklist for Autism in Toddlers), 10 CARS (Childhood Autism Rating Scale),<sup>14</sup> ADOS (Autism Diagnostic Observation Schedule),<sup>15,16</sup> and ADI-R (Autism Diagnostic Interview-Revised).<sup>17</sup> Children with associated sensory and motor clumsiness problems will also be further evaluated by our occupational therapist and physiotherapist.

## Conclusion

Firstly, making a diagnosis of ASD is in fact a collaborative effort of parents and other care-givers (including those in the preschool educational setting) and multidisciplinary team clinicians. It is understandable that the retrospective accounts and reports by parents might not be always reliable, since this depends very much on the sensitivity of parents and their understanding of early signs to be looked out for. Therefore, a multidisciplinary approach with multiple sources of information is the preferred practice.

Secondly, lack of interest in social interaction is the most important diagnostic criterion of ASD. The detailed medical and developmental history should elicit examples of early pre-verbal social communication behaviors. In addition, these and other social behaviors, including social reciprocity, should preferably be observed and assessed in both the child's familiar and unfamiliar social situations.<sup>18</sup> Features highly indicative of ASD to look for are: lack of eye-contact, gaze-monitoring, proto-declarative pointing, joint-attention, sharing of emotion, ability to demonstrate pretend and cooperative play, and imitation. These early indicators should be particularly watched out for during the early first two years of life.

Thirdly, observation of the child's social and communication abilities should take place in both structured (e.g. IQ and language assessment) and unstructured settings (e.g. interactive play assessments). Diagnosis should then be made based on evidence gathered from all available sources, against current diagnostic criteria (e.g. ICD-10; DSM-IV) and in multi-axial format. The sole reliance on standardized assessment tools or the application of the ICD and DSM diagnostic criteria alone are not recommended.

Fourthly, disclosure of diagnosis is an art, particularly when there is only a tentative working diagnosis or when the diagnosis is still ambiguous against a complicated clinical picture. It is important to help parents understand and accept the diagnosis, see the child's strengths as well as the limitations, consider a range of possible prognoses, delineate intervention priorities, and resource available services. However, all these cannot be achieved in a single consultation session, but through ongoing follow-up at critical points in the child's development.

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## **Autism Spectrum Disorders – Strategy for Early Intervention**

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The strategy for early intervention of children with Autism Spectrum Disorders (ASD) includes early diagnosis, early parent support, and early intervention by a suitable training program.

### **The Art of Breaking the “Bad News”**

14 Early diagnosis of this group of children involves sensitive identification of children through health surveillance and early referral of suspected cases for detailed assessment. Physicians who have been working with this group of children would not deny the difficulty involved in breaking the bad news of the diagnosis to parents, who may or may not have any idea about the seriousness of the problems their children face. Many of them respond with significant denial and defensiveness in view of the normal appearance of their children, apparently normal early development, and amazing savant skills (in some children) among others. Since ASD is such an invisible disability, many of the parents inevitably feel shocked, confused and doubtful about the diagnosis, especially when they think that the child behaves better at home than during the assessment. Some of them may feel angry, guilty or inadequate as a parent. Many also feel hopeless and depressed due to the loss of a “dream child”.

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6 On the other hand, as a professional, we do not want to misdiagnose a child as having ASD because of the implications of a life-long and severe disability. Unfortunately, the disorder can only be diagnosed clinically. There is no definite diagnostic test, no definite “cause” for most of the children, and no guaranteed “cure”. Most difficult of all is that the clinical features of ASD change in its developmental course. All these contribute to the difficulty in making the diagnosis, breaking the bad news to the parents, and indicating prognosis. How to explain the disability adequately, instill hope in the parents while helping them to set realistic expectation is really an art in itself.

### **Early and Long Term Parent Support**

The above discussion leads to the importance of early parent support after the disclosure of the diagnosis. It is important to adequately explain the basis of the diagnostic process, the nature of the disorder, its implication and prognosis from the parents’ perspective so as to help the parents understand and accept the child’s problems. Timely advice on child handling and stimulating skills, introduction of useful community resources and early appropriate training program are all very helpful.

ASD, being a disorder of social relatedness, is a condition more difficult than other developmental disorders for parents, especially mothers, to cope with. Apart from having to face unsurmountable pressure, the acceptance issue also seems to be a long drawn out process, and their emotional roller-coaster might come up at different times along with the child’s developmental changes, for example when the child is admitted school. In addition, children with ASD have various adjustment, learning, social, behavioral and emotional problems. Parents may be confused and at a loss as to what to do when repeatedly faced with the child’s lack of empathy, rebuff of affection overtures, self-centered and other inexplicable, insensitive and inappropriate behavior. The earlier the parents of the affected child are helped to have better understanding of their child’s conditions, services available and intervention priorities, the better will they be helped to participate in the child’s rehabilitation in a more positive and constructive way.

