whene?vhywh?me?whyme?nw? Whyene?vhywh?me?whyme?nw? Marine?vhywh?me?whyme?nw? Marine?vhywh?me?whyme?nw?

A Parent's Journey With a Preschool Child With (ASD) Autism Spectrum Disorder

by Dr Shan Narayanan

Consultant Paediatrician ICF Master Certified Coach HRDF Certified Trainer

contents

ACKNOWLEDGEMENT	8
INTRODUCTION	9
FOREWORD	12
TESTIMONIALS	14



CHAPTER 1 BEFORE DIAGNOSIS

Child Development Concerns Regarding Development Deciding Further Evaluation 17



CHAPTER 2 DIAGNOSIS

28

40

Assessment Process Diagnosis

CHAPTER 3

WHAT IS AUTISM SPECTRUM DISORDER (ASD)?

What Is Autism Spectrum Disorder? What Is the Cause? Theory of Mind





CHAPTER 4: AFTER DIAGNOSIS

53

Treatment Management

- Session 1 General Principles Early Intervention Programme
- Session 2 ABA TEACCH
- Session 3 Motor skills Sensory Processing Difficulties Attention Meltdowns
- Session 4 Communication Skills Social Skills Daily Living skills



CHAPTER 5 CONCLUSION 116

The Journey Coping With It All The Journey Continues Ten Things Every Child With Autism Wishes You Knew

APPENDIX	158				
 Diagnostic Criteria for 299.00 Autism Spectrum Disorder Meltdown Escalation / Recovery Cycle 					
REFERENCES	167				
ABOUT THE AUTHOR	173				



BEFORE DIAGNOSIS

In this chapter:

Child Development Concerns Regarding Development Deciding Further Evaluation

It is important to understand a child's normal development to decide if the child has a developmental issue.

Muhaimin, a lovely 3-year-old, started walking at the age of one. He called his daddy "*abah*" and mummy "*ibu*". As he reached one-and-a-half years, he lost these words. He would not respond when called or look at his parents' face. His mother, Puan Mohanita, was concerned about this. His father reassured her, saying he was young and needed time. He reminded her that the elderly people used to say boys tend to develop more slowly than girls. Another one-and-a-half year passed, and Muhaimin seemed to become more wrapped up in his own world. He liked to place and arrange his toys in a row. He hardly used any words. If he wanted something, he pulled his mum's hand to the item and used her hand to take it. At times he cried and they never understood why he was crying.

Puan Mohanita's maternal intuition told her something was not right. She booked an appointment with her general practitioner (GP), who felt that Muhaimin needed an evaluation of his development and referred them to me.

Puan Mohanita walked into the consultation room looking anxious and flustered. As soon as he came in, Muhaimin started wandering about the room. He did not pay me any attention; he was more keen on the objects in the room. My assistant tried to engage him in play as I greeted Puan Mohanita.

(S: Dr Shan; M: Puan Mohanita)

- S: Good morning, Puan Mohanita.
- M: Good morning, Dr Shan.
- S: How can I help you, Puan?
- **M:** Doctor, my son Muhaimin is three years old. I am concerned if his development is normal.
- S: Puan, why are you concerned about his development?

- **M:** He is three years old and he is not talking. In fact, he lost the words he had when he was one-and-a-half years old.
- **S:** Oh, I see... Puan, it will be easier to assess his condition if you understand what normal development is. Do you understand the normal development of a child?
- M: Not much, Doctor. Can you please explain?
- **S:** Sure, Puan Mohanita. Child development refers to the sequence of changes that occur from birth to adulthood in the developmental domains¹.
- **M:** Developmental domains?
- **S:** (Showing a diagram) There are four developmental domains, namely:
 - Gross Motor
 - Vision and Fine Motor
 - Hearing, Speech and Language
 - Social, Emotional and Behavioural



- M: Can you please tell me more about each domain?
- **S:** Gross motor skills are also known as physical skills. These skills involve movement of the large muscles of the arms, legs and body. The skills include sitting, crawling, standing, walking, running, jumping, throwing a ball, climbing stairs and such. Gross motor skills are important for movement and they are related to one's balance and coordination.
- **M:** I can vividly remember Muhaimin developing these skills. Now, he is running all over most of the time. He has some difficulty in throwing and catching balls.
- S: I'll take note of that, Puan; we will address it soon.
- M: Doctor, what about fine motor skills?
- **S:** Fine motor skills² involve movements using the small muscles in the hands and wrists. A child relies on these skills to do tasks in everyday life and school. Fine motor skill relies on good vision. Thus, they are grouped together.
- M: Can you please give some examples of fine motor skills?
- **S:** Sure, Puan. We use fine motor skills every day; the examples are using the hand or fork and spoon to eat, zipping and buttoning up, brushing teeth and combing hair. They are also needed for a child to assemble blocks or construction sets, and using the mouse, pencil and scissors.

- M: Muhaimin is able to eat with his hands, though the food drops all over the place. He holds the pencil like he is holding a dagger and scribbles. He has difficulty with using the fork and spoon, assembling blocks or construction sets and using the scissors.
- **S:** As before, I have taken note of what you have said; we will discuss it later.
- **M:** Thank you, Dr Shan. As I mentioned earlier, Muhaimin is not talking yet. Can you please elaborate on speech and language development?
- **S:** Certainly. Firstly, for speech and language development, hearing is important. Have you had his hearing tested?
- **M:** I have not done a hearing test but I believe his hearing is normal as he responds to music and nursery rhymes that he likes.
- **S:** I take your word that his hearing is normal. Still, it is good to have an objective test done to confirm that his hearing is fine. Is it all right with you?
- M: (Smiles) Sure.
- S: I will arrange a hearing test for him. Puan, speech and language have a great effect on a child's behaviour, social interaction, learning and ability to communicate³. Children develop speech and language at different rates³.
- **M:** The term you used is "speech and language". Aren't they one and the same?

