Dustin Hoffman's portrayal of an autistic character in the hugely popular movie *Rain Man* possibly brought the world's attention to the sufferings of an autistic man. But what if the sufferer was a child? Is it normal for a child to refuse to hug or be hugged? What if the child engages in odd ritualistic movements like rocking or uses gestures instead of words to communicate? These are just some subtle signs of autism that a parent might miss.

So what is autism? What impact does it have on the child? Can it be treated? *Living with Autism* provides important information about this developmental disorder, and the treatments and therapies available, and gives suggestions as to how families can cope with autism. This sensitively written book is essential for parents, teachers and caregivers.

Revised and updated, *Living with Autism* is part of a series of handbooks on mental health in children written by mental health professionals from the Child Guidance Clinic. Other titles in the series are:

- Attention-Deficit Hyperactivity Disorder (ADHD)
- Anger
- Discipline Issues
- Divorce and Family Issues
- Grief
- Intelligence and Learning Difficulties
- Self-harm Behaviours
- Sexuality Issues
- Stress

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**Dedicated to**
**all the children of the Child Guidance Clinic**
**and their parents**

## CONTENTS

## PREFACE

Autism is something very close to my heart and I have been working with this population for more than 10 years. Persons with Autism Spectrum Disorder (ASD) have to cope with a wide range of difficulties. While many make notable improvements with support over time, they face different challenges at various stages of life.

Support services in Singapore have grown significantly over the last 10 to 15 years. Developmental paediatricians from the KK Women and Children's Hospital and National University Hospital are skilled in early diagnosis and assessment of these children. The Adult Neuro-Developmental Service at the Institute of Mental Health supports adults with ASD. We have early intervention centres, special schools and adult centres catering to this population. The Ministry of Education has developed a team of Allied Educators to support these children in mainstream schools. Voluntary welfare organisations like the Autism Association of Singapore and the Autism Resource Centre champion their needs. Public awareness is improving with increasing media coverage and activities like the annual World Autism Awareness week organised by students from the Duke-NUS Graduate Medical School. Tertiary institutions, such as the National University of Singapore and the National Institute of Education, actively engage in local research in autism.

When the Child Guidance Clinic first started developing specialised services for ASD in 2006, we saw about 70 new cases annually. The Neuro-Behavioural Clinic (Autism Services) currently has over 300 referrals to our clinic a year. We have also refined our focus over time to specialised diagnostic assessments and managing children and adolescents with ASD and co-morbid mental health issues. We do active parent education and run training for fellow professionals in ASD. We have also incorporated ongoing research projects with our clinical services to provide a vibrant centre with different options available for our patients.

This book has been authored by a multidisciplinary team of professionals from our clinic (past and present), each with their own skill set to offer. It incorporates updated knowledge on ASD and the clinical experience our team has gained from our last 9 years of specialised practice. We also seek to offer information on the local scene and services available in Singapore to provide practical support for parents here. While knowledge in ASD and developing services for this population is certainly still a work in progress, we look forward to a better future for all persons with ASD and their families.

**Dr Sung Min**
July 2015

# PART 1

# CONCEPTS OF AUTISM SPECTRUM DISORDER (ASD)

## INTRODUCTION

Autism Spectrum Disorder (ASD) is a lifelong neuro-developmental disorder, typically diagnosed between the ages of 4 and 5. Recent prevalence studies point to an increasing trend worldwide. A study on global prevalence for autism in 2010 reported a rate of 7.6 per 1,000 or one in 136 individuals diagnosed with ASD. There are no prevalence studies on ASD done in Singapore to date. However, there is an estimated prevalence of 24,000 individuals with ASD in our population of 4 million, with 5,472 children under the age of 19 years. Approximately 216 new cases of children with ASD are diagnosed annually.

Persons with ASD face social-communication difficulties and have accompanying rigid and stereotypical behaviours. These result in a huge impact on their lives and that of their caregivers. A Ministry of Health study in 2009 using WHO's Disability Adjusted Life Years (DALYs) showed that child and adolescent mental health disorders contributed to three of the top five conditions in youths under the age of 15, with ASD having the highest disease burden, impacting patients and caregivers significantly in all aspects of life, such as financial burden, quality of life, and mortality rate.

In line with the Ministry of Social and Family Development's Enabling Masterplan (2012-2016), we hence must work towards developing the autonomy and independence of persons with ASD, empowering their families in their journey, taking on an inclusive approach and integrating them into society. This book hopes to contribute to this vision by giving an overview of ASD and providing strategies and resources for families and professionals to support them on their journey with their children.