## Early Intervention

Early intervention is now considered to be “a must” in the rehabilitation of children with ASD. Appropriate early intensive educational intervention can foster the acquisition of basic social and communicative skills. The earlier, the more intensive, the more well-planned and individualization of the program, the better the result.<sup>1</sup> The goals of the intervention are to improve the adaptive functioning of the children, enhance verbal and non-verbal communication, enhance social skills, decrease maladaptive and problematic behaviors, and last but not the least, to empower the whole family in dealing with the issues of having a family member with disability.

### *The Choice of Intervention Program*

The intervention programs of children with ASD usually consist of educational program, communication training, social skills training, training for sensori-motor dysfunction, biological treatment for specific metabolic problems, and pharmacological treatment for certain problem behaviors. Some of these treatment programs have **good scientific evidence** (numerous outcome studies, some randomized controlled trials, evidence pointing to their efficacy), others have **some evidence** (few studies or controlled trials, small scaled studies, evidence pointing to some effect of the treatment), but many have **little or no evidence** (only case studies available, no controlled trials, or controlled trials pointing to lack of efficacy of the treatment) and must be treated with great caution.

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**Approaches with good evidence** include two well-known programs: Applied Behavioral Analysis (ABA) and the TEACCH (Treatment and Education of related Autistic and Communication Handicapped Children) program.

Applied Behavioral Analysis program was developed by Ivar Lovaas at the University of California Los Angeles in 1981.<sup>2</sup> It uses the principles of operant conditioning in teaching new behavior. Target behavior is broken down into small measurable units and the children are taught systematically one unit at a time – Discrete Trial Training (DTT) – during individual training. During DTT, short and clear instructions are given, the child is prompted to follow the instructions by planned procedures, and correct responses are reinforced immediately. Several outcome studies showed good results of the program in which nearly half of the children with ASD attending the program for two years could return to normal class for learning, but less favorable results were found in later well designed randomized controlled trial.<sup>3-6</sup>

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TEACCH program was developed by Eric Schopler in North Caroline in 1971.<sup>7</sup> It has the following characteristics: it emphasizes parent professional collaboration, it hopes to improve children’s adaptation through teaching new skills and environmental accommodation, it uses structured teaching and other cognitive and behavioral therapy, and it aims at holistic orientation and life long service. There has been many researches on the basic approach of the program, but only very few outcome study.<sup>8,9</sup> One of the reasons may be due to the multiple components of the program that make overall outcome study difficult to be carried out.

**Approaches with some evidence** include: the Floor time,<sup>10,11</sup> use of Social Story to teach social skills,<sup>12</sup> teaching a Theory of Mind (TOM),<sup>13,14</sup> Picture Exchange Communication System (PECS),<sup>15</sup> Sensory Integration therapy (SI),<sup>16-19</sup> biological treatment for specific metabolic abnormality (e.g. certain enzyme defect),<sup>20</sup> and the use of atypical antipsychotic drug to reduce aggression.<sup>21,22</sup> All these approaches should only be applied after detailed assessment.

**Other approaches that have little or no evidence** of their efficacy, and few may even be harmful. These included: Psychotherapy,<sup>23</sup> Auditory Integration Therapy,<sup>24-28</sup> Music Therapy,<sup>29-32</sup> Play Therapy,<sup>33,34</sup> Lens and Spectacles,<sup>29</sup> Special diet,<sup>35-37</sup> Minerals and Vitamins supplement,<sup>38-42</sup> Secretin,<sup>43-47</sup> DMG,<sup>48</sup> Detoxification and Treatment of infection.<sup>47,49-52</sup> Clinicians should accordingly caution parents who wish to try these approaches.

## How to Choose a Program

It is important to realize that no single approach is effective for all children! Any treatment program should be based on the current knowledge of child development, should address core symptoms of ASD, and be derived from a range of sources,<sup>53,54</sup> Based on the current evidence, elements of an effective program should include: a structured environment; predictable routines; use of visual strategies; use of behavioral intervention; early, intensive, individualized program; and applicable in naturalistic settings so as to facilitate generalization of the skills learnt.

In choosing a program, our advice to parents is to always ask the following questions:<sup>55</sup>

- (1) What is the anticipated outcome of the program?
- (2) What is the potential risk?
- (3) How will the option be evaluated?
- (4) Is there any evidence of effectiveness?
- (5) Will the selection of this option have an impact on use of other options?
- (6) What are the cost, time commitment, and other demands on the family?

Ineffective treatments can be harmful if they supplant potentially more effective treatments. Also, potentially effective treatments that are misrepresented or accepted at face value as a "cure" for autism, without being subjected to controlled scientific scrutiny, can also mislead parents and squander resources.<sup>56</sup>

16

## Conclusion

In dealing with children with ASD, what we should do is captured in the acronym: ASD. That is, adequately Assess them, Support them and promote their Development through early intensive educational programs. Most important of all, whether as a parent or as a professional, love and accept them as they are, because we understand that not all of their disabilities are remediable, and that these disabilities are going to stay with them for the rest of their life.

