VOICES UNEARTHED (Excerpts From Book)

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BY DORI HOLT

Common Assumptions: Why They Are Dangerous CHAPTER 4

Let's look at the assumptions Peter and I made during Eli's first several years of speech therapy – the very same assumption I heard repeatedly from many parents as we traveled from conference to conference.

Assumption #1: A speech therapist is a speech therapist is a speech therapist...

A speech therapist or a speech language pathologist (SLP) can have vastly varying degrees of education and certifications ranging from a bachelor's degree to a Ph.D. (doctorate) with their Certificate of Clinical Competency in Speech-Language Pathology (CCC) and their Board Recognized Specialty in Fluency Disorders (BRS-FD). In some circles it is assumed that if you are calling yourself a speech language pathologist, you have your CCC designation and if you are calling yourself a speech therapist, you do not, but this is not official.

Now that your mind is buzzing with acronyms, and before you flee out the door in search of that special therapist with the Ph.D. CCC BRS-FD after their name, let's look at the reality of what's available for children who stutter. According to the United States Bureau of Labor Statistics, there are currently over 110,000 speech language pathologists who have their CCC designations. This means they have their masters degree and a:

Certificate of Clinical Competency in Speech-Language Pathology, requiring a nine month clinical fellowship/training under the supervision of a licensed and certified speech-language pathologist. This certification also signifies that the speech therapist has successfully passed the National Examination for Speech-Language Pathologists. 10

In 2010, the American Speech and Hearing Association (ASHA) revised the requirements for the CCC, so it is now possible for a speech therapist to receive this level of certification without *ever* having had a class on stuttering. So if you want a speech therapist who has had coursework around stuttering, look for

CCC and BRS-FD. This means they have their master's degree and their CCC and are certified as a:

Board Recognized Specialist in Fluency Disorders who has completed 100 hours of post graduate educational training in fluency disorders, completed 100 hours of guided and supervised clinical practice with persons who stutter and their families under the supervision of a Board Recognized Fluency Specialist Mentor, submitted a portfolio of clinical work for review and approval and passed a national fluency disorders specialty examination. 10

But wait...The Specialty Board on Fluency Disorders lists fewer than 200 names of speech language pathologists who have their BRS-FD certification. Two hundred out of 110,000 means that one speech therapist in 52 has this certification. Of course, when someone has a BRS-FD after their names, often this only means that they are very good at fluency shaping aimed at eliminating speech errors and stuttering modification techniques aimed at minimizing speech errors – both incorporating the use of speech tools that change the moment of the stutter.

The level of prior experience Eli's speech therapists had with stuttering ranged from none to years of extensive work with stutterers; their certifications ranged from having only the CCC to having both the CCC and BRS-FD certification.

Yet, perhaps a speech therapist is a speech therapist is a speech therapist after all. For the outcome with everyone of our speech

therapists was the same. Eli struggled more and stuttered more and became increasingly silent.

Dr. Barry Guitar, a professor of Communications Sciences and Disorders at the University of Vermont, (and a person who stutters) gets to the heart of the matter. He writes "Stuttering therapy is an obscure blend of techniques, applied to a baffling problem, with frequent failure." These, then, are your choices: someone completely inexperienced or someone well-trained in using (this bears repeating) "an obscure blend of techniques, applied to a baffling problem, with frequent failure."

Assumption #2: He loves his therapist and thinks therapy is fun, so it can't do any harm.

When talking to other parents at conferences, I often heard about how much fun their child had at speech therapy and about how much they loved their therapist. Eli was, for the most part, no exception. In retrospect, it was easy for us to get distracted by therapists' encouraging tone and good intentions and to lose sight of what we were trying to accomplish. Eli didn't need to go to speech therapy to make friends and have fun. Speech therapy was supposed to help him to speak more easily – and none of his therapy helped with this outside the clinic setting.

But therapy certainly didn't *hurt* Eli – or did it?

