

Me & my child with Down syndrome

PARENTAL BOOKLET

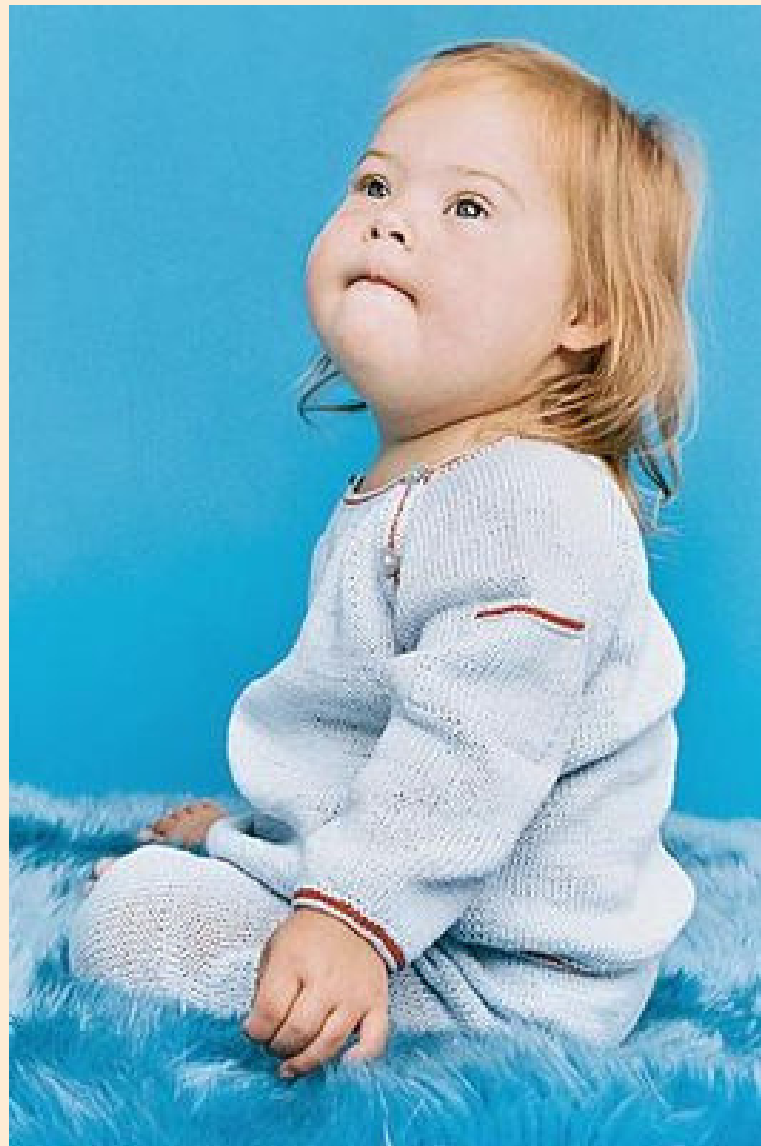
*For these
beautiful people,*

MADE BY: MARIAN LIM

INTRODUCTION

This parental booklet aims to help parents who are expecting or raising children with Down syndrome, from birth to 2 years of age, answer some questions regarding their language development, and provide useful resources and sound advice to aid you in your parenting journey.

However, it is important to remember that as with typically developing children, children with Down syndrome are individualistic and have different profiles and developmental stages; it is important to keep track of your child's milestones and progress and seek the advice of your therapist or doctor in order to determine new goals and work on strengthening necessary developmental areas.





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HOW WILL THE LANGUAGE DEVELOPMENT OF MY CHILD WITH DOWN SYNDROME BE AFFECTED?



A child with Down syndrome would typically present with cognitive delays, albeit not equal across the areas of development [26]. Therefore, it is not uncommon for them to also face developmental lag in the linguistic domain. The aspect of speech and language is typically where children with Down syndrome face the most delay in development, more so than non-verbal abilities [6]. Children with Down syndrome will nonetheless achieve progress in all developmental areas as with other children, just at a slower rate [6]. However, do not be disheartened, because majority of children with Down syndrome display strengths in the domain of motor skills, social progress and behaviour, and by the age of five, they are usually toilet-trained, able to feed themselves, put on certain items of clothing and able to follow instructions [6].



Another important factor to take note of would be the hearing abilities of your child. Many children with Down syndrome experience some form of hearing difficulty [6,24]; in the case where your child's hearing is impaired, it is crucial that you seek proper treatment and/or assessments as early as possible, so to maximise the opportunities and quality of aural language input for your child, which is vital during their early years [24]. Consequently, you might experience some trouble understanding your child's speech at times due to their hearing difficulties [6].