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# Local Services for Children with Autism Spectrum Disorders

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## Early Identification and Assessment

In Hong Kong, irrespective of other venues for detecting anomalies, all children 0-5 years old are covered by the developmental surveillance program conducted in the Maternal & Child Health Centres (MCHCs) of the Family Health Service, Department of Health. Through a process of observation and interview at key ages by the nurses and doctors of the MCHCs, children with anomalies in social communication, language development, and play are identified and referred to the Child Assessment Service (CAS) of the Department of Health for relevant assessment. After assessment in CAS, all of the newly diagnosed cases of Autism spectrum disorders (ASD) will be referred to the child psychiatric units of public hospitals for further evaluation. For borderline cases, CAS will review their progress and further referral will be made if necessary. Some of the children with ASD may also be directly referred by primary care practitioners to the psychiatric units of public hospitals by for further evaluation and management.

19

## Parent Support and Parent Training

Immediately following diagnosis, CAS provides 'interim support' for parents of children with ASD while the families await more definitive intervention elsewhere. This will be further elaborated in the paragraph on the work of CAS below. In addition, the two main parent associations of children with ASD often actively outreach to provide support. Whilst Early Education and Training Centres (EETC) target the care and training role of caregivers, and Parent/Relatives Resource Centres facilitate self-help, the focus of their programs on ASD varies with individual operators. Residential and "occasional" respite care is also available for selected children.

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## Medical Rehabilitation

Other than individual casework, most of the psychiatric units of public hospitals run treatment groups for children with ASD in their clinics in order to prepare them for intervention in the preschool or school age educational settings. Pharmacological therapy is used as an adjunct to other therapies.<sup>1,2</sup> Children with severe behavioral problems may be hospitalized or attend day hospital for treatment. The mental health team generally consists of psychiatrist, psychiatric nurse, clinical psychologist, social worker, occupational therapist, and special education teacher.

## Education and Training

### *Special Provision for Children with ASD in Special Childcare Centres (SCCC)*

Full day programs for preschool children with ASD (age from 2 to 5 years old) are mainly provided in the Special Child Care Centres (SCCC) where children with moderate or severe disability are usually

trained. The programs have the support of a professional team generally consisting of clinical psychologist, occupational therapist, physiotherapist, speech therapist, and social worker. With “special provision”, children with ASD have the support of an additional special child care worker for every six autistic children admitted to the same centre. The content of the training programs varies with service providers. The training program of SCCC ran by two big non-government organizations, the Heep Hong Society and the Spastics Association would be addressed in the last two articles.

### *Integrated Programs in Ordinary Child Care Centres (ICCC)*

These programs are suitable for those children with mild disability. Childcare workers in these settings depend on a visiting professional team for support. Children attending these centres often turn to the Hospital Authority and other service providers for various additional interventions (e.g. treatment for behaviour problems, speech therapy, occupational therapy) as required or available.

### *Special Schools*

School age children with ASD attend either special schools or mainstream schools usually depending on whether they have co-occurring mental retardation or not. Special schools for the “mild and moderate” mentally handicapped have additional resource teachers (on average one teacher to 12 children with ASD) to implement Remedial Teaching Program specifically for children with ASD to target behavioral management, and the training of communication and social skills.<sup>3</sup> Children with ASD who also have other special educational needs (e.g. physical disability) may have to attend other relevant special schools.

### *Integration into Mainstream Schools*

Children with ASD who have average intelligence usually attend mainstream schools. However, not all mainstream schools take in students with ASD or students with other special educational needs. Though guidelines are available,<sup>4</sup> programs for children with ASD, when available, vary with the school and resources. An individualized educational plan is implemented only for a proportion of students.

### *Private Services*

There are also private services organized by private organizations and some NGOs, including behaviour training, speech therapy, occupational therapy, group training and other special programs. These serve as adjuncts to Government subsidized services.

## **Work of Child Assessment Service**

### *The CAS Team*

In CAS, a multi-disciplinary team approach is often needed in the management of affected children and their families. At the initial evaluation for diagnosis and planning for rehabilitation, the medical social worker, health nurse, speech therapist, and developmental paediatrician are always involved, particularly since most children present in the young preschool age. For those with significant

behavioural and emotional difficulties, the clinical psychologist may also be involved. Other team members are involved in further evaluating associated symptoms (e.g. hypersensitivity reactions to sensory stimuli) or co-occurring conditions (e.g. clumsiness), and in excluding sensory deficiencies (e.g. hearing loss).

**Assessment**

The diagnostic process used in CAS has been addressed in detail in the last paper, and hence it will not be described in detail here.