First let's consider the logistics... hours in the car, time in the clinic, and time spent practicing therapy at home – over a five-year period. Add in the financial impact – the cost of gas, wear and tear on the car, and the therapy itself. Well worth it if the

outcomes are good. But they were not, and that's a significant chunk of time and effort out of a child's life that could have been spent engaged in activities with better outcomes such as playing with friends.

Even more importantly, I can't remember one conversation between myself and a speech therapist that didn't indicate that Eli was doing great in therapy. And yet our efforts over a fiveyear period only resulted in:

- 1. Eli becoming more and more silent.
- 2. Eli participating in fewer and fewer activities that involved meeting and talking with strangers.
- 3. Eli acquiring secondary problem behaviors including turning his chin to his shoulder, dropping his jaw, and growling to get himself started.
- 4. Eli growing increasingly depressed.

5. Eli feeling exhausted and experiencing major sleep issues.

Medical ethics include a fundamental principle of "first do no harm" stemming from Hippocratic writing *Epidemics*. Hippocrates states that "the physician must be able to tell the antecedents, know the present, and foretell the future - must mediate these things, and have two special objects in view with regard to disease, namely, to do good or to do no harm."

Assumption #3: Eli does well when he's with his therapists, so this means he needs to practice more.

Eli always got a good report after each therapy session. I sat in on many of the sessions and saw him successfully using the therapy techniques. With each therapist, I expressed my frustration that, in the real world, he seemed to be struggling more, not less. I was told initially that he just needed to practice more. his struggle just seemed to be increasing, I was told we just needed to practice more. Yet in my research, I found many experts who raised red flags about this. Bill Murphy, a Speech Language Pathologist in the Department of Audiology and Speech Sciences at Purdue University (and a person who stutters) observed:

"Parents often watch therapy in a controlled environment where fluency is more easily attained. Quite logically, parents can readily accept this quick fluency and expect the child to be capable of easily extending this into daily living situations. When SLP's and parents accept this unrealistic belief system, a conspiracy of fluency is formed. This conspiracy ultimately states that children can and should be expected to easily establish and maintain fluency." 12 In my and Peter's minds, there was some logic to the approach. If Eli didn't practice these techniques at home, how would he ever be able to use them? He was able to use them with considerable success in each speech therapist's office, so why not at home or with his friends? Maybe if he just practiced enough, we could rewire those neurotransmitters, or whatever had gone awry, and maybe then these techniques would start to come more easily for him. If he's having too much tension when talking, why wouldn't learning how to ease into a word help him? Tigger talk and easy bounces were intended to help him understand that it's okay to repeat words, everyone does it. If he stuttered on purpose, then it won't be so scary. He can identify his stumbles, stop, and start over. In fact, let's have mom and dad do intentional stumbles and see if he can catch us; that way he'll know it's okay to stumble. Relaxed breathing from the diaphragm will help him to have enough air to get the words out.

Yet, as I learned through my research, much has been written about the inability of children (and adults) to transfer their fluency during speech therapy into the real world. Edward Conture, Professor of Hearing and Speech Sciences at Vanderbilt University (and a person who stutters) and the late Oliver Bloodstein, Professor at Brooklyn College and an internationally respected author and expert on stuttering (and a person who stutters) explicitly warn us parents about this:

"Putting our collective heads in the sand and pretending, ignoring, or hoping that clinic changes absolutely and consistently mirror changes in the home, school, or workplace may provide us with a degree of comfort, but the problem will still be there once we pull our heads above ground." (Conture) 13

"Successful self-management of chronic stuttering is a complex, highly cognitive task, and failure is a common occurrence in the lives of our child clients. Significant harm may occur if the child has difficulty with self-management." (Bloodstein) 14

The movie, *The King's Speech*, is a true story about King George VI, who stuttered. With the help of maverick therapist Lionel Logue, the King was able to make public speeches with few blocks and speech errors. The movie does a beautiful job of depicting the Herculean effort King George VI put into his speeches, using the techniques and tricks Logue introduced. The goal was to get the King through the speeches and he achieved this. But he continued stuttering throughout his life.