HOW WILL THE LANGUAGE DEVELOPMENT OF MY CHILD WITH DOWN SYNDROME BE AFFECTED?



Does your child seem to be able to respond to your words/commands, but not reply/respond verbally as efficiently to your questions? That is not uncommon; most children with Down syndrome are better at receptive language than with expressive language [6,23,25] meaning that they are better at understanding you than they are at verbalising their thoughts and feelings. Their reading skills are often a strength from 2 years of age onwards [6]. It is common practice to use signs and encourage gestures alongside speech to children with Down syndrome as they may depend on non-verbal abilities i.e. gestures for a longer time as compared to other children, and this is part of their language development as their use of gestures will be replaced by signs/words acquired as they grow [5]. More specifically, they face greater difficulties in the areas of phonology and morphosyntax [23,25]- the sound inventory and the grammar of a language respectively.

Children with Down syndrome have the potential to lead independent and fulfilling lives as well as integrate into mainstream institutions, but early intervention – especially during the first three years of life – is crucial, specifically speech and language therapy in this context [10]. Some tips on how you can facilitate and aid your child's language development will be shared later in the booklet.

CAN THEY STILL BE BILINGUAL?



Living in a bilingual country, and considering the fact that children with Down syndrome would be slower in language development than typically developing peers, it is only natural that this would be of major concern. Notwithstanding the factor of delayed language development, it is possible for your child to acquire and use two languages, and there is no evidence of bilingualism being detrimental for children with Down syndrome [8,16,18,21] albeit the dearth of research regarding bilingualism and Down syndrome specifically [9,21]. However, there have been anecdotal evidences of successful bilinguals with Down syndrome [3,4].

Nevertheless, the amount of exposure and quality of language input for both languages, as well as the use of the languages are extremely important for the language development of typically developing children [19,28] and is no different for children with Down syndrome [18].



WHAT CAN I DO TO HELP THE LANGUAGE DEVELOPMENT OF MY CHILD WITH DOWN SYNDROME?

To work on strengthening your child's oral-motor muscles, some simple activities you could partake in with your child would be: blowing bubbles or horns, drinking through a straw, blowing out candles [15] and reading nursery rhymes [2]. Additionally, you could also consult your speech language therapist regarding products such as bite blocks intended for the development of oral-motor abilities [15]. Encouraging your child to breathe through the nose instead of their mouth will also help improve speech intelligibility [2].

Children with Down syndrome are typically visual-learners [12,13,15] and will benefit greatly when they have a multisensory learning experience [26], and when concrete and practical visuals aids or models are utilized when teaching words [15]. They also benefit from learning signs alongside speech due to their slower language development, which facilitates comprehension, decreases detrimental effects of delayed language production and enables them to communicate symbolically [5,26]. The use of gestures i.e. pointing should also be encouraged as they lead to language production and is part of the language development process [5].



Reading activities with your child should be a daily routine as it can be an outlet of fun and interaction for you and your child while also benefitting their language development greatly [5] because it supports language comprehension and production, and is a method for teaching your child new words [5] as well as grammar skills [20]. Be engaging and interactive- get them to bring you their favourite book, encourage them to flip the pages and point to the pictures while you read [26,27].

It is also highly advisable to start the habit of keeping a 'progress logbook' for jotting down observations and improvements in your child's daily language use including the gestures that your child uses because you will have the most opportunities to observe your child's language practices and provide constructive feedback to your speech and language therapist [23]; this will be extremely useful in identifying the areas in which your child is lacking growth, establishing the next practical goal for your child with your speech and language therapist, as well as for motivating the family [5].

Consequently, there needs to be strong support from the family unit at all times; in the words of Buckley and Prévost [7], "parents are the main therapists". Your language use to your child plays an important role in their language development as you will be spending the most time with them, hence it is important to remember that alongside quantity, quality of talk is equally vital as well [11,19].

As with any other child, friends, fun and play are very much loved and needed. Children with Down syndrome learn well in social situations with adults and friends due to their strong social learning skills [6]. Apart from reading activities, you could also engage in the following simple language learning activities suitable for children aged 0–2 adapted from Vila's *12 Booster Activities for Kids with Down Syndrome* [30]:



BABBLING

Encourage your child's babbling when it emerges in their first year; make sure your child faces you when you make vowel sounds such as 'a-ah' and 'oo-oo', and consonant sounds like 'd-d' and 'l-l' using exaggerated lip movements, so that they might start imitating you and gradually be able to discriminate the differences between the speech sounds [13]. There are a few ways to attract your baby's attention, such as calling out their name, clapping your hands or holding a colourful toy in front of them; once you have their attention, try to maintain eye contact with your child so that they pay attention to your facial expressions and mouth movements, which are important in strengthening their communication skills in the early years [5].