Autism is a fairly new concept which has only been recognised for the last 70 years. Our understanding of Autism Spectrum Disorder (ASD) has evolved over the years and will continue to do so as ongoing research broadens our knowledge base of this intriguing developmental disorder. While current descriptions of autism focus on behavioural presentations, research on the biological basis of autism is now taking the forefront.

## 1.1 THE HISTORY OF ASD

In 1943, Leo Kanner, a paediatrician and psychiatrist in the United States, described eleven children who struck him as sharing "fascinating peculiarities". The children exhibited:

- echolalia (repeating what was previously said),
- an anxious desire to preserve sameness,
- repetitive behaviours,
- a general lack of awareness of other people's existence,
- a lack of ability to play imaginatively with other children,
- pronoun reversal,
- failure to use speech to communicate.

Some of these children functioned at an impaired level in many aspects, even though they gave an impression of normal intelligence. Kanner adopted the term "early infantile autism" to describe these children. At about the same time, a Viennese paediatrician Hans Asperger described children who were quite similar to Kanner's patients and labelled their difficulties as "autistic psychopathy".

In the 1950s and 1960s, Swiss psychiatrist Bruno Bettelheim theorised that children became autistic because of their cold "refrigerator mothers". This has since been shown to be untrue. There was also controversy over the nature of the disorder as it was confused with schizophrenia in adults, which was also described by Bleuler, another Swiss psychologist, as autism. This led to clinicians using terms like '"childhood schizophrenia" and "infantile psychosis" to describe autism.

Recent studies suggest that there is a neuro-biological basis for ASD. This has led to the general acceptance of ASD to be a spectrum of disorders originating in the brain, rather than just a set of behaviours or due to the individual's environment.



## 1.2 CLASSIFICATION OF ASD

There are two sets of criteria that are currently used worldwide:

- The ICD Classification of Mental and Behavioural Disorders.
- The Diagnostic and Statistical Manual of Mental Disorders (DSM).

In the early 1970s and 1980s, these two classifications had different concepts of autism, although the diagnostic criteria for the disorder were similar:

- The ICD considered autism as "psychosis with origin specific to childhood".
- The DSM viewed autism as part of a group of disorders called the Pervasive Developmental Disorders.

These two sets of diagnostic criteria have changed over the years as people's understanding of autism grew.

Today, the ICD-10 has a classification for "Childhood Autism" while the DSM-5 combines the previous DSM-4 classifications of Pervasive Developmental Disorder Not Otherwise Specified, Asperger's Syndrome and Autistic Disorder into a single category of Autism Spectrum Disorder (ASD). This collapsing of three distinct categories into one group in the DSM-5 classification has been based on research findings suggesting that there is no clear delineation between the categories but rather a spectrum of disorders with varying presentations.

In this book, we will use the term Autism Spectrum Disorder (ASD) to refer to this spectrum of developmental disorders.

# PRESENTATION OF ASD

PART 2

Autism Spectrum Disorder (ASD) is a range of disorders of development. There is impairment in social interaction, verbal and non-verbal communication and repetitive or restrictive behaviours. A diagnosis of ASD can be made when symptoms are observed to be present in the early developmental period, although in some cases, symptoms may not be obvious till social demands exceed the individual's capacity to cope. These difficulties cause clinically significant impairment in the individual's functioning. These impairments should also not be better explained by other disorders, disabilities, or developmental delays.

ASD has often been diagnosed much more frequently in males than in females, with a ratio of 4:1. Research has suggested that this may be likely because females with ASD present differently from males and might be often overlooked in diagnosis.

Children with ASD do not display a fixed set of symptoms. This means that one child's symptoms may be different from another and the symptoms may also vary in their severity. The symptoms may also combine in a unique way for each child, thereby producing different sets of problems or difficulties among children with ASD. For this reason, this is considered a "spectrum" of disorders.

## 2.1 SIGNS AND SYMPTOMS OF ASD

Children with ASD suffer impairments in the areas of:

- social communication and interaction,
- restricted and repetitive activities and interests.

In addition, some children also display difficulties in motor activities, intellectual functioning, as well as general developmental delay. However, only the first two criteria are specific and diagnostic for ASD.

### Social Communication and Interaction

Many children with ASD do not develop functional speech. Verbal children with ASD may often display some idiosyncrasies such as echolalia ("parroting" words), repetitive speech patterns, pronominal reversal and the use of neologisms (made-up words). Many have difficulty having reciprocal conversation. Children with ASD are also often very literal in their speech and they may have difficulties in understanding sarcasm, witty puns or metaphors. They may lack spontaneity in sharing interests and experiences with others.