In reaction to this movie, the NSA states that much has changed since the 30's. I'm not so sure this is so. Speech therapists today are trained to teach techniques and tricks that do not serve them well outside the therapy sessions, just as Logue's tricks didn't serve the King much beyond his public speeches. King George VI could not sustained this fluency outside of those speeches, just as a child cannot sustain this fluency in their everyday world.

Therapists often tell their young clients that "it's okay to stutter," then promptly follow that up with stickers and praise for making fewer speech errors. These kids naturally put enormous pressure on themselves to please us and not make speech errors. Or they choose silence. Either way, their genuine level of engagement in their world diminishes.

Assumption #4: Now that Eli has his tool box, he can use any tool whenever he chooses to.

This tool box includes easy onsets, smooth movements, easy speech, easy starts, slow speech, turtle talk, easy bounces, Tigger talk, taking a breath, and thinking about what you're going to say before you say it. So we've done our job; now it's up to the child to do his.

This attitude implies that any child can readily use all these techniques, and choose the right one at the right time in the real world. It also implies that it's the child's fault if they choose the wrong one, or choose not to use them. It's the parents' fault for not doing enough homework or not having enough special time. This attitude is reflected in the SFA's video, "Counseling Parents of Children Who Stutter:

"For the most part, kids don't want to come to therapy because of their own feelings – not motivated, speech is not a priority...It's very typical for kids who stutter to not want to work on talking. It's not a priority. The child's unwillingness to participate may be a symptom of a pervasive problem – you may need to refer them to a counselor..."¹⁵

Wow. Not only is the kid being stubborn and lazy, but they need to see a counselor to address their non-compliant behavior. Never is it suggested that the lack of motivation might stem from the inappropriateness of the expectation and the inadequacy of the techniques.

Being able to communicate effortlessly is a *huge* priority for kids who stutter. Most of them instinctively sense that using all the speech techniques comfortably on a daily basis is ridiculous and impossible.

This sets up our children and their parents for continual failure. Is it any wonder why kids stop participating, stop expressing their opinions, stop asking questions, stop talking?

How many times did I remind Eli to use his tool box? How many times did I hear this same reminder from other parents – usually in a confused tone that combined resignation, absolution, and hopefulness?

Most children choose to not use their well-filled tool boxes. Why? Because it's just too hard to do without focusing all of their efforts and energy on each word, instead of just living and being kids. The higher the expectation for error-free speech, the more apt the child is to simply not talk – silence is easier than using those tools.

When a child is told "it's okay to stutter" and is then given a sticker for not stuttering, a neon sign in their head flashes on. This sign says, in giant letters, "IT'S REALLY NOT OKAY TO STUTTER, WE WISH YOU WOULDN'T DO THAT ANYMORE, BECAUSE IT'S REALLY PAINFUL FOR US TO LISTEN TO YOU STRUGGLE. WE'LL SPEND LOTS OF ENERGY TAKING YOU TO SPEECH THERAPY IN ORDER FOR YOU TO STOP TALKING THIS WAY. WE'LL

KEEP LOVING YOU EVEN IF YOU DO KEEP TALKING THAT WAY, BUT WE REALLY WISH YOU'D STOP!"

That's what a child hears when they're expected to use their tool box, and rewarded for using it.

Most children want desperately to please their parents and other important adults in their lives. But those *adults* need to genuinely believe it's okay to stutter. Does this mean we give up? Does this mean we resign ourselves to having a child who grows up having to struggle to communicate?

No. But we can be discerning and careful. We can choose to only draw on resources that:

 help kids grow up to be self-confident, happy, engaged human beings 2. don't add layers of guilt, shame, and anxiety around speaking3. do no harm

(This is from the book Voice Unearthed by Dori Holt, sold on Amazon.)