**Implementation of Rehabilitation Plan**

All children are referred for appropriate intervention as agreed with the parents, including those children in whom a diagnosis can only be made after extended assessments to observe the evolving clinical picture, as well as those with parental acceptance issues. Assessment results and recommendations for intervention and accommodations are made available to the school or training institution, sometimes involving on-site visits and discussions with relevant personnel.

Children with features suspicious of co-morbid mental health conditions, underlying biological anomalies (e.g. dysmorphic features, familial conditions) or general medical conditions are also referred to relevant clinical units for investigations and further management. Similar arrangements will be made for family members where necessary.

**Interim Support and Follow-up**

CAS provides interim support to all parents of children with ASD assessed in its child assessment centres. The aim is to provide, as soon as possible after diagnosis, essential information about ASD and local resources, and some basic skills in scheduling the child's activities and managing the child's behaviour at home while waiting for intervention and support services elsewhere. Also, for parents of children in mainstream school, this serves as a venue to share understanding of the child's emotional and behavioural difficulties and to develop basic strategies to enhance the child's social competence.

Parent education and interim support activities provided by CAS include the provision of educational pamphlet; the assessment centre's parent resource library, which contains informative books on ASD and on what parents can do in training their children; and the Parent Information Day, which is held regularly all the year round. During the information day, the CAS Team will explain the diagnosis of ASD in more details, demonstrate how to handle the children's common behavioral problems and facilitate their language development; and give a comprehensive introduction to community resources.

Parent Workshops are available for those parents who are keen to participate in early home training of their children. There are five independent but related workshop sessions running continuously round the year. These workshops aim to help parents understand the development and learning styles of their children; understand the ways to facilitate the development of learning, preverbal communication and play skills; understand the basic principles of home training, the use of structures and visual strategy to teach their child; and to build up the parents' basic skills on handling the children's problem behaviours so as to foster good parent child relationship.

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## Conclusion

From the overview of local service, we can see that services are available for the rehabilitation of children with ASD. However, resources are limited. To facilitate early intervention, parent empowerment can be enhanced to include home-based parent training programs together with appropriate support for the mental health of parents and siblings. There is need for increased awareness and early identification of children in the milder end of the spectrum who usually present in later childhood. Effective educational intervention for high functioning children with ASD in mainstream school is a challenge to the educational system in view of the increasing number of affected children but limited resources provided. To support local rehabilitation services, training of professionals (and those providing care for children with ASD) in current best practices, sharing of clinical experience, and collection of reliable epidemiological information are essential so that management is effective for this heterogeneous group of children.

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# Heep Hong Society's Holistic Training Approach for Children with Autism Spectrum Disorders

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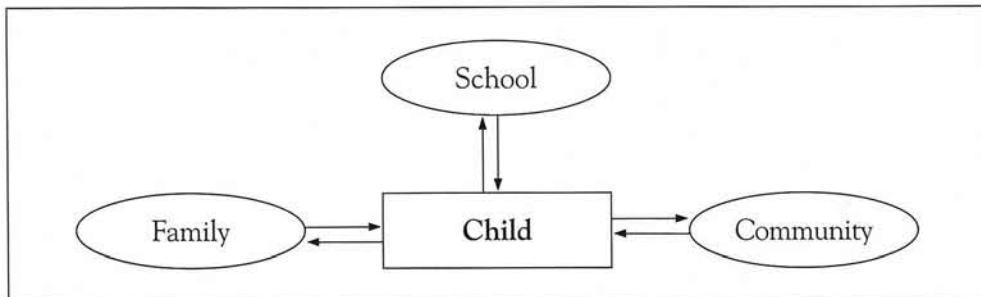
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## Introduction

Heep Hong Society has been providing professional training for children with special needs since it was founded in 1963. As children with Autism Spectrum Disorders (ASD) have become one of the major service recipients in our special child care centers, a team of professionals was formed in 1993 to provide systematic professional training for them, including clinical psychologists, speech therapists, occupational therapists, and senior special child care workers. With more than 20 training centers, Heep Hong is providing children with ASD centre-based intensive training and care, including developmental assessment and individualized educational program, centre-based individual and group training, therapeutic services, community adjustment program, parents support and psychological services. Early intervention and intensive training can enhance the basic learning skills of children with ASD, and help them better adjust to their daily lives. Statistics from the past 3 years reveal that the ratio of children who could integrate back to mainstream kindergarten and/ primary school after the intensive training in our Special Child Care Centers has been increasing steadily.

Consolidating our years of experience in working with children with ASD, and considering their uniqueness and individualized needs, we have come to the conclusion that the training curriculum for these children should adopt a holistic approach which can cater for the variety of needs and difficulties these children face. A good training program not only start and stop within the school itself, but also includes family support from the home environment and the preparation for community integration as important factors to make the whole program a success.