Children with ASD also have difficulties in understanding social cues. Many lack the intrinsic skills that help them engage in social interaction. One characteristic is that these children have difficulty establishing appropriate eye contact or using communicative gestures in their interaction with others. At times, they seem to be unaware of other people's emotions and may unintentionally say or do things that are socially inappropriate. They may also have difficulties in perspective-taking, finding it difficult to understand that another person may not be feeling or thinking the same way or about the same thing as themselves. Many have difficulties initiating interactions with others or establishing and sustaining friendships with their peers.

### Restrictive and Repetitive Activities and Interests

Children with ASD may have strong, restricted interests, such as in animals, maps or vehicles. They may have very strong preferences for doing only a few repetitive specific activities like spinning objects or arranging things in a particular order. They may also display motor mannerisms, such as flapping their hands or spinning movements. Some children may have a need to adhere to specific routines without being flexible and may become quite upset if there is a change in their routine. They may either seek or avoid specific sensory stimuli, such as certain sounds, smells, touch or sight. In addition, they may not engage in imaginary activities and pretend-play in the same way their peers might do.

Some signs and symptoms that a child with ASD may exhibit include:

- difficulty in expressing needs,
- engages in odd ritualistic movements such as rocking,
- laughs, cries or shows distress for reasons not apparent to others,
- temper tantrums,
- prefers to be alone,
- difficulty in mixing with other children or adults,
- unable to relate to others in socially appropriate ways,
- not responsive to normal teaching methods,
- not responsive to verbal cues/acts as if deaf although hearing tests are in the normal range,
- sustained play and special interest with certain toys or objects,
- over-sensitive or under-sensitive to pain,
- noticeable physical over-activity or extreme under-activity,
- uneven gross/fine motor skill development.



While these symptoms may suggest a need for further assessment, they may not be specific to ASD. Furthermore, because ASD is based on a range, rather than a clear-cut presence or absence of symptoms, the difficulties and impairments mentioned might also not be present in all individuals with ASD. There might also be a difference in severity and some individuals might have great difficulties in some areas while seemingly being unaffected in other areas.

## 2.2 PERVASIVE DEVELOPMENTAL DISORDERS

In the DSM-4 diagnostic criteria, Pervasive Developmental Disorder was an umbrella of disorders covering Autistic Disorder, Asperger's Syndrome, Rett's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified

### Asperger's Syndrome

This describes a group of children with social interaction difficulties and a pattern of repetitive, rigid interests and behaviours. There is normal cognitive and language development.

### Rett's Syndrome

This is a rare disorder that occurs mainly in girls. The child develops normally in the first six to 18 months, but after that shows a change or regression in skills and abilities. There is also a characteristic repetition of gestures or movements like hand-wringing that seem apparently meaningless.

### Childhood Disintegrative Disorder

This is an extremely rare disorder. There is a very clear regression in many areas of functioning such as loss of bowel control or language skills after two years or more of normal development which is not due to any other injury or trauma.

### Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS) / Atypical Autism

This covers the group of individuals who do not fully meet the criteria of the symptoms that are used to diagnose Autistic Disorder, Asperger's Syndrome, Rett's Syndrome and Childhood Disintegrative Disorder.

As mentioned earlier, the new DSM-5 has brought together these formally distinct disorders into a single category of Autism Spectrum Disorder (ASD). Individuals who may have difficulties in social communication and interaction, but fail to meet the criteria for an ASD diagnosis, may be diagnosed to have Social Communication Disorder.

## 2.3 THEORIES OF AUTISM

### The Mindblindedness Theory

In psychology, the "theory of mind" refers to the ability to infer other people's thoughts, beliefs, desires or intentions. This ability is an important requirement for understanding the behaviour of others. If we understand someone else's beliefs and desires, we can use that understanding to predict how that person will feel.

The mindblindedness theory postulates that the individual with ASD has difficulty with the "theory of mind" and is, hence, unable to put himself into other people's shoes and make predictions about how others will behave. This leads to poor social cognitive skills, which explains why the person with ASD often appears to "act strangely" or behave inappropriately in social settings.

### The Executive Dysfunction Theory

In this theory, the individual with ASD is believed to have difficulties with the cognitive tasks that are required for normal social interaction. This means that the individual may have problems with attention shifting, planning, working memory, impulse control, inhibition and mental flexibility, as well as for the initiation and monitoring of actions. This may sometimes explain difficulties in ASD children such as organising their activities or relating events in a clear sequence.

