

## Waiting For A Voice-The Parent's Guide to Verbal Dyspraxia

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### Foreword

Working with Monty has been an amazing journey, which has involved many giant leaps forward and some small steps back along the way. His family have moved mountains to identify and implement a whole host of interventions that are collectively impacting on Monty's development. Sharing their experiences, understanding and awareness with other parents may prove hugely effective at making a real difference for so many others in similar situations.

This book is an honest, easy-to-read guide for those who are coping with verbal dyspraxia, including an up-to-date understanding of the disorder and identification of support strategies. Sam is a parent who is dealing with the disorder day-by-day and is working with a range of healthcare professionals and teachers to ensure all interventions that are deemed suitable are in place. This is a must-read for all parents who are also 'Waiting for a Voice'.

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## INTRODUCTION

Imagine this, if you will.

About eighteen months ago I found myself sitting in an NHS speech therapy clinic room. It was a baking hot August day outside, there was only one window partially open in the room and everyone was fanning themselves with paper to create some breeze. My son, Monty, had just turned three and was there because he wasn't talking, and after various battles in actually getting him seen at the clinic, here we finally were. There were two Speech and Language Therapists (SaLTs) in the room, one asking Monty to do things ('Give the crocodile some dinner, Monty - does he want sausages or pizza?'), and the other therapist helping him to do as he was being asked. They were both nice and smiley, and Monty was quite happy and relaxed; there were lots of new and interesting toys to play with, and he did his best at imitating the animal noises that they wanted him to do ('Can you say *ahhhh*, Monty? What does the crocodile say when he opens his mouth?') I, on the other hand, was a bundle of nerves - there's nothing like wanting your child to 'perform' as expected when faced with a room of professionals and scribbling pens writing on clipboards.

Even though my husband and I knew that things weren't quite right with Monty's speech - we already had an older son and were therefore aware of the general milestones and what might be deemed to be 'normal' speech production in children - we still wanted someone to put our minds at ease and to tell us that there was nothing to worry about. I'd taken Monty to the doctors twice in the previous six months, and both times was told that he was a) a boy, and boys were often later to talk than girls, b), that he had an older sibling which had a tendency to make younger siblings late talkers due to having another small person to communicate their

needs for them, and c), that the doctor's own son had been a late talker and hadn't spoken his first words until three years old. It also didn't help that Monty had made an attempt to say the word 'spider', completely randomly, in front of her on the second visit. Look – he's said a word! Nothing wrong with him, then! Case closed, and so out the door we went.

A self-referral a few months later to the health visitor resulted in a hearing test at the Audiology clinic, which showed that Monty had excellent hearing and therefore ruled out any hearing problems or ear complications like glue ear. The Audiologist, however, noted that Monty's speech was not very clear - I think she was being polite - and from then on, after several months on a waiting list, we found ourselves in this hot and stuffy room in the Speech and Language Unit.

After about forty-five minutes, and after many pages of notes had been taken, the lead therapist turned to me and said that it was clear that Monty had a speech disorder, most probably something called developmental verbal dyspraxia. She asked if I'd ever heard of it - I said I hadn't. She then asked if I had any questions. Many thoughts were racing through my mind - the whats, the whys, but I went with a hopeful, 'I see. But - it'll resolve itself, right? Over time?'

I'll never forget the look of surprise on her face, as if I'd said something she'd not heard before. 'I'm afraid not,' she replied. 'It won't fix itself - Monty won't be able to talk clearly without intensive speech therapy, probably for a number of years.'

And then she added, apologetically, 'And I must warn you, there is at least a six month waiting list for speech therapy on the NHS in this area.'

We left the clinic and emerged into the bright sunlight; Monty walking along happily oblivious with his bag of toy dinosaurs,



me clutching a handful of leaflets on speech disorders including 'Speech Techniques to Try at Home' and feeling like the bottom had dropped out of my world. I didn't cry until we'd got into the car, when Monty was safely in the back, munching on rice cakes, and then the tears fell silently into my lap as we drove home. I called my husband, and I called my dad. No-one quite knew what to say, although my husband vowed that we'd get it sorted.

That night, and for several days after, I cried quite a bit. I suppose it was the shock, that there was something 'wrong' with our precious little boy that needed 'fixing'. We told family members and a few close friends. I cried even more after getting the laptop out and Googling 'verbal dyspraxia' along with the words 'prognosis,' 'causes' and 'cures'. Apart from not being able to easily find out much about the condition, it concerned me how little the professionals actually seemed to know about it and how little research had been done in this country. Things became a little clearer after expanding my search to the USA, where there was suddenly a wealth of information available on the web, for the most part by parents that had set up their own websites or blogs to help others.

I started this introduction by saying, 'Imagine this.' Perhaps you didn't need to imagine this story, perhaps you have one somewhat identical or maybe similar to ours. Maybe you too have felt that there is a lack of information on the condition, like I did all those months ago. When I decided to write this book I wanted it, ultimately, to be the resource that I needed (and couldn't really find) when we, as a family, first set out on this long road of discovery.

This book is generally UK-based in terms of the terminology, and information on the education system and healthcare provision, but I hope it will also be useful for those reading in other countries.

I've tried to include much of the research I've done to date, and have provided where possible information on where you can find further help. As much as possible, I've tried to break it down into bite-sized chunks, which are hopefully easy to digest, and in non-medical language. In each section you will see boxes entitled 'A Parent's Perspective.' I felt that it was important to tell as much as possible about our own story, as this is a book not just about this particular life-changing condition, but the impact it has on the child, the parents and others involved in the family's life. Hopefully I may touch on some of the issues you may be experiencing, or may experience in the future, and with any luck can provide some sense of comfort that you will most likely not be alone in what you are going through.

I should mention here that I am not a speech and language therapist, nor do I have any speech and/or language qualifications (if you exclude the BA Hons degree in English Language and Literature!) I am an author, but I am foremost a mum, and this is the story of my family and how we have aimed to deal with verbal dyspraxia, which includes the things that have worked for us, the problems we have faced, and the research that I have done. What works for one child might not work for another, so always make sure that you consult a relevant professional before you try to implement anything new. I hope it points you in the right direction for finding the resources available, so that you can do your own reading and make your own informed decisions about what is right for you and your family.

The last thing to say, perhaps, is that you are not alone, and I and countless others have felt your pain. If you are just starting down this long and bumpy road, you are perhaps likely to find yourself becoming your child's advocate, speech therapist, stress reliever and taxi driver all rolled into one, in addition to the

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demands already found in a typical parenting role. Monty is only four, and I know we have a long way to go, but I also know we are doing everything we can to give him what he needs, to get him where he needs to eventually be, and you will no doubt be the same. In my heart, I know that we will get there.

I wish you and your child(ren) the very best.

Sam Walker

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