### Holistic Training Approach



### Structured Teaching

Developed in the early 1970's by, Eric Schopler, the TEACCH approach (Treatment and Education of Autistic and related Communication handicapped Children) includes a focus on the person with ASD, and the development of a program around this person's skills, interests, and needs.

After joining a Hong Kong study team, comprising of government officials, senior executives of rehabilitation agencies and leading professionals in visiting the internationally renowned North Carolina

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TEACCH program in 1995, Heep Hong has successfully adapted this training package into the Hong Kong culture and executed the program in our special child care centers (SCCC) since then.

Organizing the physical environment, developing individual schedules and work systems, using visual materials, and making expectations clear and explicit have been effective ways of developing skills and allowing children with ASD to use these skills independent of direct adult prompting and cueing. Structured Teaching is especially important for these children who are frequently held back by their inability to do things independently in a variety of situations. Thus, the TEACCH concept has served as the backbone and fundamental ingredients for our overall training program.

## Sensorimotor Training

Research indicates that many children with ASD will have difficulty in processing information received through the senses, and have reactions towards environmental stimulations that are different from that of their age peers. These difficulties may manifest themselves in the children's daily behavioral problems and difficulties, such as inattentiveness, hyperactivity, writing difficulties and sloppiness. These behavioral manifestations would further affect their performance in learning, self care and play. The occupational therapists would design appropriate "sensory diets" according to the children's specific needs and integrate them into their daily routine activities, so as to allow them to have access to the needed sensory experience throughout the day.

Dr Jean Ayres, an occupational therapist from the University of South California in the United States, was the first to describe the child's sensory problems as a result of inefficient neurological processing, and has developed the theory of Sensory Integration Dysfunction in the 1950s and early 1960s. According to the theory, dysfunction happens in the brain: its inability to analyze, organize and connect the sensory messages resulting in the children's inability to respond to various sensory information, to behave in a meaningful and consistent way, and to plan and organize what they need to do. Most of Heep Hong's Special Child Care Centers are equipped with a sensory integration treatment room, in which our occupational therapists would conduct sensory integrative therapy for those autistic children having sensory integration dysfunctions.

Besides using sensory integration theory, our occupational therapists would also make use of the multi-sensory room to enhance the children's exposure to the different types of sensory stimulation they need and to design various sensorimotor games and activities to enhance the effectiveness of the training.

## Speech and Language Training

Children with ASD come with different degrees of speech and language difficulties, and thus training from the speech therapists are of utmost importance in facilitating the children's understanding of the world around them, and enhancing their ability to express themselves.

Training activities for each child will be tailor-made according to the developmental milestones of the child's language expression and comprehension abilities. Activities include articulation exercises, phoneme discrimination exercises, oral motor coordination and speech training.

Moreover, in order to facilitate the children's communication, the speech therapists would provide the children with the necessary tools and materials to increase their communication skills and their initiative in communicating with other people, such as the use of a picture exchange communication

book. The objective is to let the children experience an accurate and effective communication process during the training.

## Other Training Strategies

### *Motor Function Training*

The difficulty in motor function of children with ASD seems to be the most overlooked area in a treatment program plan. This might be due to the impression that these children have superior ability in running around and struggling with parents physically when their needs are not met. However, looking deeper into this area, it was found that some of the children have delayed development of locomotor skills and manipulative skills. Moreover, they also demonstrate difficulty in balancing and coordination, as well as participating in exercise and games. As such, our physiotherapists will design training activities according to the child's level of motor functioning, including basic motor function skills and game skills. Hydrotherapy and rock climbing activities would also be used to enhance the children's body awareness, gross motor skills, motor planning and coordination, muscle tone and sensory perception abilities.

25

### *Social Story*

As for the relatively weak social skills of children with ASD, Social Story, as proposed by Carol Gray in 1991, will be used to facilitate the children's understanding of social situation and to act appropriately accordingly. Using these children's relatively strong visual skills and interests in reading words, the social stories can provide them with the blueprints for what's expected in various circumstances and to teach them ways to behave in various social situations.

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## Parent Work

### *Parent-child Group*

While children with ASD can behave like an angel in the school's structured environment, parents are always puzzled and frustrated about why their children would behave so differently when in the home environment. Thus, we have organized parent-child interaction groups aiming at enhancing the parents understanding of the child's needs and in learning ways to increase the child's cooperation and ability to follow the parents' instructions. During the group, parents can learn effective parenting skills through observation and discussion with other parents and the instructor.