### The Theory of Weak Central Coherence

In this theory, it is assumed that the individual with ASD finds it more challenging to put together individual parts to form a whole and "cannot see the wood for the trees". Hence, the individual may have trouble making sense of the complexities of normal social behaviours and, as a result, have difficulties in social situations. For instance, the ASD child may be more interested in a speck of dirt on his teacher's spectacles than the lesson that the teacher is delivering.



### The Neural Connectivity Theory

Imaging of the brain has found differences in the activation, signalling and connectivity between the brains of individuals with autism and that of the general population, meaning that individuals with ASD are likely to process information differently from the general population.

All these theories may actually be related to each other in the sense that they explain the deficits that individuals with ASD have at different levels. For instance, because of executive dysfunction, the person has difficulty with putting individual parts to form a whole and because of this, he appears to lack a "theory of mind". These are all also related to the fact that the brain of the individual with autism functions differently from that of the general population and hence leads to the individual's differences in processing of information and in reaction to stimuli.

## ABOUT THE AUTHORS

### Dr. Sung Min

Dr Sung Min is a Senior Consultant at the Department of Child and Adolescent Psychiatry, Institute of Mental Health (Singapore), where she is the Programme Director of the Neuro-Behavioural Clinic (Autism Services and ADHD Services). She is also a Senior Clinical Lecturer at the Yong Loo Lin School of Medicine.

She obtained her Master of Medicine (Psychiatry) from the School of Postgraduate Medicine (National University of Singapore) and obtained her Advanced Specialist Training in Psychiatry in 2004. In 2005, Dr. Sung received the Healthcare Manpower Development Plan Fellowship Award and was attached to the Autism and Related Disorders Team at the Michael Rutter Centre for Children and Young People at the Institute of Psychiatry, United Kingdom.

Dr Sung is involved in local research projects on Autism Spectrum Disorder. She is an Independent Trainer in the Autism Diagnostic Interview — Revised and the Autism Diagnostic Observation Schedule.

### Lena Heng

Ms Heng read Psychology for her undergraduate studies and obtained a B.Soc. Sci (Hons) from the National University of Singapore. Through her undergraduate studies, Ms Heng found her interest in autism and developmental disorders and did her honours research on teaching language to children with autism. Upon graduation, she worked as a psychologist at the Child Guidance Clinic, Institute of Mental Health. During her stint there, she co-authored the first edition of this book.

Equally interested in music, Lena has since went on to further her studies in music and is currently a full-time musician as well as a lecturer at the Nanyang Academy of Fine Arts.

### Ms Magdalene Foo

Ms Magdalene Foo, a registered social worker and a trained family and systemic psychotherapist, is a Principal Medical Social Worker at the Child Guidance Clinic – Neuro-Behavioural Clinic (Autism Services). Her expertise includes therapy and intervention for children and youths diagnosed with Autism Spectrum Disorder (ASD), family therapy and parent coaching on managing challenging behaviours.

Ms Foo obtained her bachelor degree in social work at the National University of Singapore and a master degree in family and systemic psychotherapy at the Institute of Family Therapy (London) in collaboration with Middlesex University, London, UK. She was awarded the Singapore Ministry of Health's Healthcare Manpower Development Plan Fellowship at The Hospital for Sick Children, Toronto, Canada.

Ms Foo started her social work career in 1994 at a special school for children with intellectual disability. Her clinical experience also included a number of years as a counsellor in a polytechnic. Since 2001, she has been working specifically with individuals diagnosed with ASD and their families. She joined the Child Guidance Clinic, Institute of Mental Health in 2006.

### Ms Kheng Joo Lian

Ms Kheng is currently a Principal Educational Psychologist at the Child Guidance Clinic – Neuro-Behavioural Clinic (Autism Services) in Singapore. She is also a Registered Psychologist with the Singapore Psychological Society. She holds a Master of Science degree in Educational Psychology from the University at Albany, New York, USA and a post-graduate diploma in Solution — Focussed Brief Therapy.

Over the last 10 years, she has worked extensively with children diagnosed with neuro-developmental disorders such as Autism and Attention Deficit Hyperactivity Disorder as well as children with specific learning disabilities. In 2009, she was awarded the Health Manpower Development Plan Overseas Fellowship at The Hospital for Sick Children, Toronto, Canada.

She is passionate about work with children and is guided by the belief that an essential goal in the therapeutic process is to give back to the child a sense of ableness and joy in his/her own endeavours.