- S: No Puan, speech⁴ is the actual sound produced and spoken words. It involves articulation, i.e. using the mouth, lips and tongue to produce voice with the help of the vocal cords and breath. When this is done smoothly and effortlessly, the child is said to have fluency in speaking⁶.
- M: Oh... okay. What about language?
- **S:** Language⁴ is the child's ability to understand what is said to him and to express his ideas and wants. The understanding also affects the way he interprets instruction and responds to it⁶.
- **M:** It is becoming clear now... What is the pattern of speech and language development?
- **S:** We will come to it once we have discussed the next domain.
- M: Okay Doctor.
- **S:** The next domain is social, emotional and behavioural development⁵. These skills are actually a spectrum of psychological development. Examples of social skills are eye contact, sharing, using manners and listening when others talk to them.

Emotions (feelings) and behaviour are dependent on selfregulation. Self-regulation is the ability to understand and manage one's own behaviour to emotions and things happening around them. Social, emotional and behavioural skills help one to get along with peers and others.

- **M:** I am beginning to understand the development of a regular child. Do all children develop in the same way?
- **S:** Good question, Puan Mohanita. Each domain has many skills. Each skill is called a milestone. The development of each milestone follows a sequence. There is an age range for when a child should reach each milestone.
- **M:** (Looking confused) I do not understand, Doctor. Can you give an example?
- S: Well Puan, there are three parts to what I said earlier.

The first part is skills (milestones). For example, in the gross motor domain, the skills to develop are as follows:

neck control \rightarrow rolling over \rightarrow sitting with support \rightarrow sitting without support \rightarrow standing with support \rightarrow standing without support \rightarrow walking with support \rightarrow walking independently \rightarrow running \rightarrow jumping and climbing

The second part is sequence, i.e. the development of the skills (milestones) occur in a pattern. The sequence in gross motor development is from neck control to jumping and climbing. This sequence is the same for all children.

The third part is rate. There is an age range for each skill (milestone) to develop. For example, most children walk between 12 and 18 months.

Do you understand, Puan?

- **M:** (Looking puzzled) Yes...
- S: Why are you looking puzzled, Puan?
- **M:** (*Giggling*) Knowing all this, when should I be worried whether my child is developing normally?
- **S:** Excellent question, Puan. To know if your child is developing normally, you need to understand the "median age" and "red flag age" for a particular skill (milestone).
- M: Median age? Red flag age?
- S: Median age⁶ is the age at which 50% of children in that age group have achieved the skill (milestone). For example, the median age for walking is 12 months.

Red flag age⁶ is the age at which 97.5% of children in that age group have achieved the skill (milestone). The red flag age for walking is 18 months.

If a child has not achieved the skill (milestone) by the red flag age, then the child is delayed in that skill (milestones).

M: It is beginning to become clear. Do you have more examples?

Age	Gross Motor	Fine Motor	Speech & Language	Social, Emotional & Behaviour
Newborn	Flexes posture	 Follows face or light by 2 weeks 	 Stills to voice (Remains still at hearing voice) Startles at loud sounds 	• Smiles by 6 weeks
7 months	Sits unsupported	 Transfers object from hand to hand 	 Turns to voice Polysyllable babbles 	 Finger feeds Fears strangers
1 year	Walks independently	 Pincer grasp (10 months) Points 	 2-3 words Understands names 	 Drinks from cup Waves
15 to 18 months	Walks steadily	 Immature grip of pencil Scribbles 	 6-10 Words Points to 2 body parts 	 Feeds self with spoon Starts to self-dress with help

S: (Hands over a sheet of paper) Puan, you can refer to this table:

(Table 1) Developmental milestones in each domain by median age¹.

- **M:** (*After reading the table*) Dr Shan, what is the red flag age for Muhaimin to say words?
- **S:** 18 months.
- **M:** (Looking worried) Muhaimin is three years old and he says fewer than five words. So, his speech is delayed.
- S: Yes, Puan.

- **M:** Dr Shan, to be honest, I am worried about and scared for him. Can you please check his development?
- **S:** Your feelings are valid, Puan (she becomes relaxed as her feelings are acknowledged). We can check his development, but it has to be by appointment as it takes time. Hope this is okay.
- M: Sure, Dr Shan.
- **S:** (Hands over Muhaimin's appointment card with an appointment) Thanks Puan, here is the appointment. See you then.
- M: Thank you, Dr Shan. See you at the next appointment.

(As Puan Mohanita consults me, my assistant keeps Muhaimin occupied and after some time, Muhaimin falls asleep. Puan Mohanita carries him and leaves the clinic, a little less anxious than when she arrived.)

At the age of three, Muhaimin:

- Said fewer than five words.
- Communicated mainly by crying.
- · Parents could not understand why he was crying.
- At times, he pulled his parent's hand to the items he wanted.
- He was wrapped up in his own world.
- He liked to place and arrange his toys in a row.

The above features are of concern and required further evaluation. Puan Mohanita rightly made an appointment to further evaluate Muhaimin's development.



Muhaimin in his own world.