### *Community Adjustment Training*

Due to the social, communication and sensory difficulties and the difficulty in accepting changes in this group of children, they will always have difficulty when going into community settings where the environment is less structured and with many unexpected factors. As it is, parents would become worried about taking their children outside of home as the children have great difficulty in getting through daily activities and routines in public areas. For example, traveling in public transport, going to shopping center and supermarket etc. Thus, Heep Hong's special child care centers have also incorporated a community adjustment program into the children's overall training curriculum, aiming

at enhancing their abilities to go into the community and thus enhancing their life experiences, and relieving the parents' stress in doing daily routine activities. Depending on the child's own needs and existing abilities, the special child care teachers would use different strategies to help the child integrate into the community settings, such as using visual strategies, social story, role play, real time practice and effective reinforcement. By doing so, the children's awareness of upcoming events is enhanced and thus can gradually reduce their resistance to change.

## Conclusion

Effective training starts from a real understanding of the individual child's needs and abilities. By providing intensive training for children with ASD in an early stage we prepare the children with the necessary skills to deal with their future learning and integration into the community. A holistic training approach, which caters for the variety of needs of the children, is thus necessary to achieve this goal.

Nevertheless, providing training for the children in the school setting is not enough, support from family members and successful integration into the community are also needed for the children to better adjust themselves into the outside world. Thus, parental support, home training and community adjustment program from early on are important features in the training program to facilitate the children's learning and to enhance their overall quality of life.

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# An Eclectic Intervention-Planning Model for the Development of Social-Communication Skills in Young Children with Autism Spectrum Disorders

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## The Need for a Planning Framework

Research in the past decades has increasingly shown that children with Autism Spectrum Disorders (ASD) are a heterogeneous group with large variations in the associated symptoms and performance levels.<sup>1,2</sup> In view of the varied needs of this heterogeneous population, many approaches and strategies to foster their social-communicative competencies have been proposed and implemented. Broadly speaking, these strategies fall into two categories: behavioral treatment methods designed to change observable behaviors associated with the core symptoms of autism; and various alternative treatment procedures that target underlying sensory or biological processes (e.g., sensory therapies, diet and drug treatments). The present discussion focuses only on behavioral treatment methods, which represent the dominant treatment approach for autism and are most relevant for related program planning in educational settings.

Current methods for the treatment of autistic behavior could be conceptualized in terms of four types of approaches: (a) *behavioral approaches*, e.g. discrete trial training,<sup>3</sup> pivotal response training;<sup>4</sup> (b) *interactive or relationship-based approaches*, e.g., floor time,<sup>5</sup> relationship development intervention;<sup>6</sup> (c) *cognitive approaches*, e.g., theory of mind training,<sup>7</sup> social story;<sup>8</sup> and (d) *ecological approaches*, e.g., the TEACCH approach,<sup>9</sup> social integration.<sup>10</sup> These varied methods have their respective emphases on promoting adaptive social behaviors or skills (behavioral strategies), affective engagement or social orienting (relationship-based strategies), and social understanding (cognitive strategies). They reflect three related but different social-communicative deficits in children with ASD, namely the lack of intent, understanding, or skills in social interaction. Intentions to interact provide the motivation for social behaviors, while an understanding of the social situation and the availability of skills determines the appropriateness of such behaviors. Whatever methods are employed, careful designs of the context and environment that meet the needs of children with ASD always constitute an important aspect of intervention planning (ecological strategies).

While it may appear overwhelming to those who seek simple answers regarding what to teach and how to teach children with ASD, the current state of affairs actually reflects the complex nature of social behavior as well as the wide-ranging symptoms and social development needs of these children. Before more conclusive findings about the etiology and nature of ASD or more rigorous evaluation methodologies are available, it is unlikely that a most effective treatment approach could be identified. Increasingly multi-methodology programs with different emphases will be attempted and evaluated.

Thus for parents and practitioners, rather than being obsessed about finding the best treatment that is universally most effective or following recipe approaches, attention should be focused on devising individualized interventions based on a careful assessment of needs and an awareness of the range of good or promising practices available.<sup>11-13</sup> The central issue becomes how best to utilize the range of rich resources to design interventions that are most appropriate for a particular child. Thus, a planning