USE OF SIMPLE GESTURES

Leveraging on your child's strong visual abilities, you could make use of gestures with a spoken word to facilitate your child's comprehension of speech and acquisition of vocabulary. For example, using the iconic phone gesture (hand on your ear) for the word 'phone' or a scooping motion towards your mouth for the word 'eat'. It is a good practice to do this while doing everyday activities such as during mealtime, watching cartoons or when engaging in play with your child, so to maximise learning opportunities [5]. Another practical example on teaching gestures would be the action of waving goodbye; by guiding your child's hand to perform the action of waving when saying 'bye-bye' to someone encourages the gradual imitation and use of the words 'bye-bye' with the continual use of 'goodbye waves' by you and your child [5].



TURN-TAKING

This activity has more of a fun element to it and could involve more than two persons. To teach and encourage turn-taking in a conversation, you and your child could play a simple ball game- whoever pushes the ball to the other party states their name and declares their turn; if your child is pushing the ball to you, he would say "Logan's turn" as they push the ball, and you would do the same when pushing the ball to your child or another receiving party. You could also integrate pointing into this activity, by pointing to yourself when you state your name and push the ball, and have your child point to himself as well when it is his turn.



If you would like to explore teaching materials for your child, The Down Syndrome Educational Trust has published a wide range of See and Learn Kits that includes picture and vocabulary/sound cards for use from 18 months of age onwards, and they are available for purchase and download on electronic devices [14]. It is important to remember that whenever interacting with your child, follow their lead and always acknowledge and reply to your child's babbles, vocalizations [5,15]; this will encourage and speed up their production of speech sounds [13].

Every child with Down syndrome is individualistic and unique. You would have to diligently monitor and keep track of your child's learning and development, and work closely with your child's speech and language therapist to determine new goals for your child depending on their individual progress and developmental profile. The tables below serve as a mere gauge of the production and developmental milestones of a child with Down syndrome respectively:

Age	Interaction	Vocabulary	Grammar	Speech
0-12 months	Crying Eye-contact Smiling Listening/looking Vocalising - coos Turn taking	Understanding words		Babble Babble tuned to native language
12-24 months	Joint attention Gestures Conveying an increasing number of meanings in gestures and some words	Beginning to sign Beginning to say words First 10 words		Initial consonants and vowels developing as single sounds
24-36 months	Initiating conversations - pointing, requesting	First 30 words Comprehension ahead of production	Two words together	Words not very clear/intelligible

Gauge of production milestones from birth to 3 years of age [5]

	Birth	1 year	2 years	3 years	4 years	5 years
	Family	→		Social world	Preschool	School
Social	eye contact/smiling	one-to-one games	solitary play	play with peers	being in a group	
Motor	reaching/grasping holding/manipulating	rolling/sitting/standing/walking		climbing stairs colouring	running drawing	jumping writing
Speech & language	smiling, cooing, babbling, words			keyword phrases	sentences and grammar	
Self-help	feeding	using cup	spoon	fork	knife	dressing toileting
Behaviour	importance of routines	parents in control	learning self-control		able to conform, co-operate and comply with requests	
Number	experience of counting					learning to count
Reading	experience of books and stories					learning to read
Memory & thinking	attending	copying	choosing	remembering events and activities		learning and thinking skills

Gauge of developmental milestones from birth to 5 years of age [6]

WHAT OTHER HELPFUL RESOURCES ARE THERE?

It is only natural that another main concern for your child would be the type of pre-schools available and suitable for them. As your child would have already been diagnosed by a doctor in your respective hospital, you would also have been referred to **SG Enable** [29]. Through them, you will be able to get a referral to the respective centres equipped with the **Early Intervention Programme for Infants & Children (EIPIC)** appropriate for your child.

Below are some websites of the centres equipped with the EIPIC:

1) **Kindle Garden:**

<http://www.kindlegarden.com.sg/>

2) **Early Intervention Centre (EIC):**

<https://www.awwa.org.sg/services-for-children-and-youth/early-intervention-centre/>

Alternatively, you could explore the Children's Education Services (CES) catered for children with Down syndrome from birth to 18 years of age, offered by **Singapore's Down Syndrome Association (DSA):**

<http://www.downsyndrome-singapore.org/post/view/8/24>





Here are a few additional websites that might be useful in your parenting journey:

1) A Singaporean stay-at-home mother of three's blog on her parenting journey with a daughter with Down syndrome:

<https://simplylambchops.blogspot.sg/>

2) A local family blog sharing their experience with parenting and Down syndrome:

<http://thumb-prints.wixsite.com/thumbprints>

3) A helpful parenting website with a wide range of resources for topics such as autism and Down syndrome:

<http://www.parents.com/health/down-syndrome/>

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