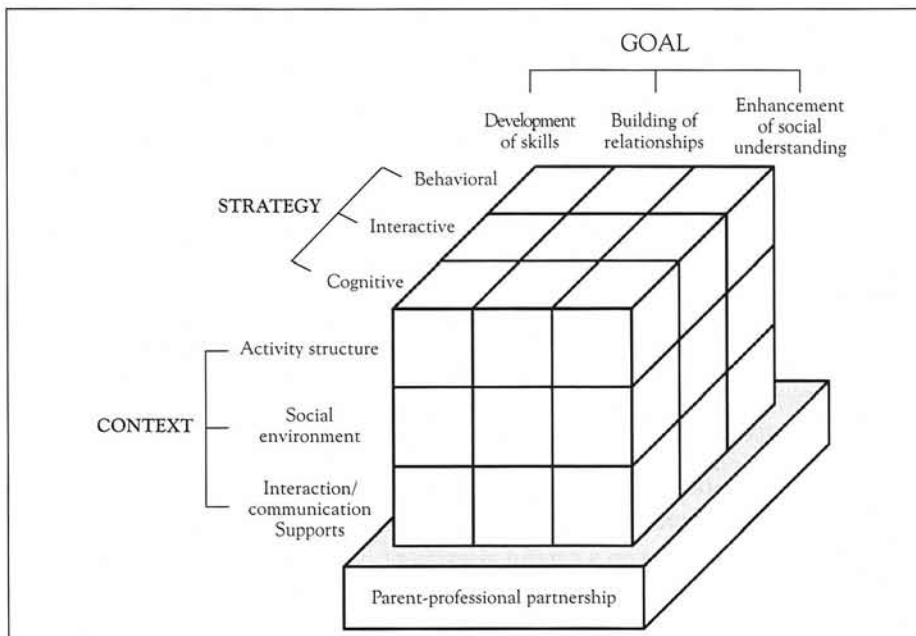
model that directly addresses important decisions that have to be made in intervention programming is very much needed. Without a clear framework for making intervention decisions, practitioners would easily succumb to piecemeal or recipe approaches that do not take into account the full range of possibilities, or be at a loss regarding how to amend their strategies when the expected intervention effects are not seen.

## Elements of the Intervention-Planning Model

The present model for individualized social-communication skills intervention planning is based on a few premises. First, children with ASD who are at different stages of development manifest varied social-communication development needs, which should be reflected in the respective emphases of their intervention goals and strategies. In other words, the importance of *individualized* intervention planning is underscored, and the most effective treatment could vary significantly for children with different needs. Second, as the development of skills using behavioral methods has best empirical support for its effectiveness for all children with ASD, this approach should remain the pillar of intervention. However, more recently developed relationship-based and cognitive strategies that enjoy extensive anecdotal support point to promising directions of development. These strategies enable us to move beyond the limitations of addressing only surface skills and behaviors. So combining these methods with behavioral strategies to support skills development appears a worthy direction for further exploration and validation. Third, these children have varied needs for structure and support in social-communication training. Thus, careful considerations of the activity and social environments are always an important aspect of intervention planning.

Accordingly a program-planning model consisting of three dimensions is proposed. The three dimensions include goal, strategy, and context, which are basic components of all intervention efforts and incorporate all salient aspects of the major methods available so far (see Figure 1). Elements

Figure 1: A model for social -communication skills intervention planning



under these dimensions represent different foci available for consideration in intervention planning rather than discrete categories that are mutually exclusive. In practice, current interventions are often characterized by multiple goals and strategies that support each other. Rather than emphasizing differences between approaches as incompatible, which sometimes leads to unnecessary antagonism, the present model focuses on how different methods that appear sound may be integrated into a coherent program with clear emphases to meet individual needs.

The process of planning is characterized by the derivation of clear goals based on a thorough assessment of needs, as well as the formulation of appropriate strategies and the arrangement of facilitative environments to attain these goals. Decisions along these dimensions directly point to the what, how, and where of intervention activities for a particular child.

### Derivation of Goals

The model specifies three broad goals of intervention reflecting the social and communication development needs of young children with ASD: (a) the development of *skills*, (b) the building of *relationships*, and (c) the enhancement of *social understanding*. These goals are all important aspects of social functioning that are mutually enhancing, with observable skills being major indicators of progress supported by the enhancement of relationships and related cognitions. Depending on the stage of development, different children with ASD would have different needs in relation to these three goals. For example, aloof children who display a distinct lack of interest in interpersonal interaction would benefit from programs that emphasize the promotion of affective engagement alongside skills development. In contrast, higher functioning ASD children with more advance cognitive and language abilities often have fewer problems with basic engagement and interaction skills. Yet many of them exhibit active-but-odd behaviors that arise from a weak theory of mind or poor empathy. Thus a main goal of intervention for these children would be to increase their understanding of more subtle social intricacies so as to support social skills development.

These three general goals for social-communication intervention are often integrated and complimentary aspects of training activities, but it is important to carry out intervention with a clear understanding of where the major deficits lie in terms of the three aspects of social behavior: intention, understanding, and skills, so that appropriate goals with matching strategies and contexts could be devised. Usually the nature of these deficits is determined by a thorough assessment of individual abilities and needs.

### Formulation of Strategies

Strategies that are most effective in achieving the desired outcomes have to be commensurate with the intervention goals and the child's developmental stage. Behavioral, interactive, and cognitive strategies are characterized by their different ways of eliciting the desired outcomes and providing feedback to the child. *Behavioral methods* directly help to establish behavioral patterns and skills, whereas *interactive methods* appear useful in the fostering of relationships and affective engagement. *Cognitive methods* have been less utilized with young children with ASD due to their cognitive limitations at an early stage of development, but their usefulness in promoting social understanding among high functioning children with ASD should not be ignored. Recent experiences have informed us that these varied strategies are not mutually exclusive but could be combined in creative ways to meet



practical needs. In intervention planning, assessment of an individual child's stage of social, cognitive, and language development as well as the matching intervention goals should determine the relative usage of this range of techniques and how they should be integrated in programs with different emphases.

## Arrangement of the Intervention Context

Practitioners need to consider whether certain goals are better achieved and certain strategies more efficiently employed in particular training contexts. Contextual arrangements for intervention include three major aspects: (a) the formulation of *activity structures*, (b) the manipulation of the *social environment*, and (c) the provision of *interaction/communication supports* where necessary.

The formulation of activity structures could be considered along three lines, namely the physical setting, time schedules, and activity routines. The extent and nature of structure provided should vary according to individual children's needs. While inadequate environmental structure would lead to communication problems as well as emotional and behavioral difficulties among children with ASD, the overuse of structure may hinder interpersonal initiatives and reinforce rigidity. In general, planned environments with a high degree of structure are required for children with lower levels of cognitive or social functioning, while higher functioning children may benefit more from interventions carried out in more naturalistic or inclusive settings. However, for many children with ASD, an appropriate mix of the two types of training environments should achieve optimal results.

The manipulation of the social environment is particularly important for effective social-communication skills intervention. For aloof children who are not affectively engaged and have not yet mastered basic skills in interpersonal interactions, one-on-one design sessions would be necessary to provide intensive interactive experiences that characterize many interactive or relationship-based approaches. In contrast, group-based interventions that allow for learning through peer interactions would meet the needs of many passive or active-but-odd children. A related consideration in program planning concerns the agent or mediator for social skills development. With traditional behavioral methods, the role of instructor is usually played by adults who are highly controlling and directive. However, the recent use of more naturalistic and interactive methods has gradually changed the role of the mediator from instructor to communication partner in some training situations, with the emphasis being shifted from being directive to facilitative. The trend of inclusion also provides more opportunities for peer-mediated intervention.

Very often social participation on the part of children with ASD could be greatly facilitated by specially designed interaction or communication supports. These supports include various forms of social routines; visual tools in the form of objects, pictures or words; and communication aids such as the Picture Exchange Communication System (PECS).<sup>14,15</sup>

## The Planning Process

Systematic program planning based on the proposed model should always start with goal setting. A thorough assessment of the child's social-communication development needs in relation to affective engagement, social skills, and social understanding will inform about appropriate goals and objectives for intervention. Then planning for activities to achieve these goals would involve considerations of strategies to be used and the appropriate contextual arrangements that would enable or support the use of these strategies.

By way of example, if a young child with ASD is assessed to be socially aloof with significant cognitive delay, characterized by an almost complete lack of social attention, communicative intent, and basic joint attention or interaction skills, appropriate social-communication intervention goals should be mainly in the areas of relationship building and skills development. The corresponding strategies to attain these goals would be mainly interactive and behavioral, aimed at providing strong and rewarding interpersonal experiences to elicit the emergence of basic social attention and interaction skills. The contextual arrangement that would facilitate these procedures should emphasize highly structured one-on-one sessions with a familiar adult as the mediator. In contrast, when a child with above average intelligence is assessed to be active-but-odd, who possesses good social initiatives as well as basic interaction or conversational abilities but displays a very egocentric style of interpersonal interaction, appropriate goals for intervention would focus on enhancing social understanding (theory of mind and empathy) to support the development of related skills. Cognitive-behavioral strategies would be most appropriate in this case, and contextual arrangements that support these goals and strategies should emphasize peer groups, naturalistic situations, and perhaps also self-regulation supports such as conversational scripts.

If intervention effects are found to be less than desirable upon the implementation of the program, adjustments could be made after a careful consideration of each of the activity dimensions (goals, strategies, and various contextual arrangements) and how well they are integrated in use. In this way the present model provides a framework for parents and practitioners to systematically and comprehensively evaluate and amend their methods on a continuous basis. This would help to ensure the best combination of methods to achieve the best outcomes. Throughout the process, parent-professional partnership serves as an important foundation for effective decision-making.

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## Conclusion

The proposal of this eclectic model is not an introduction of a new method of intervention but rather an attempt to provide a framework for understanding the relationships and relative contributions of popular methods, which are not necessarily contradictory and could be integrated for effective use. The intention is to promote optimal but proper utilization of currently available methods and to help resolve some of the controversies surrounding diverging methods. Importance is also accorded to the integration of goal, strategy and context exhibiting clear program emphases, as poor matching of these program elements would seriously hamper intervention effectiveness.

Effective programming based on this model requires accurate assessments of children's needs as well as competent judgments by parents and practitioners. The challenges ahead lie in the development of more refined tools for assessing early social-communicative functioning of children with ASD, the enhancement of related personnel expertise, as well as continued research to delineate which particular combinations of methods are best for children expressing particular autistic syndromes.

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